Video 4:

I want to tell you a little bit more about the short set of questions. They were developed for a number of reasons – we needed questions that were brief, that were simple, that were universal and allowed a certain amount of comparability among countries. These six domains of functioning are really very basic activities. Things like seeing, hearing and walking, communicating – they’re the building blocks of much more complex activities – going to the market that is something that is really important in terms of participating but that involves seeing, hearing and being smart enough to count your change and getting to the market and getting back - those are very complex. These basic activities are universal around the world everybody has these functions and they’re pretty standard that’s why we chose them for that universal component. I’ll tell you a little bit more about the questions and I’m going to read them to you so you get an idea of what they are. We say in the survey “because of a health problem … do you have difficulty seeing even if wearing glasses? do you have difficulty hearing even if using a hearing aid? do you have difficulty walking or climbing steps? Do you have difficulty remembering or concentrating?, Do you have difficulty (with self-care such as) washing all over or dressing?, Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? Those are the six questions – straight forward and simple. But you’ll notice that two of them, vision and hearing, include the use of aids – glasses and hearing aids. The reason we include that is because in most countries, in most cultures, around the world glasses and hearing aids are ubiquitous - everybody has access to those - so they become a really a part of your body. If you asked me if I have difficulty seeing without glasses I would say “a lot of difficulty”, almost I can’t see at all. But that doesn’t mean that I would be included in that group “disabled – has a disability” because it’s easily corrected and I can see perfectly. That’s why we include those. Other aids are more outside of the body - you need personal assistance or you need a wheelchair or something like that to move or get around. Those are outside of the body and we want to ask about those separately. These questions really focus on your capacity, your capacity to function without assistance – apart from vision and hearing. The other thing that’s important is as I mentioned before is that some questions are missing. It seems that some questions are missing – intellectual disability, mental functioning - but remember I said if it wasn’t possible to create a question, a single question, about that kind of function we couldn’t include it. For the purpose of the census, it’s very restrictive; we had to hold ourselves to these questions. But that doesn’t mean that we’re not including those individuals through other means of functioning – cognition, communication. A little bit about the field work that’s involved in verifying these questions, validating these questions. One of the things that we really recommend is that a screener not be added before the questions. The questions stand alone as a measure of disability in the population – as a measure of functioning in a population. If you preface the questions with a screener “do you have a disability? yes or no?” - the old way, the medical model - and then only those who say yes will ask these questions, our ‘difficulty functioning’ questions you’ve really negated the purpose of these questions. So it’s not only not recommended it’s strongly not recommended to include a screener. Another thing that’s important is when you translate the questions into other languages. We don’t recommend - the WG doesn’t recommend - a straight forward-backward translation, - a “literally translation”. In any language you can find a for the word in English but when you do that the structure of the question changes - maybe the meaning of the question changes and the wording may have no context in the country that you’re applying the question to. So what we recommend is a more involved process of discussion, getting people to talk about what the constructs are – what are we trying to capture with this question? - and then translating it using the language in the country; using what’s common in the country that captures the same meaning. Once that’s done the questions should be tested again, perhaps cognitively tested, to make sure everybody in the country - in different cultures in different societies - understand the questions the same way. That is important for universality of these questions. Another thing that’s really important is that the enumerators are well trained. If I were to collect data on my own, I’m one person and I could get uniform information from everyone that I approached, but when you have a large survey or census you have tens maybe hundreds my thousands of enumerators, each one of those brings their own personal knowledge and attitudes to the field. And we have to make sure that all of that baggage is left behind. We don’t want anybody to interpret these questions on their own. We don’t want anybody to go to a house and say “now I’m going to ask you some questions about disability”. If you remember what I just said, disability isn’t even included in the questions we ask – it is difficulties. So training is really important to get enumerators on board to understand the principles of disability data collection using this approach. Many people have asked if they can change the questions or change the answer categories. And the simple answer to all of those questions is no. In order to collect data that is uniform and comparable around the world we don’t recommend major changes to the questions. As I said, in translation, maybe the words are not the same exactly as in English but the construct and concept is the same – walking is walking, climbing has to be climbing stairs going up – however you need to say it in your culture of your language that’s the construct that should be collected. We don’t recommend changing the answer categories – not answering yes or not that defeats the purpose of maintaining that continuum of functioning. The last thing is that many people – some people – say “6 questions is too many I can’t put all 6 of them on my survey”. Well, the WG from the very beginning said that in that case there are four domains of functioning that are essential and it’s important to keep those, maintain those - vision, hearing, walking and cognition. If you have those 4 you will capture the majority of people. People with the other domains represent a minority. So if you’re pressed for time or space those 4 domains are okay but the ideal is 6.