ISWP Evidence-based Practice Working Group
Data Collection Subcommittee

August 17th, 2017 Meeting Recap

The ISWP Evidence-based Practice Working Group Data Collection Subcommittee met by conference call on Thursday, August 17th, 2017 from 10:00 a.m. to 11:00 a.m. U.S. Eastern Time. This provides a recap.

Link to Meeting Recording: **https://iswp.adobeconnect.com/pabafn70lil2/**

Next Meeting: Thursday, September 21st, 2017 at 10:00 am U.S. Eastern Time

Discussion (action items in bold/underline)

1. Kenya country data collection report

Norah Keitany, Skillpark, provided an overview of the data collection report for Kenya. A copy of the presentation is attached. The original plan was to collect data in all 47 counties throughout the country; however, due to time and budget limitations, Skillpark gather information on 16 counties which comprise the largest concentration of the Kenyan population (population of over 40 million people). Norah feels the results do apply to the entire country based on the sampling. Presentation highlights

- *Status of UNCRPD*: Keyna signed and ratified in 2008 but did not sign the optional protocol which allows committee on rights of people with disabilities to hear and see individual complaints.

- *Policy and legislation on wheelchair services*: There are entitlements for persons with disabilities in the Bill of Rights. A Council of Persons with Disability oversees programs and policies. One policy allows persons with

disabilities to receive services such as health, education, employment and other social services.

- *Government funding*: The government allocates about US$200,000 annually to support assistive devices. It does not fund wheelchair services but does mass wheelchair distributions, which do not involved qualified wheelchair service providers.

- *Insurance for wheelchair services*: Few insurance companies support wheelchair purchases. NHIF, the leading government insurer, only funds wheelchairs for government employees.

- *Training of wheelchair professionals*: Training has been conducted through APDK and the World Vision ACCESs project. No institute currently supports training wheelchair professionals.

- *Stakeholders*:   A National Wheelchair Taskforce, created through the World Vision ACCESS project, meets regularly to discuss issues to improve wheelchair services. The taskforce helped to push for policy reforms by coming up with progressive policies such as the current National disability policy which is aimed at regulating the sector and to support the WHO guidelines.

- *Research and Publications*: Only one study has been conducted on wheelchair services – JHPIEGO's study in Kenya and Philippines in 2015. Research emphasized importance of appropriate wheelchair service provision, need to invest in research and development, and creation of strong coordination mechanism.

- *Conclusion and Recommendations*: There is a huge need for wheelchair services in the country. A coordination mechanism is lacking in every

county. There is opportunity to work with institutions of higher learning (KMTC and others) to include WHO WSTP in training curriculum. The National Council needs to enforce professionalization of wheelchair services in the country and employ qualified professionals to guide in implementation.

Chandra Whetstine commented that it has been difficult to identify a true number of people needing wheelchairs in Kenya without a thorough wheelchair screening. Norah mentioned the National Fund has a long list of people who need wheelchairs; she could ask for an approximate number.

ISWP also will receive country data collection from the wheelchair needs assessment component of the ISWP affiliate project in Romania and Philippines. We plan to upload the relevant data from Kenya, Romania and the Philippines into a wiki-like format that will be housed on the ISWP website.

2. Minimum Uniform Data Set (MUD):

a. *Questionnaire versions:* The MUD long version questionnaire is being used in UCP Wheels for Humanity's Wheelchair User's Voice Project funded by Google.org. The study is currently being piloted in Indonesia; interviewers are collecting data through tablets which use the kobotoolbox software. ISWP is exploring kobotoolbox as an open data kit option.

Karen Rispin piloted the questionnaire with primary and secondary school children in Kenya in May 2017. Karen suggests that we wait until we receive all the feedback from both primary and secondary groups before changing the MUD. We are still waiting to receive the IRB approval from LeTourneau University to look into the data and the feedback. (*Update*: IRB approval received; Karen is sending de-identified questionnaires to ISWP.)

b. *Open data kit next steps:* During the August 3 Evidence Based Working Group Call, ISWP provided a demonstration of CommCare -- one of the three open data kits ISWP is evaluating. We made the most progress with CommCare; the full survey questionnaire has been uploaded, and we tested with some mock data. We are talking with CommCare and Kobotoolbox to learn more about the cost structure and other features.

Nancy to send the latest version of the MUD questionnaire and excel to Mark Harniss so he can request his colleague to review.

Dr. Pearlman suggested group start to think about publishing a paper on the data set development in a peer reviewed journal.

Nancy to send an email to the Data Collection Subcommittee members to learn if they are interested in leading/contributing to writing the paper.

4. Open Discussion

Regarding UCP Wheels for Humanity's Wheelchair User's Voice Project funded by Google.org, Jon added that ISWP was asked to take over for MIT to help design a full-scale study to start in January 2018 in Indonesia and Nicaragua. We are in the final stages of negotiating a budget with UCP.

Participants:

    Deepan Kamaraj, University of Pittsburgh

    Maria Toro Hernandez, Universidad CES

✓   Chandra Whestine, World Vision

✓   Padmaja Kankipati, SMOI

✓   Kristi Haycock, LDS Charities

    Karen Rispin, LeTourneau University

Karen Reyes, UCP Wheels for Humanity

✓ Eric Wunderlich, LDS Charities (co-chair)

✓ Mark Harniss, University of Washington

Tricia Karg, University of Pittsburgh

✓ Jon Pearlman, University of Pittsburgh

✓ Nancy Augustine, University of Pittsburgh

✓ Krithika Kandavel, University of Pittsburgh

Guest

✓ Norah Keitany, Skillspark

Prepared by: Krithika Kandavel and Nancy Augustine