

# Health professionals' experiences with the PEDI-UG

*What do Ugandan occupational therapists say about the utility and value of the Pediatric Evaluation of Disability Inventory (PEDI-UG) for children with disabilities?*

**Author(s)**

Ekwan, Francis; Satink, Ton; Kamwesiga, Julius; Schulze, Christina

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## RESEARCH ARTICLE

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# Health professionals' experiences with the PEDI-UG: What do Ugandan occupational therapists say about the utility and value of the Pediatric Evaluation of Disability Inventory (PEDI-UG) for children with disabilities?

Francis Ekwana<sup>1,2</sup> | Ton Satink<sup>3,4</sup> | Julius Kamwesiga<sup>5</sup> | Christina Schulze<sup>4,6</sup> 

<sup>1</sup>Department of Health and Rehabilitation Sciences/Department of Paediatrics and Child Health, University of Cape Town, Cape Town, South Africa

<sup>2</sup>Department of Occupational Therapy, Mulago National Referral Hospital, Kampala, Uganda

<sup>3</sup>HAN University of Applied Sciences, Nijmegen, The Netherlands

<sup>4</sup>European Masters of Science in Occupational Therapy, Hogeschool van Amsterdam, Amsterdam, The Netherlands

<sup>5</sup>Uganda Allied Health Examinations Board, Kampala, Uganda

<sup>6</sup>ZHAW University of Applied Sciences, Zurich, Switzerland

## Correspondence

Francis Ekwana, Occupational Therapy Department, Mulago National Referral Hospital, P.O. Box 27235, Kampala, Uganda.  
Email: [ekwanfr@yahoo.com](mailto:ekwanfr@yahoo.com)

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## Abstract

**Background:** The Uganda version of Pediatric Evaluation of Disability Inventory (PEDI-UG) was culturally adapted and validated from the PEDI-US, a tool used to evaluate the functional capability of children with or without disability aged 6 months to 7.5 years in the areas of self-care, mobility and social domains. A group of Ugandan occupational therapists with experience of using PEDI-UG participated in this study to explore the question: What do Ugandan occupational therapists say about the utility and value of the PEDI-UG for children with disabilities?

**Methods:** A qualitative research design was chosen to explore the participants' viewpoints concerning the utility and value of the PEDI-UG for children with disabilities. Purposive sampling was used to recruit health professionals for the focus group discussions. Focus group discussions were carried out with 18 occupational therapists and nurses. Thematic analysis was performed to establish patterns and themes.

**Results:** Several challenges concerning the contextual use of PEDI-UG were reported. For example, PEDI-UG being culturally adapted in two languages (English and Luganda) makes it difficult for health professionals to use it for children whose caregivers are non-English or non-Luganda speakers. In addition, participants reported adapting the way they asked the assessment questions, struggling with how they interpreted the scores and observing the child's skills if required during PEDI-UG interviews with caregivers.

**Conclusions:** The findings of this study suggest that health professionals are challenged with the use of the PEDI-UG assessment in diverse cultural contexts and/or languages. These challenges are important considerations for the PEDI-UG translation in different Uganda cultural languages and training health professionals on the use and value of PEDI-UG for children with disabilities.

## KEYWORDS

child development, child disability, evaluation, paediatrics, rehabilitation

## 1 | INTRODUCTION

The number of children with disabilities is considerably higher in African countries than Western countries, with approximately four out of five children with disabilities reported to be living in Africa and other low/middle income countries (UNCF & University of Wisconsin School of Medicine and Public Health, 2008). Evidence from several paediatric disability studies conducted in Africa indicates that most African countries lack culturally appropriate, language-specific, validated paediatric disability assessment tools (Abubakar et al., 2008; Gladstone et al., 2010). The Ugandan version of the Pediatric Evaluation of Disability Inventory (PEDI-UG) is the first of its kind in Africa intended to measure the child's capability in the three domains: self-care, mobility and social function (Amer et al., 2018; Kakooza-Mwesige et al., 2018). Because PEDI was developed from a high-income country (USA) (Haley et al., 1992), translated and adapted to Uganda cultures (Amer et al., 2018; Kakooza-Mwesige et al., 2018), its eventual use might be challenging for health professionals including occupational therapists. With a growing number of occupational therapists and other health professionals being trained in PEDI-UG administration, and being allowed to use the PEDI-UG assessment tool by the PEDI-UG first author, it would be useful for the further implementation of PEDI-UG to understand the experiences of these health professionals concerning the utility and value of PEDI-UG for children with disabilities.

The term PEDI is used synonymously with PEDI-US, the first version of this tool, which was developed in North America to assess the capability of American children. The main difference between PEDI and PEDI-UG is that PEDI has three scales: functional skills, caregiver assistance and modification (Berg et al., 2008; Law, 2003), while PEDI-UG has only two scales: functional skills and caregiver assistance (Amer et al., 2018; Kakooza-Mwesige et al., 2018). This adaptation was made to the tool because most Ugandan children with limited capability, and needing environmental or technical modifications to enhance their functional independence, did not have access to such modifications (Kakooza-Mwesige et al., 2018).

PEDI-UG is being used in research work in Uganda (Andrews et al., 2020, 2022; Saloojee et al., 2021). Occupational therapists are among the health professionals involved in the use of PEDI-UG (Saloojee et al., 2021), and better understanding their experiences of using PEDI-UG may enhance its implementation especially in clinical practice. This type of understanding was not found from a literature search. Thus, this study was designed to answer the question: What do Ugandan occupational therapists say about the utility and value of the Pediatric Evaluation of Disability Inventory (PEDI-UG) for children with disabilities?

## 2 | METHOD

### 2.1 | Study design

A qualitative research design was chosen to explore participants' viewpoints concerning the utility and value of the PEDI-UG for

### Key messages

The known on this topic:

- Therapists often value the opportunities to assess a child within his/her daily life cultural context using standardized assessments.
- PEDI scores alone do not tell the entire story of a child's functional abilities.
- PEDI assessment scores are sometimes not used because professionals find them too difficult or lack the knowledge on how to interpret them

The new knowledge this study adds:

- The health professionals value the use of the PEDI-UG assessment in diverse cultural contexts and/or languages.
- The occupational therapists recommend observation of the child's skills during PEDI-UG interviews with caregivers.
- When an assessment is used correctly and consistently, only then the occupational therapists can interpret it in meaningful ways.
- The main challenges in the use of PEDI-UG by occupational therapists in Uganda is cultural diversity.

children with disabilities (Arthur & Nazroo, 2004). Using this approach, the researcher engaged participants in a collective discussion of each other's viewpoints (Guba & Lincoln, 2005), with a group where participants shared what has been their experiences of using the PEDI-UG for children with disabilities (Guba, 1990). This study was grounded in the constructivist theoretical perspective, which rejects any single representation of reality to which all human experiences refer (Charmaz, 2006).

### 2.2 | Ethical considerations

Ethical approval for this study was sought and obtained from the Mulago Hospital Research and Ethics Committee (MHREC 1540). Written consent was obtained from all the eligible study participants, following receipt of an information letter. A hard copy of data from the study was kept in a locked cabinet, only accessible to the first author, to ensure participant confidentiality. No amendment was made to the study proposal after ethical approval from the Research and Ethics Committee.

### 2.3 | Sampling and recruitment

A total of 18 participants earlier trained in PEDI-UG administration by the first author of the PEDI-UG and with experiences of using

the PEDI-UG were recruited to take part in this study. The participants included 15 occupational therapists and three nurses with a background of occupational therapy practice in paediatrics. As part of the recruitment criteria, each of the 18 participants had performed at least four PEDI-UG assessments with caregivers of children with disabilities. These participants also met all other inclusion criteria; that is, they were fluent in both English and Luganda languages, and the nurses had practiced occupational therapy in a paediatric setting. The list of the 18 participants was obtained from the secretary of the Uganda Association of Occupational Therapists, who had also participated in the PEDI-UG administration training. The lead researcher decided to include the three nurses with an occupational therapy practice background to allow for diversity during group discussions, as they met the inclusion criteria (Carter & Little, 2007). This study was limited to central Uganda because the occupational therapists and nurses identified as eligible participants were all working in the Kampala, Wakiso and Mukono districts of central Uganda.

All the selected participants consented to participate in the study upon being contacted via phone calls. Participants were aged between 23 and 50 years, seven were females and 11 were males (see Table 1).

## 2.4 | Data collection

Focus group discussions were the chosen method for data collection. This method was chosen to generate diverse views relevant to the study question (Guba & Lincoln, 2005). All 18 participants were invited to take part in discussions, in February 2019. The lead researcher created three groups of six participants, each with mixed gender, ages and qualifications (for example each group had a nurse participant), for the purpose of enabling diversity in viewpoints during the discussion (Elo et al., 2014). The lead researcher

facilitated all three group discussions, which were guided by eight questions (Box 1).

### Box 1 Guiding questions for focus groups

- (1) What is your opinion about the use of PEDI-UG in occupational therapy?
- (2) What can you say about the importance of PEDI-UG in occupational therapy?
- (3) From your experience, how do you think PEDI-UG can be used in occupational therapy?
- (4) What kind of occupational therapy context can promote the use of PEDI-UG?
- (5) How can PEDI-UG scores be administered for children with disabilities?
- (6) What procedures can be undertaken to secure consistency in the rating of PEDI-UG scores?
- (7) How can PEDI-UG change scores be calculated for children with disabilities participating in occupational therapy?
- (8) Who do you think can be able to best use PEDI-UG in occupational therapy?

Focus group discussions were conducted in English because this was the most suitable language for all participants. The focus group sessions lasted between 45 and 60 min. Sessions were audio recorded by a research assistant and transcribed verbatim by the first author.

## 2.5 | Data analysis

Data analysis was carried out by the four authors, following the six-step process for thematic analysis described by Braun and Clarke (2006). In step 1, the recorded data were listened to several times and transcribed. The transcribed data and notes taken during the focus group discussion were read and re-read for purposes of achieving familiarity with the data. In step 2, data segments that related to the study question were highlighted, and a list of codes generated. The data set was reviewed to ensure completeness of the codes. In step 3, themes were created by collating, grouping and regrouping codes. In step 4, the themes and the entire data set were reviewed to create an initial thematic map. In step 5, final themes were named and described to fit the final thematic map. In step 6, a research report was produced, illustrating the themes with appropriate data segments.

**TABLE 1** Characteristics of participants in the focus groups ( $n = 18$ )

Characteristics	
Profession	
Occupational therapy	15
Nursing	03
Gender	
Male	11
Female	07
Year(s) of practice	
Less than 3 years	06
Three to 5 years	06
More than 5 years	06

### 3 | FINDINGS

This study yielded two major themes and four subthemes (see Table 2). The first theme relates to contextual use of the PEDI-UG assessment, and the second theme relates to interpretation of the PEDI-UG assessment.

#### 3.1 | Theme 1: Contextual use of the PEDI-UG assessment

Participants described how certain contexts can impact on the administration of the PEDI-UG assessment. This is because the same questions in the PEDI-UG assessment are asked of caregivers without consideration of their language and/or culture. One participant shared the contextual challenges encountered:

There are some cultures that states that a child is not supposed to eat using a fork ... and yet this is a question we find in PEDI-UG ... therefore we need to interpret PEDI-UG depending on the culture of a particular community.

Participants reported that it was challenging to use the PEDI-UG in Uganda because of the many languages used in parallel with the two languages (English and Luganda) for which the tool was adapted. They found it problematic to administer the PEDI-UG assessment in a standardized manner because different languages are conceptually different. For example, one participant said:

There can be challenges if a caregiver brings a child for PEDI-UG assessment and that caregiver cannot speak both English and Luganda ... which are languages for which the tool was adapted into Uganda cultures.

#### 3.2 | Investigating the child's capability

Some participants reported that to correctly investigate child's capability using the PEDI-UG; therapists should inform caregivers that it is intended to measure the capability of the child. This means the child

can only be scored 1 if they have mastered the skill being assessed and 0 for any skill not mastered. Trying a skill does not mean the child has mastered it. This was mostly noted with the functional skill scale. One participant said:

Some parents respond to PEDI-UG questions ... saying the child is trying ... therefore be clear about the difference between mastering and not yet mastered ... scored as 0 and 1 respectively.

Participants talked about the fact that PEDI-UG can sometimes measure trying instead of mastering, especially if the therapist decides to explain to the caregiver about the question being asked. This point was emphasized by one participant, who said:

Sometimes when one explains and go off the question the caregiver who wants to say the child can try ends up saying the child has mastered ... that means inconsistent scores.

#### 3.3 | Observing the child's skills if required during PEDI-UG interviews with caregivers

Study participants reported that, in most cases, the PEDI-UG assessment can be supported with observation of the child's skills, if required, during PEDI-UG interviews with caregivers. This is especially useful for clarifying how the child goes about performing tasks in their own context. For example, one participant said:

Instead of using only verbal questions we can also observe the child's activity during an assessment ... for instance giving the child a piece of biscuit to eat when assessing feeding.

Observation can be helpful in situations where the therapist has a feeling that the caregiver is not giving responses that accurately reflect the child's ability. This was emphasized by one participant, who said:

If the parent says ... I never tried that activity with the child ... you need to do a practical assessment and observe the child's activity for that particular item.

#### 3.4 | Theme 2: Interpretation of the PEDI-UG assessment for planning interventions

While talking about the interpretation of the PEDI-UG, participants reported that accurate scoring can support shared understanding of the child's capability. One participant said:

Whatever activity the child cannot do or just tries is scored 0 and if the child has mastered is scored 1.

**TABLE 2** Summary of thematic findings

Main themes	Subthemes
Contextual use of the PEDI-UG assessment	(a) Investigating the child's capability (b) Observing the child's skills if required during PEDI-UG interviews with caregivers
Interpretation of the PEDI-UG assessment for planning interventions	(c) Scoring the two scales consistency (d) Deriving meaning from the scores

Participants reported that the times between baseline assessment, intervention and follow up assessment often informed decisions made about what to expect when interpreting the change scores. For example, one participant said:

When the intervention period is shorter, for instance less than four months, it is more realistic to go by change scores in the specific skill areas with particular attention to change scores in areas where goals were generated from ... When the intervention period is longer, for example; six months and above, it is more realistic to go by average and/or total change scores.

### 3.5 | Scoring the two scales consistently

There is a temptation to go too fast, when one is familiar with the PEDI-UG tool, or too slow, when one is a beginner in using the tool. Being too fast or too slow can lead to inconsistency as reported by one participant, who said:

Avoid doing PEDI-UG assessment too fast or too slowly to avoid inconsistency ... for instance in 20 minutes or 2 hours ... set an average time for instance between 40 minutes to 1 hour to ensure concentration.

A lack of accuracy may mean the assessor starts to interpret incomplete assessment data, for example, when all the functional skills scale and caregivers' assistance scale items have been scored and nothing is written in the comments section which makes it difficult to interpret the scores effectively. One participant said:

Comments should be written in the space at the end of each domain section to answer the why question about the score ... for instance the child expected to score 1, i.e., capable in a particular functional skill, may not be able because cognition is a limiting factor ... such comment should be written in the space.

### 3.6 | Deriving meaning from the scores

While discussing the interpretation of PEDI-UG scores, most participants used terms that reflect how they understand and have been utilizing the tool. In their use of such terms, participants shared the challenges raised by the absence of normative data for PEDI-UG. One participant said:

To interpret scores of children under two years one needs to use normative data to explain such very low scores ... I think this can be a huge problem because PEDI-UG does not have normative data.

The interpretation of change scores was expressed by most participants as a way to inform other stakeholders about the child's functional status after a stated period of intervention. They thought there should be some sort of two-point score (baseline and follow up) to show the amount of change. One participant said:

If at baseline the child scored 40 and then in the follow up the child scored 45 it is a minimal improvement ... +5 and I would take it as a positive change.

Another participant said:

If it was 40 at baseline and now it is 30, which is -10 at follow up ... it is a regression or negative change.

Participants also talked about instances where no change was recorded. In such cases, they used the term *stagnation* when interpreting the scores. Stagnation can also mean a positive-negative change balance, as reported by one participant:

Sometimes the total scores remain the same because there could be a positive - negative change balance in different areas within the same domain.

Finally, to visualize change against the intervention period, the use of statistical analysis was suggested by one participant:

To calculate the change scores after a stated period of time one can use statistical analysis such as average mean scores, standard deviation and correlation.

## 4 | DISCUSSION

This study explored the question: What do Ugandan occupational therapists say about the utility and value of the PEDI-UG for children with disabilities? The study produced two key findings: contextual use of the PEDI-UG and interpretation of PEDI-UG scores. Concerning the contextual use of the PEDI-UG, study participants described how context can make it more difficult or easier to use the PEDI-UG for measuring the capability of children with disabilities. For example, participants pointed out that the caregivers who do not speak English or Luganda may find it difficult to get their children assessed using the PEDI-UG. This issue came up because the PEDI-UG was culturally adapted in two languages (English and Luganda). This finding indicates that occupational therapists valued the use of the PEDI-UG assessment in diverse cultural contexts and/or languages. According to Kinebanian and Stomph (2009), cultural diversity in language use and item use have the effect of including or excluding individuals and groups. Based on participants' experiences, it can be argued that culturally adapting the PEDI-UG in two Ugandan languages that is English and Luganda (Amer et al., 2018; Kakooza-Mwesige



et al., 2018) makes it more useful and valuable for assessing children with disabilities whose caregivers speak those languages.

Additional findings linked to the contextual use of the PEDI-UG include the following: investigating the child's capability and observing the child's skills if required during questionnaire administration. Some participants reported using the PEDI-UG as an investigative tool for measuring the child's capability by informing caregivers that, since it is intended to measure the capability of the child, the child can only score 1, if a skill is mastered. If a skill is not mastered or only tried, the child is scored 0. Other studies have attested that therapy practitioners value opportunities for assessing a child within his/her daily life context and in meaningful ways (Dillard et al., 1992; Eakin, 1989; Fricke & Unsworth, 1992; Leonardelli Haertlein, 1992; Oien et al., 2009; Smith, 1992). Further, some participants reported that observing the child's skills during the assessment with the caregiver could make the PEDI-UG more valuable. This finding supports the view that occupational therapists value opportunities to promote people's abilities in daily life tasks (Fisher, 2009). Similarly, Gannotti and Handwerker (2002), in their study involving the use of PEDI, noted that measurements of the impact of disease and health intervention for children should be supported with observation or other forms of ADL assessment. Vargus-Adams et al. (2011) also found that PEDI scores alone do not tell the entire story of a child's functional abilities, supporting the recommendation by participants in this study that observation of the child's skills should be carried out during PEDI-UG interviews with caregivers.

The other key finding is that study participants reported several challenges when using the PEDI-UG, including the time required to complete the assessment, deciding which score to give (0 or 1) and choosing the optimum length of time between baseline and follow up assessments to give the most effective comparison of scores. For example, some participants reported adapting the way they asked the assessment questions to include explanations: Although this is possible when using the PEDI assessment, there may be a danger of confusing the caregiver with the use of explanation. This indicated that participants are not always using the PEDI-UG assessment in the way they were trained to use it because of lack of clarity about certain knowledge areas. Similar findings have been reported from other studies; the PEDI assessment scores are sometimes not used because professionals find them too difficult or lack knowledge of how to interpret them (Garland et al., 2003; Swinkels et al., 2011). It seems that assessment scores can only be interpreted in meaningful ways when the tool has been administered correctly and consistently. This point has been highlighted by several authors: the incorrect or inconsistent use of a standardized measure leads to the risk of failure to demonstrate treatment effectiveness and, hence, that therapy services are clinically relevant (Fawcett, 2007; Garland et al., 2003).

This study found that therapists will often spend a longer time than required to complete the PEDI-UG assessment; doing PEDI-UG assessment for longer than 1 h can make caregivers to lose concentration and start providing inconsistent responses that lead to inaccurate scores. The negative consequence of taking an excessively long time to complete the PEDI-UG assessment has been reported in other

studies into the use of assessments in general (Copeland et al., 2008; Duncan & Murray, 2012; O'Connor et al., 2016; Upton et al., 2014). This shows that the challenges faced by the Ugandan occupational therapists, in terms of the time taken to administer an assessment, is similar to the challenges of assessment in general.

## 5 | STRENGTHS AND LIMITATIONS

- This study included both occupational therapists and nurses with occupational therapy practice background, which allowed for diversity during group discussion.
- The development of occupational therapy in Uganda might have influenced what occupational therapists said about the utility and value of the PEDI-UG. For example; including the three nurses with occupational therapy experience might have influenced the group to discuss stakeholders as part of the PEDI-UG meaning making process.

## 6 | CONCLUSION

The findings of this study suggest that health professionals are challenged with the use of the PEDI-UG assessment in diverse cultural contexts and/or languages. These challenges are important considerations for the PEDI-UG translation in different Uganda cultural languages, and training health professionals on the use and value of PEDI-UG for children with disabilities.

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## CONFLICT OF INTEREST

No competing interests detected.

## AUTHOR CONTRIBUTIONS

FE conceptualized the study and led the data collection and analysis based on his previous understanding of the Ugandan context. In addition, FE produced the study report, drafted the paper and approved the final paper for submission. TS conceptualized the study and contributed to data collection, analysis, report production and writing the paper. JK conceptualized the study and was involved in data collection, analysis, report production and writing the paper. CS

conceptualized the study and supervised data collection and analysis. In addition, CS participated in report production, drafting the paper and approving the final paper.

## ETHICS STATEMENT

Ethical approval for this study was sought and obtained from the Mulago Hospital Research and Ethics Committee (MHREC 1540).

## ORCID

Christina Schulze  <https://orcid.org/0000-0002-5662-5347>

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