

Testing the New UNICEF/WG Survey Module on Child Functioning and Disability in South Africa

1. Introduction/Background:

The issue of disability and its prevalence is of national and global interest. More so, the issue especially as it has to do with childhood disability is even of more concern especially in the recent time. This is so as the number of children with disabilities is not only said to be substantial, but grossly underestimated. Requiring special need and attention, evidence suggests that children with disability account for a large proportion of children who drop out and do not complete primary education especially in sub-Saharan Africa (Rosenbaum, 2009; Natasha, 2014). Statistically, evidence suggest that broadly, people with disabilities make up approximately 10 percent of the world's population and may constitute up to 20 percent of the world's poorest people (Elwan, 1999, UN, 2011). And generally, on average; children and young people with disabilities constitute about 4-6.5% of these population in many countries (Rosenbaum, 2009).

The 2015 Sustainable Development Goals (SDGs) as an amendment of the Millennium Development Goal (MDG) committed to a new global partnership to reduce extreme poverty and setting out a series of time-bound targets (UN, 2000). Yet, there seemed to be a striking gap in those SDG's with respect to persons with disabilities. There is no mention of the issue of disability across any of the 8 goals and their targets or indicators to see to the estimated 10% of the world population (about 1 billion people worldwide) who is believed to live with one or more physical, sensory (blindness/deafness), intellectual or mental health impairments (UN, 2011). As a result of these and in the face of a growing consensus among researchers, experts and disability advocates that in order to address poverty effectively across the globe, there is a need not only to address the issues faced by persons with disabilities, but to also specifically give special attention to children with disabilities as they are not only part of the features but also the leaders of tomorrow.

Also, there is a growing concern as evidence suggests a large information gaps existing with regards to what is known about disabilities especially amongst children internationally. Among others, these concerns include limited comparable and reliable data on disabilities amongst children, their activity limitations, definitional (sensitivity issues) and measurement issues. This is particularly so having it in mind that the concept of disability is an evolving phenomenon. Therefore, since 2001, the Washington Group on Disability Statistics (WG) has been involved in promoting and co-ordinating international co-operation in the area of health statistics, focusing on disability measures suitable for censuses and national surveys, in order to promote internationally comparable disability measurement and statistics. In line with these, the group proposed a new survey module on how to measure child functioning and disability for use in surveys and censuses across the globe.

The proposed module provides adequate validity and reliability for measurement of prevalence of disabilities amongst children in the target age group of 2 to 17 years old. And was born out of the fact that an earlier model proposed as a standard tool in measuring disability by the group was not suitable in measuring disability in children who are still going through the developmental stages to adulthood. Therefore, to address these gaps; Statistics South Africa (Stats SA) in collaboration with the Department of Social Development (DSD) and the United Nations Development Programme (UNDP) South Africa, in line with what have been done in other countries (India, USA, Belize, Oman, Montenegro, Cameroun, Italy and Haiti), conducted series of research into the viability of this new module for the child disability measurement in its future national census and surveys. The general objective of the study was to tests the new UNICEF/WG survey module on child functioning and disability in South Africa by testing various specific objectives. This paper briefly outlines how the research study was conducted, findings and recommendations.

2. Methodology:

2.1 Study Design and Analysis:

The study is a case study research using primary data collected in an uncontrolled and controlled (“Glass test”) environment. Adopting a mixed method (qualitative and quantitative) approach, the qualitative approach involved the use of a two phase qualitative project in testing the use of the UNICEF/WG childhood disability measurement module for household based surveys in South Africa. These are the Focus Group Discussions (FGD) and the In-depth interviews (IDI). The quantitative approach of the study is basically validity enquiries through the calculation of the true positive rate (definitional test), timing and associations using the Fishers Model test.

In the first phase of the qualitative study, a series of focus groups were conducted with parents/caregivers of children with disabilities across various communities. The results from the focus groups were used to refine the module to ensure semantic and conceptual equivalence (in terms of the layout, question wording and response categories) based on the South African context. The revised module was then administered during the second phase to parents/caregivers of children in a controlled environment in order to assess the effectiveness of the module in a survey setting across varying respondent profiles in terms of age, population group, LSM and child disability status. On the other hand, in the quantitative approach, i.e., the research second phase, a further three tests of measures in different natures were conducted by the research team. These are the definitional or sensitivity, average time taken and the Fishers Exact model test respectively. During the setup of the interviews 15 Parents/caregivers (drawn from the overall respondents) were selected for the interview based on the fact that they had at least 1 child (in the reference age range of 2 to 17 years old) in their care who was disabled. Test was done at a 10% significance level, expressing findings in graphs, figures and tables.

2.2 Target Population, Sample size and processing:

Overall, the target population of the study are purposefully selected parents/caregivers of children with or without disabilities, depending on the phase of study. Specifically, participants of the focus groups were selected parents/caregivers of children aged 2-17 years with disabilities. The language pre-test FGDs were conducted as a series of seven (7) focus groups each in a different language. The selected languages were Afrikaans, IsiXhosa, IsiZulu, Tshivenda, Xitsonga, Setswana and Sepedi. The languages were chosen because combined they are the most spoken languages in South Africa. The UNICEF/WG module of questions to measure childhood disability was translated into each of the selected languages and the translated modules were used to develop the discussion and notetaking guides to use during the focus groups so that discussions in the sessions can also be conducted in those languages. The focus groups were conducted in Cape Town (Afrikaans and IsiXhosa), Pinetown, KwaZulu-Natal (IsiZulu), Soweto (Setswana, Tshivenda and Xitsonga) and Polokwane (Sepedi). Participants of the focus groups were parents/caregivers of children aged 2-17 with disabilities and also speaking the language through which the focus group was to be moderated. The parents/caregivers were recruited with the help of disability organisations operating in those areas, and it was required that they reside around the areas where focus groups were to be conducted to minimise travelling. A total of 42 participants took part in the focus groups and there were 4-10 participants per focus group. The focus groups were also audio-recorded and the collected information was analysed.

With the in-depth interview, a total of 32 parents/caregivers of children aged between 2 and 17 years were selected based on different profiles of population group, age group, living standards (using the living standards measure (LSM)) and disability status of the child (i.e. whether the child has a disability or not). Different profiles of respondents were selected to ensure that the testing of the module was undertaken on a diverse sample covering different scenarios that might be encountered in the field. Half of the respondents (16 respondents) were parents/caregivers of children aged between 2 and 4 years old and the other half were parents/givers of children aged between 5 and 17 years old.

3. Findings:

Figure 1: Respondents' understanding of the term "difficulty" by age group

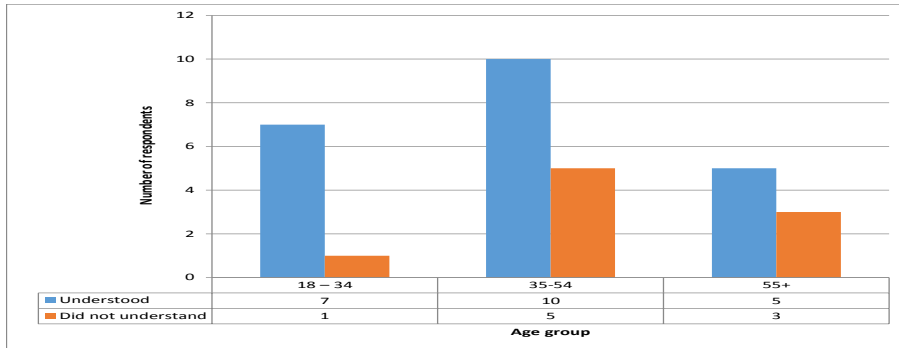


Figure 2: Respondents understanding of the term "difficulty" by LSM group

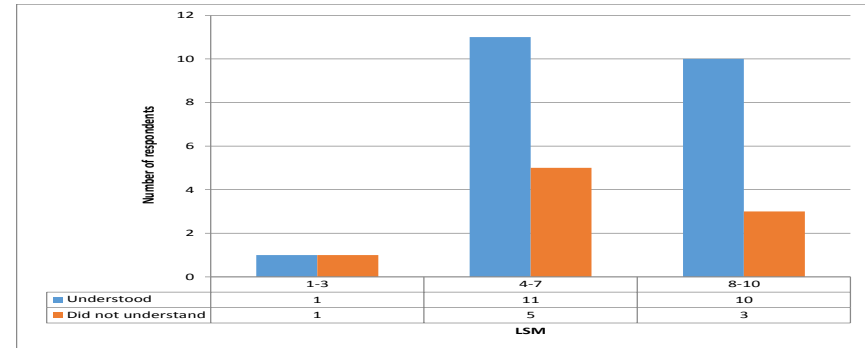


Figure 3: Respondents' understanding of the term "difficulty" by population group

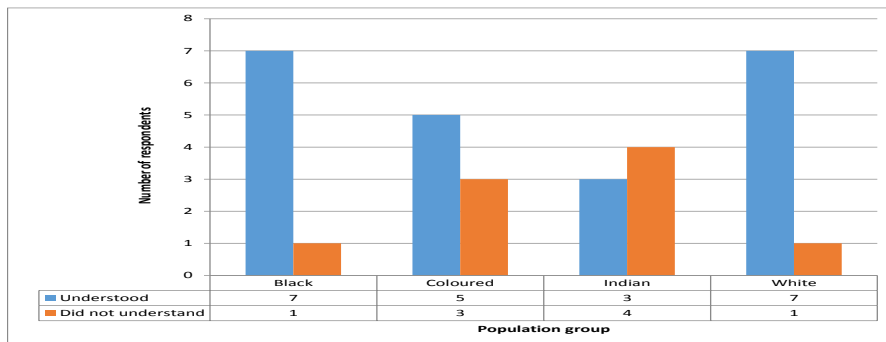
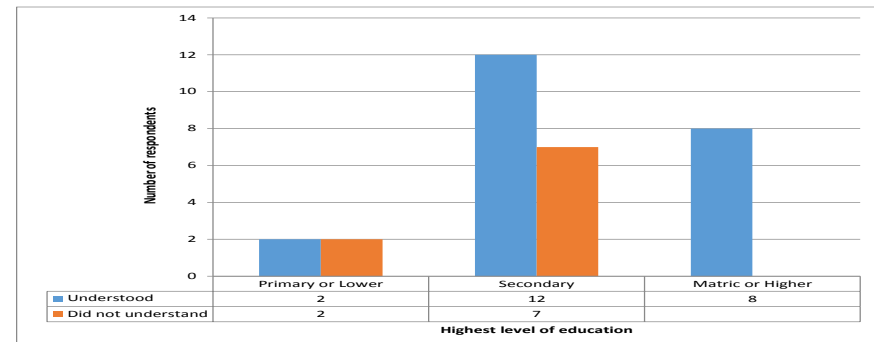


Figure 4: Understanding of the term "difficulty" by level of education



4. Discussions, Conclusion and Recommendations:

Overall, the first phase of the research study i.e., Focus Group Discussions (FGD) resulted in some changes to the initial module in terms of the layout, question wording and response categories used. The revised module was then tested in a controlled survey setting (“Glass test”) during the second phase. In general, both the 2 to 4 year module and 5 to 17 year module were found to have adequate reliability in measuring childhood disabilities. The observation of the interviews indicated that generally there was good flow during the interview in terms of the communication and understanding of the module content between the interviewer and respondent, with some minor revisions required on some of the response options in order to provide further clarification to respondents (for example, the response option “a few times a year”). During the study it was also found that level of understanding and ease in responding to some of the questions was related to the education level, LSM and/or age of the respondents being interviewed.

Specifically, in the in-depth study, issues were observed among parents/caregivers of children with disability especially with that of aged 2-4 years old. Among others, issues observed include the loss of concentration/focus by the respondent, as well as further clarification required by the interviewer. Others are the issue of hesitation/unease like when answering questions about moving around, etc. However, with the 5-17 years module, all domains were observed to have no further issues. Few issues observed with the module were however observed under the Africans respondent and mostly in the seeing and self-care domains. The result shows that almost all the respondent in the In-depth interview understand the analogy of a soccer field.

In the focus groups discussion, a number of key characteristics of the childhood disability module were investigated and some notable points were made/observed across all the focus groups. In general, the result however shows a contrast of finding from the In-depth interview and the focus group in terms of the use of analogy of a soccer field, understanding of “*Somewhere between a little and a lot of concern*” and original list vs the revised list even by disability function and demographic profile. Overall, the result shows that most respondent prefer the original list as compared to the revised list in all list test carried out.

In terms of time taken to complete the module, the 2 to 4 year old module took on average 6 minutes to complete per household (with 18 questions), while the 5 to 17 year module took on average 20 minutes to complete per household (with 43 questions). The number of questions in the module and time taken to complete (especially for the 5 to 17 module) could pose some issues in terms of respondent burden and length of interview if these modules are to be used in general surveys settings with multiple themes competing for interview space. Also, the results show that the expanded definition is able to correctly classify all the children in the reference group with a disabled status (i.e. 100%) and the moderate definition only 80%. The strict definition is the list as it only manages to capture 40% of the disabled children in the 2 to 4 year age group and 67% in the 5 to 17 year age group using the module responses. Although the type of definition used is related to the level of disability that the child experiences (i.e. a mild, moderate or severe form of disability) the results clearly show that in order to adequately identify disabilities amongst children the expanded definition is the most appropriate. Fishers test carried out in the study reveals that all tested variable were significant at 5% and 10% level of significant. Thus further complementing the findings from the Focus Group Discussions (FGD) and In-depth Interviews (IDI) carried out earlier in the study.

Overall the results concludes that the childhood disability module/s as it was tested by the research team can be used in household surveys to adequately measure childhood disabilities in South Africa. However, there are some recommended minor revisions necessary in order to improve the modules based on the interviews undertaken during this study.