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ORIGINAL ARTICLE

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The Uganda version of the Pediatric Evaluation of Disability Inventory (PEDI). Part I: Cross-cultural adaptation

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Abstract

Background: The Pediatric Evaluation of Disability Inventory (PEDI) was developed and standardized to measure functional performance in American children. So far, no published study has examined the use of the PEDI in sub-Saharan Africa. This study describes the adaptation, translation, and validation process undertaken to develop a culturally relevant PEDI for Uganda (PEDI-UG).

Method: The cross-cultural adaptation and translation of the PEDI was performed in a series of steps. A project manager and a technical advisory group were involved in all steps of adaptation, translation, cognitive debriefing, and revision. Translation and back-translation between English and Luganda were performed by professional translators. Cognitive debriefing of two subsequent adapted revisions was performed by a field-testing team on a total of 75 caregivers of children aged 6 months to 7.5 years.

Results: The PEDI-UG was established in both English (the official language) and Luganda (a local language) and comprises 185 items. Revisions entailed deleting irrelevant items, modifying wording, inserting new items, and incorporating local examples while retaining the meaning of the original PEDI. Item statements were rephrased as questions. Seven new items were inserted and 19 items deleted. To accommodate major differences in living conditions between rural and urban areas, 10 alternative items were provided.

Conclusions: The PEDI-UG is to be used to measure functional limitations in both clinical practice and research, in order to assess and evaluate rehabilitative procedures in children with developmental delay and disability in Uganda. In this study, we take the first step by translating and adapting the original PEDI version to the culture and life conditions in both rural and urban Uganda. In subsequent studies, the tool's psychometric properties will be examined, and the tool will be tested in children with developmental delay and disability.

KEYWORDS
Africa, cross-cultural adaptation, PEDI, translation, validity

1 | INTRODUCTION

Disability arises from the interaction between the decreased functioning of an individual and social and environmental barriers limiting participation in ordinary daily life (Rosenbaum & Stewart, 2004). The consequences of living with disabilities seem to be more limiting in low- and middle-income countries (LMICs) than high-income countries (HICs), because many HICs have developed active policies to reduce societal barriers and promote health and functioning (Leonardi et al., 2006). Measuring the conditions and situation of children with developmental delay and disability requires valid and reliable assessment tools that measure various dimensions of the complex interaction

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between body function and body structure, activity and participation, and health according to the World Health Organization's (WHO, 2001) International Classification of Functioning, Disability, and Health model. Such tools are needed both for planning and monitoring clinical interventions and for research.

There is a lack of culturally appropriate and language-specific validated disability assessment tools in LMICs (Abubakar, Holding, van Baar, Newton, & van de Vijver, 2008; Gladstone et al., 2010). Irrespective of the variety of disability assessments developed in HICs, most are not tailored to assess the disability of children in LMICs who live in environments that differ in dressing and grooming norms, hygiene facilities, modes of transportation, climate, and socio-economic status (Hartley & Newton, 2009). Considering that approximately four in five children with disabilities live in LMICs (United Nations Children's Fund & University of Wisconsin School of Medicine and Public Health, 2008), there is an urgent need to develop assessment tools for measuring the performance of children living in these countries.

The Pediatric Evaluation of Disability Inventory (PEDI; Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992) is an assessment tool for children with and without disabilities, capturing important aspects of function in daily life. It evaluates daily activities of children aged 6 months to 7.5 years in the self-care, mobility, and social function domains. It was developed and standardized for children living in the USA, whose living conditions, customs, and social behaviour differ markedly from those of Ugandan society (Manyak & Mujtaba, 2013), making the assessment inappropriate in sub-Saharan Africa. An assessment tool for Africa must take into account whether children are living in urban or rural areas as well as their socio-economic circumstances. The PEDI was earlier adapted and validated for several non-American cultures (Al-Khudair & Al-Eisa, 2014; Berg, Aamodt, Stanghelle, Krumlinde-Sundholm, & Hussain, 2008; Chen, Hsieh, Sheu, Hu, & Tseng, 2009; Erkin, Elhan, Aybay, Sirzai, & Ozel, 2007; Stahlhut, Gard, Aadahl, & Christensen, 2011); however, there is no published version adapted to any African country. Our purpose was accordingly to develop a version of PEDI culturally relevant to Uganda. In this first study of populations of typically developed Ugandan children, we describe the adaptation, translation, and validation process undertaken to ascertain the applicability of the PEDI modifications to their particular cultural environment and living conditions (Geisinger, 2006). The psychometric properties are analysed in a separate study (Amer et al., 2018), and the applicability of PEDI to Ugandan children with developmental delay and disability will be tested in a later phase.

Key messages

What is known on this topic:

- There is a lack of appropriate tools for assessing functional limitations of children with developmental delay and disability in sub-Saharan Africa, whereas such tools have been developed in Western high-income countries, for example, the Pediatric Evaluation of Disability Inventory (PEDI).
- To use assessment tools developed in Western countries, they must be translated and adapted, according to established principles and guidelines, to the life conditions and cultural context in the area where they will be applied.

What this study adds:

- This study describes the process of translating and adapting the original PEDI developed in North America, into a Ugandan version (PEDI-UG) in both English and Luganda.
- The PEDI-UG tool provides a culturally appropriate instrument for measuring the functional performance of children in both rural and urban Uganda.
- The PEDI-UG tool could be used in both clinical practice and research to assess and evaluate rehabilitative procedures in children with developmental delay and disability in Uganda and neighbouring countries in sub-Saharan Africa. However, the psychometric properties must first be examined and the tool tested in children with developmental delay and disability.

2 | METHODS

2.1 | Procedures

The procedure of adapting the original version of PEDI to Ugandan conditions comprised several steps and was inspired by previous guidelines for cross-cultural adaptation (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Bullinger, Anderson, Cella, & Aaronson, 1993; WHO, 2016; Wild et al., 2005). In Step 1, PEDI's items were adapted to Ugandan culture and living conditions by a technical advisory group (TAG). In Step 2, the culturally adapted version was translated from English to Luganda, the local language. In Step 3, the Lugandan version was back-translated into English and compared with the first adapted version. In Step 4, the Lugandan version was revised to become more similar to the culturally adapted English version, and a first revised Ugandan version in both Luganda and English was produced for validation. In Step 5, the first version was validated through field tests and in-depth interviews; these validation results were used to undertake a second revision. In Step 6, this version was validated and modified, producing a final Ugandan version of PEDI (PEDI-UG) in both English and Luganda.

In a subsequent process, the psychometric properties were examined by testing the instrument's rating scale functioning, internal structure, and test–retest reliability (see Amer et al., 2018).

2.2 | Project manager and TAG

The first author, A. K. M., acted as project manager preparing and coordinating the translation project and overseeing each step of the process. A. K. M. is a native Ugandan, fluent in both English and Luganda. She works as a paediatric neurologist at Mulago Hospital,

the main National Referral Hospital of Uganda and teaching hospital for the Makerere College of Health Science. A. K. M. convened a TAG comprising two paediatricians, three occupational therapists, two physiotherapists, one speech/language therapist, and two mothers of children (>7.5 years old) with no disability. All TAG members were fluent in both languages. The TAG professionals were selected based on their work experience (minimum 6 years) in providing medical and rehabilitation services to children with neurodevelopmental disabilities. All were employed by Mulago Hospital. The TAG was involved in culturally adapting PEDI, revising both versions, and creating the final version of PEDI-UG.

2.3 | The original PEDI

In March 2007, permission was obtained from the authors of the original PEDI, Haley et al. (1992), to adapt the original PEDI to Ugandan conditions. The PEDI measures the child's capability and performance in functional activities using three main measurement scales, that is, the Functional Skills Scale (FSS), Caregiver Assistance Scale (CAS), and Modifications Scale. It can be administered as an interview with parents/caregivers or through observation by professionals familiar with the child. The raw scores from each domain can be converted to both normative and scaled scores (criterion scores; Haley et al., 1992).

2.3.1 | Functional Skills Scale (original PEDI)

This measures the child's performance and capability in functional skills in areas where she/he demonstrates mastery and competence. It covers 40 diverse content areas assessed using 197 items scored *unable* (0) or *capable* (1). The self-care domain comprises 73 items covering use of utensils, personal hygiene, grooming, toileting tasks, and so forth. The mobility domain has 59 items covering transfers, such as normal use of toilet/potty, getting into/out of a bed or chair, and indoor and outdoor locomotion. The social function domain has 65 items covering word comprehension, communication, problem solving, playing with adults and peers, and so forth.

2.3.2 | Caregiver Assistance Scale (original PEDI)

This measures the amount of caregiver help provided. It covers 20 diverse content areas assessed using 20 items scored on the following escalating 6-point scale: *independent*, *supervision*, *minimal help*, *moderate help*, *maximum help*, and *total help*. The items cover the self-care domain (n = 8), mobility domain (n = 7), and social function domain (n = 5).

2.3.3 | Modifications Scale (original PEDI)

This measures any environmental or technical modifications needed to enhance the child's function. In this study, the Modifications Scale section was not used due to the limited availability of technical aids in Uganda.

2.4 | Cultural adaptation of PEDI (Step 1)

The TAG reviewed the various questions in the FSS and CAS sections of the original PEDI regarding their content and applicability in the Ugandan cultural context. The adaptation process was performed during face-to-face meetings at the Makerere University School of Medicine Campus, next to Mulago Hospital in Kampala. The project manager recorded the minutes of the meeting. The wording and relevance of each PEDI item were reviewed concurrently, and possible changes were suggested by consensus after extensive discussion. Relevant changes covered item formats, vocabulary, subject matter, and sentence structure. In cases of disagreement, the majority view was adopted. The first culturally adapted version of the PEDI was made in English.

2.5 | Translation of the adapted version of PEDI into Luganda (Step 2)

Two certified translators from the Department of Languages at Makerere University, Kampala, independently translated the first adapted English version of the PEDI into Luganda (Beaton et al., 2000). The two translations were reconciled into a single forward translation to the target language by the project manager after discussions with the translators and TAG to ensure conceptual equivalence, that is, that the intended meaning of the source language was preserved (Wild et al., 2005).

2.6 | Back-translation into English (Step 3)

Two other professional translators with Luganda as their mother tongue, fluent in English and with no prior knowledge of the PEDI, performed the back-translation of the reconciled translation into the source language. The aim of the back-translation was to attain conceptual rather than literal equivalence. To ensure that the Ugandan version was measuring the same construct as the original PEDI, the professional back-translators were fluent in the idioms and colloquial forms of the source language, that is, English. Their back-translation helped reveal unexpected meanings and interpretations.

2.7 | Revision of the Luganda version (Step 4)

The back-translated English version was compared with the first culturally adapted PEDI version in English (from Step 1) prepared by the TAG. In cases of disagreement between the two English versions, the wording of the Luganda version was altered to come closer to the first adapted English version while maintaining conceptual equivalence. This resulted in the *first Ugandan PEDI version* in both Luganda and English.

2.8 | Validating the first Ugandan version of PEDI (Step 5)

Cognitive debriefing of the new PEDI version in Luganda and English was performed through a field test of caregivers, followed up by in-depth interviews (see Wild et al., 2005). Thereafter, the TAG reviewed the results of the cognitive debriefing and revised the first Ugandan PEDI version, producing the *second Ugandan PEDI version* in both Luganda and English.

2.8.1 | Field testing the first version of the adapted PEDI

The principal aim of field testing was to check whether the items could be understood by caregivers. The emphasis was on exploring any need for further clarity of the items. The field-testing team comprised two physiotherapists, two speech/language therapists, and three occupational therapists, all with over 6 years' experience in paediatric

rehabilitation. They were specifically trained by the project manager in how to ask the PEDI questions. All team members were fluent in both English and Luganda, and half were TAG members. The team members administered the first version of the adapted PEDI to a convenience sample of 35 caregivers using the language of preference. The caregivers were accompanying their children (aged 6 months to 7.5 years) to the hospital for other reasons. The children were first tested with the Ten Questions Screen (Durkin et al., 1995) to confirm that they were developing typically and had no developmental disorder. The caregivers' and children's characteristics are shown in Table 1. Over half the caregivers were mothers from the urban environs of the hospital. The PEDI items were read verbatim and further explained and discussed as needed. In addition to completing the adapted PEDI form, research team members took abbreviated notes during the interviews regarding any issues requiring further clarification.

TABLE 1 Characteristics of the sample in the first field testing of the adapted Pediatric Evaluation of Disability Inventory

Demographics	Number	Percent (%)
Gender		
Male	20	57.1
Female	15	42.9
Age group		
6 months–1.5 years	8	22.8
1.5–2.5 years	5	14.3
2.5–3.5 years	3	8.6
3.5–4.5 years	5	14.3
4.5–5.5 years	3	8.6
5.5–6.5 years	6	17.1
6.5–7.5 years	5	14.3
Address		
Urban	20	57.1
Rural	15	42.9
Caregiver interviewed		
Mother	25	71.4
Father	5	14.3
Other (grandmother, aunt, and brother)	5	14.3
Educational level of caregiver		
Less than secondary school	12	34.3
Up to secondary school	12	34.3
Postsecondary diploma	5	14.3
University +	6	17.1
Caregiver's occupation		
Unskilled	11	31.4
Semi-skilled	9	25.7
Skilled	7	20.0
Highly skilled	5	14.3
Unspecified	3	8.6

Note. Definitions of occupation types: (a) Unskilled—job comprises simple duties requiring minor independent judgment or no previous experience, even though the worker ought to be familiar with the occupational environment; for example, messenger and full-time housewife. (b) Semi-skilled—job comprises duties usually requiring a well-defined skill and ability, but the assigned duties are executed in a relatively narrow job, in which important decisions are made by others; for example, shop attendant and waitress. (c) Skilled—job comprises duties requiring significant independent judgement in carrying them out responsibly, with in-depth knowledge of the trade or craft concerned; for example, carpenter and mechanic. (d) Highly skilled—job comprises duties in which the person is competent to work professionally and supervise the work of other skilled employees; the person possesses a thorough and comprehensive knowledge of the trade or craft; for example, manager and accountant.

2.8.2 | In-depth caregiver interviews after PEDI testing

Ten caregivers, from both urban and rural settings, participating in the interviews about the first version of the adapted PEDI were randomly selected for subsequent in-depth interviews (Table 1). The interviews were informal, using open-ended questions selected to better understand how the caregivers interpreted the questions, provide feedback on the wording used, and determine whether any words or expressions were unacceptable or impolite. Some of the questions were "What challenges did you face in answering these questions?" and "What changes if any should we make to these questions?" The in-depth interviews were conducted by the project manager and two members of the field-testing team conversant with qualitative interviews, using the caregiver's language of preference. The interviews were informal, conducted as casual conversations with caregivers concurrently with observing the children. Abbreviated notes were taken during the interviews.

2.8.3 | Second revision of the adapted Ugandan PEDI

The results of the PEDI field testing and the in-depth interviews were analysed and summarized by the project manager. These results were discussed in two TAG meetings in which problems interpreting the wording and content of the items were identified, leading to further modifications of the adapted Ugandan PEDI. In addition, a child psychologist from Makerere University College of Health Sciences was consulted to clarify the revisions made to the social function domain in the FSS. Further TAG discussions were held until consensus was reached regarding the adjustments needed to produce the *second Ugandan version of PEDI* in both English and Luganda.

2.9 | Validating the second Ugandan version of PEDI (Step 6)

2.9.1 | Field testing the second version of the adapted PEDI

The team engaged in the first field testing of the adapted PEDI participated in testing the second field version with the project manager. The sample comprised 40 caregivers of typically developing children aged 6 months to 7.5 years. The Ten Questions Screen (Durkin et al., 1995) was used to exclude children with developmental delay and functional limitation. Participants were from both rural and urban settings and of different socio-economic backgrounds and genders, as recommended in WHO (2016) guidelines. The PEDI interviews were conducted in participants' homes, as in the first field test. The caregivers' and children's characteristics are shown in Table 2. Caregivers from urban areas preferred the English version more often than did caregivers from rural areas.

2.9.2 | Third (final) revision of the adapted PEDI

The results of the field test of the second version of the adapted PEDI were summarized by the project manager. This summary, together

TABLE 2 Characteristics of the sample in the second field-testing of the adapted Pediatric Evaluation of Disability Inventory

Demographics	Number	Percent (%)
Gender		
Male	20	50.0
Female	20	50.0
Age group		
6 months −1.5 years	9	22.5
1.5–2.5 years	6	15.0
2.5–3.5 years	3	7.5
3.5–4.5 years	7	17.5
4.5–5.5 years	2	5.0
5.5–6.5 years	5	12.5
6.5–7.5 years	8	20.0
Address		
Urban	24	60.0
Rural	16	40.0
Caregiver interviewed		
Mother	34	85.0
Father	2	5.0
Other (grandmother, aunt, and brother)	4	10.0
Educational level of caregiver		
Less than secondary school	14	35.0
Up to secondary school	11	27.5
Postsecondary diploma	7	17.5
University +	8	20.0
Caregiver's occupation		
Unskilled	8	20.0
Semi-skilled	12	30.0
Skilled	14	35.0
Highly skilled	5	12.5
Unspecified	1	2.5

with feedback from caregivers and the field-testing team, was considered and discussed by the TAG, leading to several additional modifications and resulting in a *final Ugandan version of PEDI* (*PEDI-UG*) in both English and Luganda for children aged 6 months to 7.5 years.

2.10 | Ethical considerations

Permission to use and adapt this instrument was obtained from the Health and Disability Research Institute of Boston University, USA, and ethical clearance to conduct the study was obtained from the Makerere University Research and Ethics Committee and the Uganda National Council of Science and Technology (Reference HS 628). All caregivers interviewed gave written informed consent.

3 | RESULTS

3.1 | Cultural adaptation of PEDI (Step 1)

Culturally inappropriate terms were revised for FSS, but the TAG found that no revision of CAS was necessary. The brief statements of each PEDI item in the original version were rephrased as questions according to Ugandan customs. No PEDI item was deleted, but some additional items were created, alternative questions inserted, and certain examples replaced with local examples (Tables 3–5). The additional questions were created to capture culturally relevant norms regarding the intended subject matter while maintaining the general concepts of the instrument. New items mainly concerned mobility and transfers to and from a bathroom (see Table 6). To have questions appropriate for the different living conditions of urban and rural areas, alternative series of items were created for these content areas: toileting tasks, toilet transfers, and bed mobility/transfers (Table 4). This means that the caregivers could choose which alternatives were relevant to them (e.g., either the flushing toilet or pit latrine). The TAG felt it was important to emphasize local examples for several items to make them more culturally appropriate. For example, "child initiates hanging up coat when coming indoors" was revised because coats are not worn in Uganda, being replaced with "once home from school, child initiates removing school uniform and puts on home clothes." Other examples needing clarification were in the social function domain where, for example, the item "Can child make transaction in neighbourhood shop without assistance?" was clarified by being worded "Can child go into a shop without an adult and buy salt or sugar?" making the question more concrete. Revised word choice and modified questions were important parts of this process.

The culturally adapted English version was subsequently translated into Luganda (Step 2) and then back-translated into English (Step 3). After comparing the two English versions, a first revised Ugandan version, in both Luganda and English, was made (Step 4) for field testing.

3.2 | Validating the first Ugandan version of PEDI (Step 5)

Experience from the first field testing and in-depth interviews indicated that most of the items in the adapted Ugandan version of PEDI were understood by the caregivers, even though the CAS scale was difficult to score and several items were still nonillustrative of Ugandan culture. Further cultural adaptation involved rewording, modifying, deleting, and replacing certain items. In the self-care domain, for example, most caregivers reported that knife and fork use was not part of the culture, as spoons or finger feeding were commonly used. Another suggested change was "use of drinking containers" modified to read, "Can child pour liquid from a large (*ofwono*) Coca-Cola bottle with minimal spilling?" In the section on "hand washing," the wording "managing water faucets in a bathroom sink" was replaced with "managing water taps, or pouring water from containers to wash hands" to clearly depict the local situation, exemplifying the complexity of choosing the appropriate wording. In the social function domain, regarding "peer interactions," the item "plays activities or games that have rules" cited examples of games that were inappropriate. Local examples were substituted, as in "plays simple card games such as *Matatu* or simple board games such as snakes and ladders or Ludo" (Table 3).

In some cases, the caregivers had difficulties scoring an item. To clarify whether this was due to the child's inability to perform the skill or whether the item was irrelevant, an introductory question was added before the main question was asked. The question would ask

TABLE 3 Some examples of specific modified items

Functional skills		
Self-care domain		
	Original item	Final item
A. Types of food textures	Eats all textures of table food	Does child eat all textures of table food, such as adult bite-sized unground meat, chicken, cassava, sweet potatoes, millet bread, and *posho*, with no spilling out of the mouth?
B. Use of utensils	Uses a fork well (minimal spilling)	Does child use a spoon/fork well or finger feed, with no spilling occurring?
C. Use of drinking containers	Pours liquid from carton or pitcher	Does child pour liquid from a large (*ofwono*) Coca-Cola bottle with minimal spilling?
L. Shoes/socks	Put shoes on correct feet; manages Velcro™ fasteners	Does child put shoes on the correct feet and does not need reminders to help orient the shoes?
Mobility domain		
J. Outdoor locomotion: Distance/speed	Moves 10–50 ft (1–5 car lengths)	Does child move 3–15 m?
	Moves 10–50 ft (5–10 car lengths)	Does child move 15–30 m?
	Moves 100–150 ft (35–50 yards)	Does child move 30–45 m?
	Moves 150 ft and longer, but with difficulty (stumbles; slow for age)	Does child move 45 m and longer, but with difficulty and at slower speed than is expected at his/her age?
	Moves 150 ft and longer with no difficulty	Does child move 45 m and longer with no difficulty and at an age-appropriate speed?
Social function domain		
G. Peer interactions (with children of similar age)	Plays activities or games that have rules, such as go fish, Candyland, Simon says, or checkers	Does child play activities or games that have rules (plays simple card games such as *Matatu* or simple board games such as snakes and ladders or Ludo)?

the caregiver whether the child was familiar with a particular activity. For example, "Do you transport your child in a car/taxi/van?" In many rural areas, the children were exposed only to buses or large public taxis, having no experience of small cars. If the answer to this

TABLE 4 Alternative questions in three different content areas

Functional skills		
Self-care domain		
61. Determine which type of toilet the child uses normally and choose the questions to ask accordingly for (a) flushing type or potty or (b) pit latrine		
M. Toileting tasks	61(a) Flushing type: Child must be able to do all three respective tasks in order to receive credit for this item. Does child: ■ Raise or lower the toilet seat? ■ Get toilet paper or improvised paper/water? ■ Flush the toilet?	61(b) Pit-latrine type: Child must be able to do all three respective tasks in order to receive credit for this item. Does child: ■ Push aside the pit latrine cover? ■ Get toilet paper or improvised paper/water? ■ Cover the pit after use?
Mobility domain		
Determine which type of toilet the child uses normally and choose the questions to ask accordingly for flushing type or potty or pit latrine		
A. Toilet transfers	Flushing type or potty 1. Does child sit on potty or on a toilet *supported* by equipment or the caregiver? 2. Does child sit *unsupported* on the toilet or potty (the child can be safely left on his/her own)? 3. Does child *climb or slide on and off* a potty? 4. Does child *climb or slide on and off* adult-sized toilet *using his/her own arms* for support? 5. Does child *get on and off* adult-sized toilet *without using own arms* to support the transfer?	Pit latrine 1. Does child squat over the pit *supported* by equipment or the caregiver? 2. Does child squat *unsupported* over the pit? 3. Does child *initiate positioning him/herself above* a non-raised pit? 4. Does child *initiate positioning him/herself above* a raised pit *using his/her arms* for support? 5. Does child *squat and stand up from raised pit without using own arms* to support the transfer?
Does your child use an "actual" bed (i.e., wooden or metal frame raised from the floor with a mattress on the top) OR a bed on the floor, such as mattress on floor, papyrus reed mat, or pieces of cloth sewn together to make a mattress, that is, floor bed?		
D. Bed mobility/ transfers	Actual bed 15. Does child rise to sitting position in his/her bed or crib? 16. Does child sit at the edge of the bed and lie down in the bed? 17. Does child climb on and off the bed using upper extremities for support or using upper extremity support to transfer from a wheel chair to a bed? 18. Does child get in and out of own bed without requiring upper extremity support for balance or lift?	Floor bed 15. Does child rise to sitting position in his/her bed or crib? 16. Does child kneel at edge of bed before lying down? 17. Does child lower self from kneeling at edge of bed using upper extremities for support to lie down on bed or using upper extremity support to transfer from a wheel chair to a bed using a sliding transfer? 18. Does child lower self from kneeling at edge of bed without upper extremity support for balance or lift?

TABLE 5 The deleted items

Functional skills	
Self-care domain	
	Items deleted
H. Washing body and face	Washes body thoroughly not including face. Dries body thoroughly.
Mobility domain	
D. Car transfers	Manages seat belt or chair restraint
E. Tub transfers	All items in section deleted (5)
L. Upstairs	All items in section deleted (5)
M. Downstairs	All items in section deleted (5)
Social function domain	
K. Time orientation	Regularly checks clock or asks for time in order to keep track of schedule.

TABLE 6 New items in Pediatric Evaluation of Disability Inventory for Uganda

Functional skills	
Self-care domain	
	Items added
F. Nose care	26. Does your child attempt to care for his/her nose using what is available (fingers/hanky/shirt/dress)?
Mobility domain	
E. Bathroom/shower transfers	19. Does child sit supported by the caregiver in a washbasin? 20. Does child sit unsupported with ability to play with items placed in the washbasin? 21. Does child walk to bathroom supported and stand with support while being bathed? 22. Does child walk to bathroom unsupported and stand without support while being bathed? 23. Does child independently carry own washbasin with water to and out of the bathroom?
H. Washing body and face	37. Does child completely rinse the soap from his/her body?

introductory question was "no," no further question was asked for this section. Examples of culturally inappropriate items that were deleted include "regularly checks clock or asks the time in order to keep track of schedule" (Table 5). Time management is not emphasized to young children in Ugandan culture, as it is often the parents' responsibility. Others expressed caution regarding the use of stairs, stating they did not permit even older children to use them without an adult close by. The items "upstairs" and "downstairs" in the mobility domain resulted in failing scores because of parental fear, so they were deleted (Table 5). Questions about "tub transfers" in the mobility domain were modified to address "bathroom/shower transfers." Adult-sized bathtubs are very rare; most children use either an enclosed room with/without a shower appliance or a makeshift shelter a few metres from the main house with no access to running water. The new questions are shown in Table 6.

3.3 | Validating the second Ugandan version of PEDI and establishing the final version (Step 6)

This second field testing also resulted in minor rewordings and example clarifications before the final version was created. The final Ugandan version of PEDI included 185 of the original 197 FSS items; 19 FSS items were deleted, 7 new items inserted, and 10 alternative items provided. In the self-care domain, there were 73 items, that is, the same as in the original PEDI. One alternative for toileting tasks was included, one item added, and one item deleted (Tables 4–6). The mobility domain was the most challenging content area. In it, 48 items remained versus 59 in the original PEDI. This domain included nine alternative items for toilet, bed, and mobility transfers. Several items were deleted, for example, regarding car, tub, and upstairs/downstairs transfers. Some new items were inserted (see Tables 4–6). The social function domain contained 64 items versus 65 in the original PEDI; the deleted item concerned time orientation (see Table 5). Because the items in all domains were rewritten from statements to questions and local examples were added, the PEDI-UG has been slightly modified to suit the local Ugandan context, with great care taken to preserve its original core concepts.

All 20 of the original items in the CAS were retained with no adjustment.

4 | DISCUSSION

Our study illustrates the importance of culturally adapting Western developmental assessment tools before using them in other cultural settings, especially in LMICs. If children are assessed using inappropriate instruments, they may be recorded as unable to perform items that are unfamiliar to them, whereas skills relevant to their own context are not assessed (Gladstone et al., 2008). To develop a more appropriate and easily understood instrument, we adapted the PEDI to the cultural and social context of Uganda by deleting some original PEDI items, modifying other items, adding some new items, and creating alternative items.

4.1 | Challenges in keeping the construct of PEDI

One obvious challenge was the decision to rewrite short statements as questions. In Ugandan culture, formal style is important when asking

and answering questions, and oral communication is a fundamental means of interaction and information exchange (Otiso, 2006). We therefore used properly formulated questions with clear examples in a language that the caregiver was comfortable with, to avoid confusion arising from more loosely formulated statements. To achieve semantic equivalence, certain words nonillustrative of local conditions were replaced with more appropriate ones. Experiential equivalence was achieved by citing examples, such as local games, that clearly captured local Ugandan conditions.

Another challenge was the large variation in living circumstances. Creating alternative questions made it possible to use the PEDI-UG in both urban and rural areas. The purpose of alternatives was to clarify the activity to the caregivers, so they could identify appropriate living conditions for their children. The dilemma, however, was that the alternative items may not be equally difficult and that some alternatives might be too easy and others too difficult relative to the original version. Managing personal care and hygiene might be more difficult in rural areas with less convenient facilities.

Most changes were made in the mobility domain due to differences in the hygiene and transportation situations. Some items had to be deleted despite being functionally relevant; for example, "use of stairs" was deleted because many parents expressed fear of children falling from stairs. This may illustrate an element of caregiver overprotectiveness, which may hinder child development. Although eliminating stairs limits the assessment of motor development, we believe that the contributions of other culturally adapted items in the PEDI-UG can compensate for this. Another concern was "time" in the social function domain, where regularly checking the clock or asking the time was deleted. Respect for timeliness is much less emphasized in Uganda than in developed countries. Particularly in traditional and rural parts of Uganda, it is more important to take as much time as needed to complete an activity, rather than interrupt the flow of events in the interest of timeliness (Otiso, 2006).

4.1.1 | Strengths and limitations

Among the strengths of this study was its rigorous process following good cross-cultural adaptation and translation practices (Wild et al., 2005). In addition, we performed two subsequent cognitive debriefings, instead of the usual one, to fine-tune the final version and ensure that it captured vital information. Using notes documenting the test interviews and in-depth interviews, we could identify relevant cultural issues and establish high-quality conceptual, experiential, and semantic equivalence for the PEDI-UG version, including local examples and alternative questions (WHO, 2016; Wild et al., 2005). In line with previous recommendations on creating culturally appropriate assessments (Bullinger et al., 1993), we emphasized conceptual rather than literal equivalence to the original version. This is because even simple tasks might not be understood even though their descriptions are correctly translated. This has been highlighted in the cultural adaptation of other assessments in Uganda (Kamwesiga, von Koch, Kottorp, & Guidetti, 2016) and Saudi Arabia (Al-Khudair & Al-Eisa, 2014). Another strength of our adaptation was the innovative composition of alternative questions, making it possible to apply the PEDI-UG in both rural and urban areas. In Uganda, most people still live in poor rural areas where living conditions differ greatly from those of more developed areas in terms of hygiene and home environment. Because the PEDI is known to be sensitive to cultural differences (Berg et al., 2008; Rodger et al., 2003), it is important to capture this difference.

A limitation of this study, and of the final PEDI-UG version, is that two languages were used, and differences in nuance between them may have generated different caregiver answers. The existence of multiple languages in Uganda is a challenge when developing any assessment tool for the whole country. English has been the first official language since colonial times, whereas Swahili, the lingua franca of Eastern Africa, has more recently become the second official language. In addition, there is a large diversity of indigenous languages and dialects. Luganda is a Bantu language spoken in central and Southern Uganda, including in the capital, Kampala. Because not all Ugandans are fluent in English, it would be impossible to use only one language, so we chose to use the first official language (English) and the local language (Luganda) of the region where the study was performed. To use the PEDI-UG in Eastern and Northern Uganda, it will have to be translated into the languages used there, because some inhabitants are not fluent in English. In this study, about half the caregivers, particularly in rural areas, preferred Luganda. To minimize differences caused by language differences, TAG members had bilingual expertise and strove to adapt and revise the two versions to be as similar as possible, based on translation and back-translation by skilled translators focusing on conceptual equivalence. In later studies, it might be worthwhile to study differences between the two language versions, though this might be difficult because the social strata differ between caregivers choosing Luganda (mainly rural residents) and English (mainly urban residents), which would also influence the responses.

Although the PEDI-UG is intended to assess functional limitations in children with developmental delay and disability, we only tested children with typical development in this first study. This was done to understand the relevance of the PEDI questions to the Ugandan context and to see what typically developing children do in daily life depending on the environment and cultural context where they live. A later study will validate the PEDI-UG in a group of children with developmental delay and disability.

There was a small dominance of caregivers living in urban versus rural areas (see Table 1). However, we do not think that this discrepancy mattered because we had relatively large samples in both field tests, with more than enough caregivers from rural areas to collect reliable information. Despite efforts to make the items relevant to Ugandan culture, several items, for example, experience travelling in small cars, may not be applicable to all children in rural areas whose typical mode of transport is the motorcycle taxi (*boda boda*). In the future, it would be worthwhile to consider including items in the mobility section regarding this common means of transport and to consider reintroducing the item on stair use.

5 | CONCLUSION

The detailed cross-cultural adaptation of the PEDI performed here is the first step to create a relevant assessment tool usable in clinical practice and research in Uganda. The next step is to study the

instrument's internal validity and item response pattern and to examine whether its psychometric properties can be used to reliably assess the functional capability of Ugandan children aged 6 months to 7.5 years. A study of these matters has been performed and is being published in parallel (see Amer et al., 2018). The third step will be to test the PEDI-UG on a group of children with developmental delay and disability and examine its test–retest reliability.

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CONFLICT OF INTERESTS

The authors state that they have no potential, perceived, or real competing interests known.

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