Author’s response to reviews

Title: Rethinking Disability

Authors:

Alarcos Cieza (ciezaa@who.int; sabariegoc@who.int)
Carla Sabariego (Carla.Sabariego@med.lmu.de)
Jerome Bickenbach (jerome.bickenbach@paraplegie.ch)
Somnath Chatterji (chatterjis@who.int)

Version: 1 Date: 06 Dec 2017

Author’s response to reviews:

Dear Mrs. Schiavo,

We thank you very much for considering our manuscript suitable for publication.

We thank both reviewers very much for their comments and suggestions. We have addressed below all their points.

Reviewer #1

I enjoyed reading this article, which outlines a new approach for measuring disability. I believe that this piece will be of interest to a general readership, as well as those already working on disability-related issues. I have some comments that I hope will help to improve the article further.

The Model Disability Survey can make an important contribution to the literature on disability by helping to generate data to identify where interventions are needed, evaluate the impact of interventions, and monitor progress, as the authors rightly point out. It would be helpful to situate their tool within the wider framework, to give more comprehensive understanding to the non-
specialist. For instance, it is not designed for use in a census, and this is where short tools such as the Washington Group Short Set may be valuable.

Furthermore, it does not aim to generate impairment specific data that may be needed in developing health programmes, and here blindness and hearing impairment surveys and so on have a role.

In the last page of the main text, it would also be useful to provide a bit more information about the MDS (even as a stand-alone box): how many items does it include and which domains does it specifically measure?

As suggested, we have included a box in the appendix of the manuscript.

There are certain instances when some more information may be useful, particularly to make the article accessible to the general readership. For instance:

1. Main text, line 7. It may be useful to explain DALYs and what they are.

Although we understand the point, we feel that since there is no mention of DALYs in the text, only ‘health burden’ that it would complicate the point being made here (i.e. that NCD will become the major cause of health burden) if we took the space to unpacked the Global Burden of Disease methodology.

2. Main text, line 46. It may be useful to give an example here, to make the model more understandable to the lay reader.

An explanatory example is added.

There are some minor issues that could also be addressed:
1. Abstract. Describing disability as "etiologically neutral" without further explanation may be confusing to lay readers.

The term is replaced by a more accessible phrase.

2. Background, line 7, the sentence "There has been a recent global focus on disability as a development issue, but disability is also have a global impact" is not clear to me.

The sentence was revised for clarity

3. Background, line 15. I would argue that it is important to consider disability as well as mortality, not over and above mortality.

The sentence was revised to avoid this implication.

4. Background, line 39. While I firmly agree with the authors that disability is a continuum, it may be useful for advocacy to provide estimates of the number of people above a certain threshold.

Two sentences were altered to make this point clear, without losing the thread of the argument.

5. Main text and abstract. It would seem to me that it would be clearer to make the points of disability being a universal human experience and being on a continuum as points 1 and 2, rather than 1 and 3.

We have given this suggestion much thought but after trying various approaches, in the end we feel that the argument is stronger using the order of points that we did.
6. Main text, page 3, paragraph 1. Are there references to support these points made (i.e. that ADLs and IADLs do not capture mild/moderate decrements in health)?

References have been included.

7. Concluding sentence - this is not very clear to me - I am not sure what point the authors are making.

Sentence was changed.

Reviewer #2

Please see my comments and edits in the manuscript.

More clarification is needed on how disability can be "universal" and also one can have "no disability" and be "fully functional." I understand that the authors use the idea that anyone may become disabled at any point in their life. But this is not the same as disability being "universal" and existing on a continuum. Basically, I am arguing that the authors need to reconcile the notion that an individual can live with "no disability" with the idea that disability is a universal human experience. Are we, indeed, all disabled in one way or another? Do we all experience limits in functioning over the course of our lives and in different settings? Or is disability a unique minority experience? Is an inability to function in certain ways or certain situations "disability"? Or is disability a politicized minority identity? Disability can exist on a continuum and also be seen as a minority identity. I like the

assertion that we have to move away from the disabled/nondisabled dichotomity. For this short piece, the authors may be able to reconcile these issues with minor text revisions and perhaps explanation or citation in the notes.
Clarification of this point is included at the end of the paragraph, Main Text, Second page, where WHO’s three principles are explained.

In text comments:

Abstract

“These two points seem to contradict one another. If disability is a universal human experience then how can "no disability (full functioning)" exist? You cannot have one and also the other.“

We decided to address this point in the text rather than complicate the abstract

Main Text, first page, second paragraph

“There is an important and liberating paradigm. The fact that disability carries a significant amount of social stigma that results in discrimination and social isolation means that disability is often experienced as a minority identity.”

We agree and have changed the sentence accordingly. Later in the same paragraph we have added the underlined phrase:

“This continuum can be partitioned by a threshold identified as fit for purpose, including, for example, advocacy for policy change.”

Main Text, third page, second paragraph

“This is not an "either or” situation. All three need to be done.”
We agree, text changed to reflect this.

Same paragraph

“Cut and replace with: "Adequate, effective, and reasonable interventions in all three domains can only be..."

We agree, change made

Main text, fourth page, second paragraph

“Quantity or quantify”

Change made.