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Field testing a draft version of the UNICEF/Washington Group Module on child functioning and disability. Background, methodology and preliminary findings from Cameroon and India

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Abstract

Background.—Global child disability data are generally non-comparable, comprising different tools, methodologies and disability definitions. UNICEF and The Washington Group on Disability Statistics (WG) have developed a new tool on child functioning and disability to address this need.

Aims.—The aim of this paper is to describe the development of the new module, and to present an independent field test of the draft module in two contrasting settings.

Methods.—UNICEF and the WG developed a parent-reported survey module to identify children aged 2–17 years with functional difficulties in population-based surveys through: review of existing documentation, consultation with experts and cognitive testing. A field test of the draft module was undertaken in Cameroon and India within a population-based survey. Functional limitation in each of 14 domains was scored on a scale comprising "no difficulty", "some difficulty", "a lot of difficulty" and "cannot do".

Results.—In all, 1713 children in Cameroon and 1101 children in India were assessed. Sixty-four percent of children in Cameroon and 35% of children in India were reported to have at least some difficulty in one or more domain. The proportion reported to have either "a lot of difficulty" or "cannot do" was 9% in Cameroon and 4% in India. There were no significant differences in reported functional difficulties by sex but children aged 2–4 were reported to have fewer functional difficulties of any kind compared with older children in both countries.

Conclusion.—Comparable estimates were generated between the two countries, providing an initial overview of the tool's outputs. The continued development of this standardised questionnaire for the collection of robust and reliable data on child disability is essential.

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Disclosure of interest

The authors declare that they have no competing interest.

RÉSUMÉ

Les données globales sur les enfants handicapés sont difficiles à comparer étant donnée la variété des outils, des méthodologies et des définitions du handicap utilisées. L'UNICEF et le Washington Group (WG) ont développé un nouvel outil pour documenter le fonctionnement et le handicap de l'enfant.

L'objectif de cette note de recherché vise à décrire le développement de ce nouvel outil et à présenter un test du module provisoire qui a été fait de manière indépendante sur deux terrains différents.

L'UNICEF et le WG ont développé pour l'enquête un module dans lequel des parents sont interrogés afin d'identifier les enfants âgés de 2 à 17 ans ayant des difficultés fonctionnelles dans les enquêtes en population : examen de la documentation existante, consultation d'experts et tests cognitifs. Le module provisoire a été testé sur le terrain au Cameroun et en Inde dans des enquêtes en population. Les limitations fonctionnelles dans chacun des 14 domaines ont été mesurées avec une échelle allant de « aucune difficulté », « quelques difficultés », « beaucoup de difficultés » à « ne peux pas faire ».

Au total, 1713 enfants ont été évalués au Cameroun et 1101 en Inde à partir de ce module. Soixante-quatre pour cent des enfants au Cameroun et 35 % des enfants en Inde ont rapporté avoir au moins quelques difficultés dans un ou plusieurs domaines. La proportion d'enfants ayant déclaré « beaucoup de difficultés » ou « ne peux pas faire » était de 9 % au Cameroun et de 4 % en Inde. Il n'y avait pas de différences significatives selon le sexe dans les difficultés fonctionnelles déclarées mais les enfants âgés de 2 à 4 ans ont déclaré moins de difficultés fonctionnelles de manière générale par rapport aux enfants plus âgés dans les deux pays.

Des estimations comparables ont été produites dans les deux pays, fournissant un premier aperc¸ u des potentialités de l'outil. La poursuite du développement de ce questionnaire standardisé pour collecter des données robustes et fiables sur le handicap de l'enfant est essentielle.

Keywords

Child disability; Functioning; Measurement; Field testing

Mots clés :

Enfants handicapés Le fonctionnement Essais sur le terrain

1. Introduction: measuring child disability

Global, national and sub-national population-based data on child disability have historically differed in methodology and rigour, forestalling comparison between countries and over time. A recent global review of child disability datasets by Cappa, Petrowski, & Njelesani (2015) summarised the heterogeneity of available data, much of which predated or otherwise dissented from the prevailing bio-psycho-social conceptualisation of disability as per the International Classification of Disability, Functioning and Health (ICF) and the United

Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Cappa et al., 2015; The United Nations, 2006; World Health Organization, 2001).

The most frequently cited tool for child disability measurement in population-based data collection efforts is the Ten Questions (TQ) Tool for children aged 2–9 years, used or adapted in a handful of studies of childhood disability in various Low- and Middle-Income Countries (LMICs), and integrated into the third round of the United Nations Children's Fund (UNICEF) Multiple Indicator Cluster Survey Guidelines (Couper, 2002; Hartley & Wirz, 2002; Khan et al., 2009; Muga, 2003; UNICEF, 2008). The TQ documents caregiver-reported health conditions, impairments and activity limitations experienced by children, but has recognised limitations including dichotomous response options, validation only amongst younger children, and low sensitivity for specific impairments (Durkin, Hasan, & Hasan, 1995). Alternative caregiver-reported tools for children have also been developed, including the Rapid Assessment of Disability (RAD) child module and the World Health Organisation Disability Assessment Schedule (WHODAS 2.0) child module, but these have not been validated or widely used (Centre for Eye Research Australia and Nossal Institute for Global Health, 2013; Scorza et al., 2013).

Assessment of disability in children is particularly complicated given the continuum of development experienced throughout childhood. Whilst progression against developmental milestones has been shown to significantly predict developmental outcome in a number of settings, cultural variation can lead to low transferability of milestone-based tools, the majority of which were not developed in LMICs (Brothers, Glascoe, & Robertshaw, 2008; Scherzer, Chhagan, Kauchali, & Susser, 2012).

The dearth of quality evidence on the prevalence and spectrum of child disability reflective of the prevailing framework curtails efforts to advocate, monitor and evaluate disability-inclusive policy and programmes, particularly in the emerging post 2015 agenda. Advancing a consistent definition of disability for both data collection and data disaggregation is therefore urgent.

This paper has two aims:

- to describe the development of a new survey module by UNICEF and the Washington Group on Disability Statistics (commonly known as the Washington Group) to meet this need;
- to present the results of a field test of the draft version of this module in Cameroon and India, comparing findings across the two sites.

2. Development of the UNICEF/Washington Group Extended Set on child functioning and disability

Responding to the lack of agreed tools and methodologies for the assessment of child disability, UNICEF and the Washington Group have developed a parent-reported survey module to identify children with functional difficulties in population-based surveys.

The UNCRPD definition of disability was operationalized in the design of the module, and the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) was selected as a conceptual framework for question development (World Health Organization, 2007).

The specific purpose of the module is to identify children with functional difficulties that may place them at a greater risk of experiencing limited participation than children without functional difficulties, as a proxy for equalization of opportunity.

Existing documentation relating to the measurement of childhood disability was collated and analysed to determine appropriate ICF-CY domains for inclusion (Cappa et al., 2015). Extensive consultations with international specialists in child development (paediatricians, developmental psychologists, speech therapists etc.) were also undertaken to further refine the draft question set.

The module focuses on children aged 2–17. Whilst the importance of early detection and intervention for children with functional difficulties is recognised, below the age of two the development process is rapid and varied, can be subjective and culturally influenced, and may not represent the presence of functional limitation. Age-range specific variations of some questions were developed to account for the continuum of development across childhood.

Following established Washington Group validation procedures, the module underwent extensive cognitive testing between 2012 and 2014 in India, Belize, Oman, Montenegro, and USA (Madans et al., 2004; Crialesi, De Palma, & Loeb, 2015).

The remainder of this paper presents the results of an independent field test of a draft version of the module as part of two surveys of disability in Cameroon (2013) and India (2014). Since its application in this research, the module has undergone several modifications and revisions.

3. Methods

Two population-based surveys of disability including people of all ages were conducted by the International Centre for Evidence in Disability (ICED) at the London School of Hygiene & Tropical Medicine, in Cameroon (2013) and India (2014). Representatives from both UNICEF and the Washington Group participated in the study's advisory committee but were not members of the study team. The aim of the overall study was to develop a comprehensive population-based disability survey methodology (using both self-reported functional limitations and objective tools to measure clinical impairment) compatible with the ICF, and to explore the relationship between different components of disability within this framework.

The remainder of this manuscript focuses on the use and results of the draft UNICEF/ Washington Group module on child functioning and disability to determine reported functional limitations in children aged 2–17 years.

The sample-size was calculated using a conservative expected all-age prevalence of moderate/severe hearing, vision and physical impairment of 4% (World Health Organization, 2011). A minimum all-age sample-size of 4056 per country was calculated, assuming 20% precision, 95% confidence, a design effect of 1.5 and 20% non-response.

We used a two-stage sampling procedure; fifty-one clusters of eighty people were selected using probability-proportionate-to-size sampling, using the most recent census for the sampling frame. Within clusters, households were selected using compact segment sampling. Each enumerated child aged 2–17 was assessed using a draft version of the UNICEF/Washington Group module on child functioning and disability.

In this draft version, 14 functional domains (D1-D14), separated into “Basic Function” and “Complex Function, Emotion and Participation” domains, were assessed. Domains are coded as follows in Table 1. Age-relevant variations were included for some domains (e.g. playing) and certain domains were included only for children aged 5–17. The draft version of the module used in the study is available upon request.

Functional limitation in 12 of the 14 domains were reported on a 4-point scale: “no difficulty”, “some difficulty”, “a lot of difficulty” and “cannot do at all”. The response categories for the remaining two domains (controlling behaviour and anxiety/sadness) were “the same or less”, “more” and “a lot more”. Usage of glasses and hearing aids were also included. To standardize proxy-respondent responses to generally accepted stages of child development, where appropriate, questions were prefaced with the clause “compared with children of the same age…”.

Parents or adult primary caregivers reported for children under the age of 9 or unable to communicate independently. Children aged 9 and above were interviewed directly where feasible and appropriate.

In India, a single question “do you consider yourself [age 9–17]/your child [age 2–8] to have a disability?” was included for comparison purposes.

Three survey teams per country received 10 days training on disability awareness, project protocols and tools, ethics and practice interviewing. Teams consisted of 3 clinical team members, 5 field assistants, and 2 interviewers. Field assistants in each team were responsible for completing the UNICEF/Washington Group module.

Ethical Approval for the study was granted by:

- the London School of Hygiene and Tropical Medicine;
- Cameroon National Ethics Committee for Research in Human Health;
- Cameroon Baptist Convention Health Board Institutional Review Board;
- Public Health Foundation of India Institutional Ethics Committee;
- Government of India Health Ministry Screening Committee.

Basic medicines (vitamins, anti-inflammatories, ear and eye drops) were distributed by clinical team members as needed, and all participants with unmet health needs were referred to relevant and available health, rehabilitation or educational services.

Caregivers of all children aged 2–17 were read an information sheet about the study and given the opportunity to ask questions. If they agreed to participate, written/finger print consent was taken from the caregiver and assent was provided by children aged 9 and above. Caregivers were required to remain present throughout the interview process.

In both settings, the questionnaires were cognitively tested for context relevance and adapted accordingly. The module was translated into Telegu in India and verbally translated into Pigin English in Cameroon, using a phrase sheet of appropriate phonetic translations.

Data was double-entered into Microsoft Access, corrected for inconsistencies between entries using the EpiInfo Data Compare utility and merged in STATA 12.0 for analysis. The svy command was used to derive prevalence estimates with 95% confidence intervals (CI) at different functional thresholds (“no difficulty” in any, “some difficulty” in at least one domain, “some difficulty” in at least two domains, “a lot of difficulty” in at least one domain and “cannot do” in at least one domain), accounting for the cluster sampling design. Domain-specific analyses are reported as “at least some difficulty” and “at least a lot of difficulty”, given small numbers. Associations between reported limitations (both aggregate domains and for each specific domain), age group and gender were assessed using a Chi2 test of association. Pearson’s correlation coefficient analysis (*r*) was computed to assess pairwise relationships between endorsed domains.

4. Results

4.1. Overall ressults

Findings use the age grouping 2–4, 5–8, 9–12 and 13–17 years to accommodate age-range specific questions, and are presented as the minimum level of limitation endorsed. “Reported” refers to both caregiver report for children age 2–8 and self-report for children 9–17.

Table 2 presents the study cohort descriptors. A total of 1713 children aged 2–17 were assessed in Cameroon, and 1101 in India. Fifty percent of the study children were male in Cameroon and 52% in India.

Aggregate domain endorsement across all domains and stratified by domain type (basic versus complex) are presented in Table 3. Two thirds of the sample in Cameroon reported at least some difficulty in at least one domain (63.9%, 95% CI 60.0–67.6), compared with one third in India (34.9%, 30.8–39.2). Prevalence declined with increasing reported difficulty in both samples. In Cameroon, 42.0% (38.0–46.0) reported some difficulty in any two domains, 8.9% (7.1–11.2) reported a lot of difficulty in any one domain and 0.7% (0.4–1.2) reported inability to do any one domain. In India 19.8% (16.5–23.6) reported some difficulty in any two domains, 3.5% (2.3–5.1) a lot of difficulty in any one, and 0.9 (0.5–1.7) inability to do any one. This trend repeated when disaggregated by basic versus complex domains in

both countries, with higher proportions identified in Cameroon at the level of some difficulty in one, or two domains (basic or complex) than India, but similar, much lower prevalence estimates at the higher levels of difficulty.

Table 4 presents overall endorsement of basic and complex domains disaggregated by age. Children in the youngest age group (2–4) were least likely to have any difficulties in any domains in both countries ($p < 0.001$). In Cameroon, age group was strongly associated with reporting some difficulty in one or more basic or complex domain ($p < 0.001$), but there was no clear trend by age. In India, age group was associated with reporting some difficulty in one or more complex domain ($p < 0.01$) only. Reporting a lot of difficulty or higher in any basic or complex domain was not significantly different by age group in either country. There was no statistical difference by sex in overall endorsement of basic and complex domains in either country (data not shown).

Table 5 presents the overall proportion of children in Cameroon and India reporting at least some difficulty and at least a lot of difficulty by specific domain.

4.2. Results by functional domain in Cameroon

In Cameroon, the most commonly reported limitations in basic domains at the some or greater difficulty level were learning and remembering (20.8% and 28.8% of children 2–17 and 5–17 respectively, Table 5). Common difficulties in other basic functional domains were at least some difficulty hearing (7.6%) or seeing (5.8%).

The most common complex domains in which at least some difficulty was reported were controlling behaviour (23.2% of children 2–17), accepting change (22.6% of children 5–17) and feeling worried/sad (20.0% of children 5–17). Less than 1% of the sample in Cameroon reported a lot of difficulty or higher in any basic domain, with the exception of remembering (1.1% of 5–17 year olds). Amongst complex domains, 3.2% of children 2–17 reported a lot of difficulty or higher controlling their behaviour, 3.4% of children aged 5–17 reported a lot of difficulty or higher with worrying or feeling sad, and 2.0% of children aged 5–17 reported a lot of difficulty or higher in accepting change. Less than 2% reported a lot of difficulty or more in completing tasks (1.6%), playing (0.6%) or getting along with other children. There were no statistically significant differences by sex in any specific domain at any degree of difficulty (data not shown here).

Table 6 (overleaf) stratifies the proportion of children in Cameroon and India reporting at least some difficulty in each basic and complex domain by age group. In Cameroon, reporting at least some difficulty in seeing and hearing (2–17 years), and remembering and feeling worried/sad (5–17 years) were positively associated with age group ($p < 0.001$–$p < 0.01$), whilst being understood (2–17 years), self-care and completing a task (both age 5–17) were negatively associated ($p < 0.01$). Walking, learning and playing (all 2–17 years) were all associated with age ($p < 0.05$), but with no directional trend. There were no significant differences by age in the proportions of children reported to experience a lot of difficulty or inability to complete any basic domain or complex domains, although cell sizes were very small (data not shown here).

4.3. Results by functional domain in India

Basic domains related to cognition were the most frequently reported in India (some or greater difficulty in understanding: 7.6%, being understood: 7.0%, learning: 11.4% and remembering: 17.4%), whilst less than five percent reported some or greater difficulty in the remaining basic domains (seeing: 4.2%, hearing: 3.5%, walking: 3.5% and self-care: 3.8%), as shown in Table 5. Commonly reported complex domains included 10.7% of children aged 2–17 reporting at least some difficulty in controlling behaviour, and amongst those aged 5–17, 8.2% reporting at least some difficulty completing tasks and 6.8% feeling worried or sad. Less than two percent of children reported a lot of difficulty or greater in any basic or complex domain.

There were generally no clear differences by sex in reporting some or greater difficulty in different domains (data not shown here), and fewer associations between specific domains and age group than in Cameroon (Table 6). Some or greater difficulty understanding (2–17) or with self-care (5–17) were negatively associated with age ($p < 0.05$), whilst seeing, walking and learning (all 2–17) were associated but showed no trend.

4.4. Relationship between endorsed domains

Appendix 1 presents the pairwise correlation matrix between domains for Cameroon endorsed at the level of some difficulty or higher. No strong, significant relationships ($r > 0.7$, $p < 0.05$) were identified between any two domains. A moderate positive relationship was identified between understanding and being understood ($r = 0.55$, $p < 0.05$). Weak but significant positive relationships were also identified between remembering and learning, and between completion of a task and accepting change (both $r = 0.36$, $p < 0.05$).

In India, the only strong and statistically significant pairwise relationship at the level of some or greater difficulty was between understanding and being understood ($r = 0.77$, $p < 0.05$), presented in Appendix 2. Four pairs demonstrated moderate positive relationships, and 20 pairs demonstrated weak but positive relationships. In particular, at least some difficulty playing was significantly associated (all $p < 0.05$) with at least some difficulty in the domains of self-care, understanding, being understood, learning, worrying/feeling sad, controlling behaviour, completing tasks, accepting change and getting along with others. Similarly, at least some difficulty in getting along with others was significantly associated with at least some difficulty in self-care, being understood, worrying/feeling sad, completing tasks and accepting change.

4.5. Single question on disability

In the Indian sample, 2.5% answered “yes” to the question “do you consider yourself [age 9–17]/your child [age 2–8] to have a disability” (Table 7). Less than one percent of those who did not report any difficulties in any domain answered affirmatively, compared with 6% of those who reported some or greater difficulty in any domain, and 44.7% of those who reported a lot or greater difficulty in any domain.

5. Discussion

5.1. Aggregate domain endorsement

Two thirds of the sample in Cameroon reported at least some difficulty in at least one domain, compared with one third in India. Just under half of the sample reported some difficulty in any basic (43.7%) or complex (43.1%) domain in Cameroon, compared with 28.0% and 17.3% respectively in India. However, at the higher threshold of a lot of difficulty or greater, less than three percent reported difficulties in any basic domain in either country (2.5% in Cameroon and 2.0% in India), and less than ten percent in any complex domain (7.4% and 2.3% respectively). At the highest level cannot do, less than one percent in either country reported difficulties in either basic or complex domains. Gender does not appear to be related to functional limitations as endorsed in this study in either country. However, children in the youngest age group (2–4) were least likely to report any difficulties in any domain in either country, albeit with no discernible trend at the aggregate level.

As already discussed, there are limited available data with which to compare these findings. The Cameroon MICS (2006) estimated a prevalence of 13.9% amongst children 2–9 in North West Cameroon using the Ten Questions (TQ) tool (Institut National de la Statistique, 2012). The tool was used in the study without a second-stage assessment, which is estimated to lead to 300% overestimation of serious disability (Durkin et al., 1995). Data from the Indian Census (2011) estimates disability amongst children 0–9 in India of 1.6% at the national level (Government of India Ministry of Home Affairs, 2011). The census used a disability screener (“Is this person mentally/physically disabled”) followed by a list of 8 types of disability; a method previously shown to underestimate the proportion of people with disabilities (Mont, 2007; Office of the Registrar General and Census Commissioner, 2013).

The large variation between the all-age proportion of children reported to have “some” difficulty between Cameroon and India may suggest different cultural interpretations of the term, reinforcing the importance of contextual translation. In addition, lowest agreement between countries was found in the 9–12 age group, who were the youngest group to self-report. This may indicate that this age group is not consistent in self-reporting, adding to debate on proxy versus self-report in children.

The all-age aggregate domain similarity between countries at the higher thresholds of “a lot of difficulty” and “cannot do” may suggest that whilst “some difficulty” may be reported in relation to regular variation in the child’s general development, this is distinct to reporting a perceived substantial limitation at the level of “a lot of difficulty” or “cannot do”.

5.2. Endorsement by domain

Domain-specific analyses provide further insight. In both countries, reporting some difficulty in basic domains related to cognition (learning, remembering, understanding, being understood) was higher (up to 30%) than sensory or mobility domains, or self-care (less than ten percent) in both countries. Some or greater difficulty in complex domains were generally endorsed more frequently than basic domains, ranging between 4% and 24% in Cameroon, and 5% and 11% in India. Most commonly these were controlling behaviour,

accepting change and feeling worried or sad. It will be important to further probe whether these responses are related to functional limitation or natural variations in child development appropriate to age.

No individual domains (basic or complex) in either country were endorsed at the level of a lot or greater difficulty by more than five percent of the respective samples, and the majority were endorsed by less than one percent.

5.3. Endorsement by age group

Further breakdown of domain endorsement by age group shows numerous directional and non-directional associations between reporting some or greater difficulty and age group.

A significantly higher proportion of young children aged 2–4 were reported to experience at least some difficulties in domains related to milestones of early childhood development (walking, understanding, being understood, learning) than older children. Gladstone et al. (2010) examined the reliability in Malawi of several tools developed in High Income settings to assess early childhood development. The study found that items related to gross motor or language development milestones were generally reliable, but items related to social skills showed poor reliability in a Malawian setting (Gladstone et al., 2010).

Older children were also more likely to report “some” difficulties in seeing, hearing and remembering than younger children (whose caregivers reported on their behalf) in Cameroon. Similarly, older children were also more likely to report some difficulty seeing in India. Previous studies have shown that caregivers may experience difficulty identifying sensory impairments in children at an early age, which may account for the comparatively lower proportions of parental-reported younger children reported to experience sensory limitations (Omondi, Ogol, Otieno, & Macharia, 2007; Rahi, Cumberland, & Peckham, 2010).

Further, the reliance on proxy report adds a second dimension of complexity given potential for mis-reporting by caregivers (Eiser & Morse, 2001). Older children (who self-reported) were significantly more likely to report feeling worried/sad than younger children (reported for by proxy) in Cameroon. A systematic review of the relationship between parental and child self-reported health-related quality of life (HRQoL) found greater agreement on “observable” functioning such as physical functioning and symptoms of somatic distress, and lower agreement in domains related to emotional or social HRQoL issues (Eiser & Morse, 2001). Further work is needed to validate whether parental report on emotional and behavioural domains are acceptably in agreement with the perspective of the child.

5.4. Pairwise Domain Relationships

Limited pairwise correlations were identified in either country. Namely, with the exception of a strong and predictable correlation between at least some difficulty in both understanding and being understood in India (and none in Cameroon), there were no strong statistically significant pairwise relationships between domains to justify combination algorithms of reporting some difficulty in two or more domains as a threshold for prevalence estimations.

5.5. Comparison with a Single Question

The inclusion of a single question on disability perception in India further emphasises the need for the UNICEF/Washington Group module. Less than 2.5% of the overall sample responded affirmatively to this question, including less than half of those who reported a lot of difficulty or greater in one or more domain. This shows that not only does a single question lead to under report of significant limitations in functioning in children, but also the clear difference between reporting some difficulty in functioning (6% of who also responded yes to the singe question) and a lot of difficulty/inability to complete (44.7%).

5.6. Strengths and Limitations

The study sample in Cameroon and India of a combined 2814 children aged 2–17 represents one of the first field tests of the draft UNICEF/Washington Group module on child functioning and disability. This data is urgently needed to respond to calls for a consistent method for child disability data collection and disaggregation.

A potential limitation of the study is that all children aged 9 and above who were able to communicate independently were interviewed directly in the presence of a primary caregiver, whist children aged 2–8 or unable to communicate independently were interviewed via adult proxy report. Consequently, the findings are part parental-reported and part self-reported by children, which limit comparability between age groups.

In addition, further comprehensive field tests by UNICEF and the Washington Group, including comparison of findings against established tools, determination of response distributions, module behaviour tests (e.g. non-response rates and sample-size calculations) were completed in mid-2015. These results and the final version of the module will be presented in a separate publication, and may not be fully reflected in the results presented here.

5.7. Implications for further research

The very high and moderately high proportions of children reported to have at least “some” difficulty in one or more domain in Cameroon and India respectively warrants further investigation, to identify whether the threshold accurately identifies functional limitation or generates false positives. In particular, future research should clarify whether this issue was compounded by translation errors in Cameroon, or whether this is a common finding. The issue is further complicated by the use of a proxy respondent, given previous findings on the capacity of proxies to gauge limitations in emotional or social domains. Field testing of the final module will include probing questions to address the nuances of a parental report of “some” difficulty, so as to address this issue. Additionally, a forthcoming research study conducted by the Question Design Research Laboratory (QDRL) at the US National Center for Health Statistics (NCHS) will compare self and proxy respondents to the UNICEF/Washington Group module on child functioning and disability for a sample of youth aged 15–17 years of age and their parent.

The final round of field testing will further progress the capacity of the UNICEF/Washington Group module to adequately and accurately identify children at risk of experiencing limited

participation and consequently the availability of appropriate methodologies for generating child disability statistics.

6. Conclusions

During this field test of the draft UNICEF/Washington Group module on child functioning and disability, comparable overall estimates were generated at the “a lot of difficulty” and “cannot do” thresholds across the two study settings, although an absence of similar prevailing studies prevents us from validating or rejecting these estimates. It is hoped that this endeavour to produce a standardised questionnaire will greatly advance the collection of child disability data statistics in providing a robust and reliable methodology for the determination of disability status among children in survey settings.

Appendix 1.: Relationship between domains in India–Pearson’s Correlation Coefficient (r)

D1	*r*	1												
	p													
D2	*r*	0.0849[a]	1											
	p	0.0048												
D3	*r*	0.1319[a]	0.0984[a]	1										
	p	0	0.0011											
D4	*r*	0.1230[a]	0.1127[a]	0.1969[a]	1									
	p	0	0.0002	0										
D5	*r*	0.0939[a]	0.0956[a]	0.2781[a]	0.2705[a]	1								
	p	0.0018	0.0015	0	0									
D6	*r*	0.0851[a]	0.0847[a]	0.2557[a]	0.2651[a]	0.7663[a]	1							
	p	0.0047	0.0049	0	0	0								
D7	*r*	0.0684[a]	0.0421	0.1947[a]	0.2225[a]	0.4687[a]	0.4182[a]	1						
	p	0.0233	0.1625	0	0	0	0							
D8	*r*	0.1015[a]	0.0982[a]	0.0807[a]	0.2551[a]	0.2136[a]	0.2220[a]	0.3317[a]	1					
	p	0.0007	0.0011	0.0074	0	0	0	0						
D9	*r*	0.0914[a]	0.0655[a]	0.1508[a]	0.2420[a]	0.2203[a]	0.2194[a]	0.2200[a]	0.2803[a]	1				
	p	0.0024	0.0298	0	0	0	0	0	0					
D10	*r*	0.1331[a]	0.0632[a]	0.2195[a]	0.2146[a]	0.2875[a]	0.2849[a]	0.2647[a]	0.3228[a]	0.2435[a]	1			
	p	0	0.0361	0	0	0	0	0	0	0				
D11	*r*	0.0745[a]	0.0719[a]	0.0897[a]	0.2792[a]	0.2728[a]	0.3050[a]	0.2441[a]	0.2931[a]	0.2495[a]	0.4709[a]	1		
	p	0.0134	0.017	0.0029	0	0	0	0	0	0	0			
D12	*r*	0.1090[a]	0.0316	0.0778[a]	0.2979[a]	0.2366[a]	0.2862[a]	0.1727[a]	0.2725[a]	0.3202[a]	0.3951[a]	0.5889[a]	1	
	p	0.0003	0.2951	0.0098	0	0	0	0	0	0	0	0		
D13	*r*	0.1319[a]	0.0445	0.0962[a]	0.3409[a]	0.2966[a]	0.3135[a]	0.2567[a]	0.2950[a]	0.4781[a]	0.2989[a]	0.4098[a]	0.5067[a]	1
	p	0	0.1399	0.0014	0	0	0	0	0	0	0	0	0	
D14	*r*	0.0787[a]	0.1183[a]	0.2750[a]	0.3054[a]	0.4100[a]	0.3665[a]	0.3297[a]	0.2273[a]	0.3755[a]	0.3020[a]	0.3513[a]	0.4201[a]	0.6163[a]
	p	0.009	0.0001	0	0	0	0	0	0	0	0	0	0	0
		D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11	D12	D13

Key: D1 Seeing, D2 Hearing, D3 Walking, D4 Self-Care, D5 Understanding, D6 Being Understood, D7 Learning, D8 Remembering, D9 Feeling worried/sad, D10 Controlling Behaviour, D11 Completing a Task, D12 Accepting Change, D13 Getting along with other children, D14 Playing.

[a]Indicate that r is statistically significant at the 5% significance level.

Appendix 2.: Relationship between domains in Cameroon–Pearson's Correlation Coefficient (r)

D1	*r*	1													
	p														
D2	*r*	0.0896[a]													
		0.0002													
D3	*r*	0.029	0.0675[a]	1											
	p	0.2305	0.0052												
D4	*r*	−0.0187	0.0421	0.0824[a]	1										
	p	0.4399	0.0816	0.0006											
D5	*r*	0.0003	0.0855[a]	0.0393	0.1151[a]	1									
	p	0.9887	0.0004	0.104	0										
D6	*r*	0.014	0.0996[a]	0.0419	0.1059[a]	0.5457[a]	1								
	p	0.5621	0	0.0828	0	0									
D7	*r*	0.0084	0.1243[a]	0.0800[a]	0.0791[a]	0.2309[a]	0.1921[a]	1							
	p	0.7275	0	0.0009	0.0011	0	0								
D8	*r*	0.0572[a]	0.1451[a]	0.0673[a]	0.1137[a]	0.1055[a]	0.0987[a]	0.3610[a]	1						
	p	0.0178	0	0.0053	0	0	0	0							
D9	*r*	0.0835[a]	0.0740[a]	0.0646[a]	0.1020[a]	0.0679[a]	0.0652[a]	0.1143[a]	0.2369[a]	1					
	p	0.0005	0.0022	0.0075	0	0.0049	0.007	0	0						
D10	*r*	0.0478[a]	0.0359	0.0088	0.0573[a]	0.1018[a]	0.1080[a]	0.1508[a]	0.1457[a]	0.1010[a]	1				
	p	0.0481	0.1375	0.7149	0.0176	0	0	0	0	0					
D11	*r*	−0.0255	0.005	0.0382	0.1752[a]	0.0625[a]	0.0517[a]	0.1388[a]	0.1796[a]	0.0795[a]	0.1769[a]	1			
	p	0.2908	0.8372	0.1137	0	0.0096	0.0325	0	0	0.001	0				
D12	*r*	0.0221	0.0222	0.0366	0.1960[a]	0.0747[a]	0.0087	0.2045[a]	0.2658[a]	0.2226[a]	0.2326[a]	0.3611[a]	1		
	p	0.3616	0.3584	0.1295	0	0.002	0.7195	0	0	0	0	0			
D13	*r*	0.0493[a]	0.0184	0.0819[a]	0.0958[a]	0.1325[a]	0.1065[a]	0.1080[a]	0.1272[a]	0.1102[a]	0.1390[a]	0.1109[a]	0.1966[a]	1	
	p	0.0415	0.4465	0.0007	0.0001	0	0	0	0	0	0	0	0		
D14	*r*	0.0511[a]	0.0086	0.0164	0.0824[a]	0.1025[a]	0.1474[a]	0.1434[a]	0.0736[a]	0.0487[a]	0.1267[a]	0.1239[a]	0.1220[a]	0.2544[a]	1
	p	0.0346	0.7233	0.4968	0.0006	0	0	0	0.0023	0.0439	0	0	0	0	
		D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11	D12	D13	D14

Key: D1 Seeing, D2 Hearing, D3 Walking, D4 Self-Care, D5 Understanding, D6 Being Understood, D7 Learning, D8 Remembering, D9 Feeling worried/sad, D10 Controlling Behaviour, D11 Completing a Task, D12 Accepting Change, D13 Getting along with other children, D14 Playing.

[a]Indicates that r is statistically significant at the 5% significance level.

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Table 1

Module domains.

Basic function domains		Complex function, emotion and participation domains	
D1	Seeing	D9	Feeling worried/sad[a]
D2	Hearing	D10	Controlling behaviour
D3	Walking	D11	Completing a task[a]
D4	Self-care[a]	D12	Accepting change[a]
D5	Understanding	D13	Getting along with other children[a]
D6	Being understood	D14	Playing
D7	Learning		
D8	Remembering[a]		

[a]Children 5–17 only.

Table 2

Cohort descriptors.

	Cameroon			India		
	Male	Female	Total	Male	Female	Total
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (100%)
2–4	166 (19.6)	200 (23.2)	366 (21.4)	113 (19.7)	120 (22.8)	233 (21.2)
5–8	270 (31.8)	237 (27.4)	507 (29.6)	163 (28.4)	140 (26.6)	303 (27.5)
9–12	222 (26.2)	226 (26.2)	448 (26.2)	138 (24.0)	135 (25.7)	273 (24.8)
13–17	191 (22.5)	201 (23.3)	392 (22.9)	161 (28.0)	131 (24.9)	292 (26.5)
Total	849 (100)	864 (100)	1713 (100)	575 (100)	526 (100)	1101 (100)

Table 3

Aggregate domain endorsement in Cameroon and India.

	Cameroon, *n* = 1713 % (95% CI)	**India, *n* = 1101 % (95% CI)**
No difficulty in any domain	36.1 (32.4–40.1)	65.1 (60.8–69.2)
All domains		
At least some difficulty in one domain	63.9 (60.0–67.6)	34.9 (30.8–39.2)
At least some difficulty in two domains	42.0 (38.0–46.0)	19.8 (16.5–23.6)
At least a lot of difficulty in one domain	8.9 (7.1–11.2)	3.5 (2.3–5.1)
At least cannot do in one domain	0.7 (0.4–1.2)	0.9 (0.5–1.7)
Basic domains		
At least some difficulty in one domain	43.7 (39.8–47.8)	28.0 (24.1–32.2)
At least some difficulty in two domains	19.7 (17.0–22.7)	12.3 (9.7–15.4)
At least a lot of difficulty in one domain	2.5 (1.8–3.5)	2.0 (1.2–3.4)
At least cannot do in one domain	0.4 (0.1–0.9)	0.7 (0.4–1.4)
Complex domains		
At least some difficulty in one domain	43.1 (39.7–46.5)	17.3 (14.0–21.1)
At least some difficulty in two domains	18.3 (16.1–20.8)	7.1 (5.3–9.4)
At least a lot of difficulty in one domain	7.4 (5.7–9.5)	2.3 (1.5–3.5)
At least cannot do in one domain	0.6 (0.3–1.0)	0.5 (0.2–1.3)

Table 4

Aggregate domain endorsement in Cameroon and India.

	2 to 4		5 to 8		9 to 12		13 to 17		χ^2	*p*
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**		
Cameroon										
No difficulty in any domain	193	52.7	172	33.9	139	31.0	115	29.3	57.7	< 0.001
Basic Domains										
At least some difficulty in one domain	101	27.6	207	40.8	229	51.1	213	54.3	68.3	< 0.001
At least some difficulty in two domains	40	10.9	79	15.6	118	26.3	101	25.8	44.8	< 0.001
At least a lot of difficulty in one domain	7	1.9	13	2.6	11	2.5	12	3.1	1.0	0.8
At least cannot do in one domain	1	0.3	5	1.0	0	0	0	0	8.9	< 0.05
Complex domains										
At least some difficulty in one domain	81	22.1	257	50.7	209	46.7	191	48.7	84.9	< 0.001
At least some difficulty in two domains	4	1.1	124	24.5	103	23.0	83	21.2	94.0	< 0.001
At least a lot of difficulty in one domain	27	7.4	44	8.7	31	6.9	24	6.1	2.3	0.5
At least cannot do in one domain	0	0	8	1.6	1	0.2	1	0.3	12.5	< 0.01
India										
No difficulty in any domain	169	72.5	193	63.7	173	63.4	182	62.3	7.3	0.06
Basic domains										
At least some difficulty in one domain	55	23.6	82	27.1	80	29.3	91	31.2	4.0	0.3
At least some difficulty in two domains	25	10.7	46	15.2	33	12.1	31	10.6	3.7	0.3
At least a lot of difficulty in one domain	5	2.2	5	1.7	6	2.2	6	2.1	0.3	1.0
At least cannot do in one domain	4	1.7	1	0.3	1	0.4	2	0.7	4.3	0.2
Complex domains										
At least some difficulty in one domain	22	9.4	59	19.5	53	19.4	56	19.2	12.7	< 0.01
At least some difficulty in two domains	4	1.7	25	8.3	21	7.7	28	10.0	13.8	< 0.01
At least a lot of difficulty in one domain	6	2.6	7	2.3	6	2.2	6	2.1	0.2	1.0
At least cannot do in one domain	1	0.4	1	0.3	2	0.7	1	0.3	0.7	0.9

Table 5

Proportion endorsing each domain–Cameroon and India.

	Cameroon				India			
	At least some difficulty		A least a lot of difficulty		At least some difficulty		At least a lot of difficulty	
	n	%	*n*	%	*n*	%	*n*	%
Basic domains								
2–17								
Seeing	99	5.8	6	0.4	46	4.2	3	0.3
Hearing	130	7.6	6	0.4	38	3.5	5	0.5
Walking	93	5.4	13	0.8	39	3.5	9	0.8
Understanding	86	5.0	6	0.4	84	7.6	10	0.9
Being understood	83	4.9	7	0.4	77	7.0	8	0.7
Learning	357	20.8	11	0.6	125	11.4	10	0.9
5–17[a]								
Remembering	388	28.8	15	1.1	151	17.4	7	0.8
Self-care	79	5.9	4	0.3	33	3.8	6	0.7
2–17								
Controlling behaviour[b]	397	23.2	55	3.2	118	10.7	11	1.0
Playing	69	4.0	11	0.6	54	4.9	12	1.1
5–17[a]								
Feeling worried/sad[b]	270	20.0	46	3.4	59	6.8	7	0.8
Completing task	253	18.8	22	1.6	71	8.2	8	1.0
Accepting change	305	22.6	27	2.0	49	5.6	9	1.0
Getting along with other children	59	4.4	5	0.4	39	4.5	9	1.0

[a] Question valid age 5–17 only, denominator reflects this.

[b] Maximum option is “a lot more”, not “cannot” for this question.

Table 6

Proportion endorsing at least Some Difficulty in Cameroon and India.

	Cameroon										India									
	2 to 4		5 to 8		9 to 12		13 to 17		χ^2	*p*	2 to 4		5 to 8		9 to 12		13 to 17		χ^2	*p*
	n	%	*n*	%	*n*	%	*n*	%			*n*	%	*n*	%	*n*	%	*n*	%		
Basic domains																				
2–17																				
Seeing	6	1.6	17	3.4	33	7.4	43	11.0	38.5	< 0.001	3	1.3	3	1.0	15	5.5	25	8.6	27.8	< 0.001
Hearing	7	1.9	28	5.5	45	10.0	50	12.8	38.7	< 0.001	3	1.3	12	4.0	14	5.1	9	3.1	5.9	0.1
Walking	17	4.6	19	3.8	24	5.4	33	8.4	10.1	< 0.05	15	6.4	4	1.3	8	2.9	12	4.1	10.7	< 0.05
Understanding	28	7.7	23	4.5	21	4.7	14	3.6	7.4	0.06	26	11.2	26	8.6	17	6.2	15	5.1	7.8	< 0.05
Being understood	30	8.2	22	4.3	17	3.8	14	3.6	11.7	< 0.01	23	9.9	23	7.6	16	5.9	15	5.1	5.2	0.2
Learning	69	18.9	84	16.6	115	25.7	89	22.7	13.6	< 0.01	39	16.7	34	11.2	23	8.4	29	9.9	9.6	< 0.05
5–17 only[a]																				
Remembering	–	–	112	22.1	140	31.3	136	34.7	19.1	< 0.001	–	–	53	17.5	46	16.8	52	17.8	0.1	1.0
Self-care	–	–	60	11.8	16	3.6	3	0.8	55.5	< 0.001	–	–	19	6.3	8	2.9	6	2.1	8.1	< 0.05
Complex domains																				
2–17																				
Controlling behaviour	92	25.1	118	23.3	108	24.1	79	20.2	3.0	0.4	16	6.9	32	10.6	33	12.1	37	12.7	5.3	0.2
Playing	15	4.1	21	4.1	9	2.0	24	6.1	9.2	< 0.05	14	6.0	12	4.0	14	5.1	14	4.8	1.2	0.7
5–17 only[a]																				
Feeling worried/sad[b]	–	–	84	16.6	85	19.0	101	25.8	12.1	< 0.01	–	–	18	6.0	18	6.6	23	7.9	0.9	0.6
Completing task	–	–	132	26.0	72	16.1	49	12.5	29.8	< 0.001	–	–	26	8.6	18	6.6	27	9.2	1.4	0.5
Accepting change	–	–	122	24.1	102	22.8	81	20.7	1.5	0.5	–	–	20	6.6	9	3.3	20	6.8	4.1	0.1
Getting along with other children	–	–	24	4.7	15	3.3	20	5.1	1.8	0.4	–	–	13	4.3	11	4.0	15	5.1	0.4	0.8

[a]Questions valid age 5–17 only, denominator reflects this.

[b]Maximum option is “a lot more”, not “cannot” for this question.

Table 7

Single question responses in India.

	n	Yes		No	
		n	%	*n*	%
No difficulty in any domain	717	4	0.6	713	99.4
Some or greater difficulty in one or more domain	384	23	6.0	361	94.0
A lot or greater difficulty in one or more domain	38	17	44.7	21	55.3
Total	1713	27	2.5	1074	97.6