ISWP Evidence-based Practice Working Group
Data Collection Subcommittee

June 15th, 2017 Meeting Recap

The ISWP Evidence-based Practice Working Group Data Collection Subcommittee met by conference call on Thursday, June 15th, 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/puxa0w7gw0lu/**

Next Meeting: Thursday, July 20th, 2017 at 10:00 am U.S. Eastern Time

Discussion (action items in bold/underline)

1. ISWP Wiki

a. Layout

Erin Higgins presented the wiki layout. The design has a map view; a user can choose a country from the dropdown menu after which 4 categories of information about that particular country would be displayed: Products, Policy, Provision and Personnel. Other features will include:

- Drop pins or flags which indicate data is available for a particular country.
- Banner or indication on top of the page when new data has been added/updated.

ISWP members would be invited to contribute data, which ISWP would review before posting.

We are expecting to receive data from the Philippines and Romania as part of the affiliate project, which will impact the design and presentation of information.

b. Intended Audience

Knowing more about the intended audience would help to create a template for reporting information. Karen Rispin suggested that faith-based medical institutions would be one of the intended audiences. These hospitals might be interested to know how many people are impacted by disability in a particular location, including the person who is disabled plus related members (family, caregivers). She also suggested that in Kenya, there are trunk support wheelchairs available to children but not adults. It would help to know how many adults need complex seating wheelchairs in a particular country/region. This information could help charitable organizations to fill their donated containers with an appropriate mix of wheelchairs (proactive procurement, not reactive) and to help individuals locate wheelchairs.

Nancy to send the data collection matrix to the group.

Data Collection Subcommittee members are requested to give ISWP feedback on the intended audience.

ISWP team to develop a prototype data after we receive the Kenya data.

2. Minimum Uniform Data Set (MUD):

a. 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.

b. Karen Rispin piloted the questionnaire with primary and secondary school

children in Kenya in May 2017. Nancy Augustine provided highlights of feedback on the short questionnaire version which was used with the primary school students. A copy of the presentation is attached.

Regarding Question 19, regarding where a person currently uses a wheelchair, it was suggested "transportation" be changed to "sit in a wheelchair on/in a vehicle." Karen asked whether we are asking whether the person actually sits in the chair while in the vehicle or has a chair which can be taken onto a vehicle, and the person sits in a different seat. ISWP clarified it is whether the person sits in the wheelchair while in the vehicle.

Karen suggested adding a question: 'Do you need to transport your chair from one place to another?'

Karen suggests that we wait until we receive all the feedback from both primary and secondary groups before changing the MUD.

ISWP to follow-up with Tricia Karg to be sure to have the IRB protocols in place to accept data from Karen's team.

Taavy mentioned that it would be helpful to add pictures (e.g., smile/sad face) to clarify ratings.

Karen suggested putting the questionnaire on as few pages as possible to reduce printing and to help interviewers move through the document more efficiently. She also suggested to add to the instructions requesting respondents not guess on a question if they don't know but to leave the answer blank or choose don't know/no answer.

3. Country Data Collection:

Norah Keitany is helping with the data collection in Kenya. ISWP expects the final report on June 22.

Participants:

Deepan Kamaraj, University of Pittsburgh

Maria Toro Hernandez, Universidad CES

Chandra Whestine, World Vision

Padmaja Kankipati, SMOI

Richard Schein, University of Pittsburgh

✓ 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

Kimberly Robinson, University of Pittsburgh

Guests

✓   Taavy Miller, UNC Charlotte (working this summer with Dr. Mary Goldberg)

Prepared by: Krithika Kandavel and Nancy Augustine