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Working group on "Development of specific question modules designed to measure disability among children"

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Background

Although children with disabilities are one of the most marginalized and excluded groups of children, experiencing widespread violations of their rights, the lack of accurate worldwide data impedes the development, implementation and evaluation of disability policies and programmes for children.

The Convention on the Rights of the Child, adopted in 1989 (Unicef, 1989), was the first explicit provision relating to the rights of children with disabilities. It included a prohibition against discrimination on the grounds of disability (art. 2), and obligations to provide services for children with disabilities, in order to enable them to achieve the fullest possible social integration (art. 23).

The more recent Convention on the Rights of Persons with Disabilities (UN, 2006), adopted in 2006, further strengthened the rights of children with disabilities with a dedicated article on children (art. 7). This outlined the obligation on States to ensure the realization of all rights for children with disabilities on an equal basis with other children, to promote their best interests, and to ensure their right to be heard and taken seriously. It incorporates, within its general principles (art. 3), respect for the evolving capacities of children with disabilities and their right to preserve their identities, and introduces a general obligation (art. 4) to consult with children, through their representative organizations, when developing relevant legislation and policies.

The UN Convention on the rights of Persons with Disabilities encourages States to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention (art. 31).

The limits of the data available and the importance of improving statistical information on disability in order to develop internationally comparable indicators for policy purposes has been also stressed by the UN General Assembly 2011 - special section on “Status of the Convention on Rights of the Child” and in the World Disability Report 2011 (WHO-World Bank).

The work done

The primary purpose of the workgroup is to develop a questions set to investigate the opportunities of participation of children with disabilities compared with same age children taking account the definition of disability set out in the UN convention: a long-term physical, mental, intellectual or sensory impairments which and their interaction with various environmental barriers (art. 1).

Consistent with the activities of the Washington Group (WG) and based on the consensus from the 2010 WG meeting, the ICF-CY is the conceptual framework from which the relevant domains of disability are selected. The aim is to produce a set of questions that is going to be current, relevant and sustainable.

The group took into account the work of the WG in the development of the short and the extended set of questions for adults. It is also aware that although both sets of questions are not specifically designed for children and young people they were considered a good start point. It is expected that the Short Set of questions will work as intended (identifying the majority of those with difficulties in the six domains) for those aged 5 years and above. The WG acknowledge that infants and children under 5 will be missed (only the seeing and hearing questions apply) – and that the short set will not cover important domains for children and youth such as learning and behaviour.

However, since the beginning of the work of WG, it was clear that it would be necessary to create specific questions to measure disability in children. Several methodological issues have been presented and discussed during the WG meetings.

Documentation relating to the measurement of childhood disability has been collected and analysed, especially questionnaires of surveys on children already conducted in several countries. All questions related to children disabilities were mapped onto the ICF-CY Check list to see which domains had been covered in at least one of the survey (Annex 1).

The ICF-CY Check List has been sent to all members of the group asking them to rate each ICF-CY domain on 6 criteria (Relevance, Accuracy, Reliability, Coherence and comparability, Clarity, Validity)[1] for the purpose of creating a WG set of questions for children. Each criteria could be given a score from 1 to 5 (were 1 is the minimum and 5 is the maximum). The criteria were selected according to the Recommendation of the Commission of the European Communities on the independence, integrity and accountability of the national Community statistical authorities (Commission of the European Communities, 2005).

From the results of this rating exercise and based on the work of McConachie et al. (2006), the working group selected a group of domains to work on to design a first set of questions. This involved a review of all the questions used on the selected domains (see Annex n. 2).

[1] Relevance (the information meet the needs of users); Accuracy (the information collected is accurate); Reliability (the information provide a reliably portray reality); Coherence and comparability (the information is consistent internally and comparable among regions and countries); Clarity (the information is clear and understandable); Validity (there is consensus on the part of users and experts that the indicator is related to the dimension it is supposed to assess and cover the whole dimension it is supposed to assess, it is related to other information measuring the same dimension and it has a predictive power).

Some guiding principles

The workgroup agreed on some guiding principles that should be taken into account for the development of a disability measure for children.

1) the primary purpose is to develop a questions set to investigate the opportunities of participation of children with disabilities compared with same age children adopting the definition of disability set out in the UN convention: a long-term physical, mental, intellectual or sensory impairments which and their interaction with various environmental barriers (art. 1).

2) the ICF-CY is the conceptual framework to be used for the selection of the relevant domains to produce a set of questions that is going to be current, relevant and sustainable.

3) the distribution of types of disability are different for children compared with adults, as reported in publications from studies at the national and international level. In adults the major problems are mobility, seeing and hearing, personal care - especially so with advancing years, while in children the main disabilities by far are related to intellectual functioning, affect and behaviour. Therefore the group should select domains also consistent with this.

4) the reference age for the new set of questions is 0-17 years, as stated in the ICF-CY. The group is also aware that children are constantly developing and in transition - from infancy to childhood, from childhood to adolescence and from adolescence to adulthood. For this reason the selection of the activity could change from one stage of life to another as well as the wording should be adapted to each specific age considered.

5) the responses will be elicited from proxies, at least for the moment. There are studies indicating differences in the answers provided by parents and children (O Dickinson H., 2007) to the same set of questions. Frequently, children and parents have a different perception of reality. Nevertheless, sets of questions addressed directly to the children, Activities Scale for Kids (Young, 2002), are rare.

6) the questions should refers to “life situations” ideally applicable to children in different countries in order to facilitate international comparability. Therefore the group agreed to include examples in the wording, if it needed, giving the possibility to each country to use culturally equivalent examples.

Selected Domains

McConachie H, et al., 2006 suggests that the domains to be considered in assessing child disability should encompass basic activities (such us seeing, hearing, mobility, communication, learning) and more complex activities essential for normal development (such as relationship-social interaction, and playing).

The workgroup selected the following ICF-CY domains:

- seeing
- hearing
- mobility
- communication
- learning and applying knowledge
- relationships
- playing

Some of the selected domains may require more than one question. The domain of self care will be considered in a second stage of the work.

Draft questions

The following is a first draft of questions: the selection of questions was done using, wherever possible, the questions that have already been tested and adopted by the WG (questions in red). Therefore questions on “seeing”, “hearing”, “mobility” for children aged x>=4 years, and “communication” for children aged x>=5 years are the WG questions.

When available, questions already age-specific were proposed while in other cases they were adjusted for specific ages.

The wording of the questions and the answer categories were changed to fit WG question design in order to harmonise the set of questions and to obtain a gradation of difficulty and not only the presence / absence of the difficulty.

Questions regarding "mobility" and "communication" domains were mainly taken from the GB survey because it is the only one with specific questions for each age group. For the smallest - children aged 1 year<=x<=2 years- the question proposed on “communication” is adapted from UNICEF “Ten questions set”.

For the "learning" domain have been selected activities of the ICF-CY short list, the only one that takes into account the different age groups and it does not have a medical approach. For the

smallest -children aged 1 year<=x<=5 years- the question from UNICEF “Ten questions set” was used as a reference (“learn to do things”) although it is very general.

As for the "relationships" domain, the ICF-CY short-list questions have been used as a reference because these are the only ones that analyse the child's ability to relate to other persons. The other available surveys, indeed, measure mainly participation in sport, recreational or leisure (cinema, theatre....) that, especially for children, are very influenced by educational level and employment of the child's household.

For the domain "playing" was selected the question proposed by the ICF -CY short list because is the only one available that investigates exclusively the activity of play.

Challenges

The work group is aware that the set of questions proposed is only a starting point for the future work and that for some crucial issues it is necessary a further discussion in order to proceed in the work.

1) Reference age of population surveyed

As mentioned before, the reference age for this set of questions is 0-17 years; nevertheless the inclusion of children of 0-2 aged could be subject to new debate as it represents a age range in which the development process is very subjective and culturally influenced, and any delay is often not a symptom of limitation. A similar problem can be observed also for the age group 3-5.

The choices at this point would be: a) to maintain the reference age as it is and take this into account when defining the criteria for determining the population at risk, b) to change the age range of the reference population from 0-17 to 2-17 or 5-17.

2) Age Threshold

Since many questions are age specific we need to identify a suitable age range in order to avoid, as far as possible, to count children who are in only slow-growing development instead of in a long-term situation.

This first draft version of questions has been brought to the attention of an Italian paediatrician who suggested, in some cases, different age range that have been reported in parentheses. The choice should be done according with the different cultural experience and taking also into account the opinion of other paediatricians.

Moreover different age groups in different questions can arise problems with the interviewer.

3) Use of culturally equivalent examples in the questions.

There are advantages and disadvantages to giving examples in questions. Some argue that it adds specificity, so less prone to ambiguity; others argue that it limits the focus, i.e. respondents only think of the examples given and not the general category referred to by the examples. If examples are given then they must be universal. Using culturally equivalent examples could be dangerous.

4) Mobility domain

The difficulty in the mobility area could be measured in terms not only of distance but also in terms of time spend to do a single activity. The group will take into account if it is better for the respondents to refer to distance or to time.

SEEING

Children aged 0<=x<=17 years

1) Does [he/she] have difficulty seeing [even when wearing his/her glasses]? Would you say… [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all/unable
7) Don't know
9) Refused

HEARING

Children aged 0<=x<=17 years

2) Does [he/she] have difficulty hearing, [even when using a hearing aid(s)]? Would you say… [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

MOBILITY

Children aged 6 months<=x<1 year (10 months<=x<=15 months)

3) Compared with children of the same age does [he/she] have difficulty standing holding on to furniture? Would you say… [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged 1 year<=x<2 years (15 months<=x<=24 months)

4) Compared with children of the same age does [he/she] have difficulty walking few steps without help or without holding on to something? Would you say….[*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged 2 years<=x<3 years

5) Compared with children of the same age does [he/she] have difficulty walking on a flat firm surface at least 50 meters without help from someone? Would you say…..[*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do

7) Don't know

9) Refused

Children aged 3 years<=x<5 years

6) Compared with children of the same age does [he/she] have difficulty walking on a flat firm surface at least 200 meters without help from someone ? Would you say….[*Read response categories*]

1) No difficulty

2) Some difficulty

3) A lot of difficulty

4) Cannot do at all / Unable to do

7) Don't know

9) Refused

Children aged x>=5 years

7) Compared with children of the same age does [he/she] have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks without help from someone? Would you say… [*Read response categories*]

1) No difficulty

2) Some difficulty

3) A lot of difficulty

4) Cannot do at all / Unable to do

7) Don't know

9) Refused

COMMUNICATION

Children aged 1 year<=x<2 years

8) Compared with children of the same age does [he/she] have difficulty naming at least one object (animal, toy, cup, spoon)? Would you say….. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged 2 years<=x<3 years

9) Compared with children of the same age does [he/she] have difficulty asking questions or joining 2 or more words together to make sentences like 'car go' or 'mummy eat'? Would you say…[*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged 3 years<=x<5 years

10) Compared with children of the same age does [he/she] have difficulty telling you what he has been doing or about something that has happened to him/her? Would you say…. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty

4) Cannot do at all / Unable to do

7) Don't know

9) Refused

Children aged x>=5 years

11) Compared with children of the same age and using [his/her] usual (customary) language, does [he/she] have difficulty communicating, for example understanding or being understood? Would you say….. [*Read response categories*]

1) No difficulty

2) Some difficulty

3) A lot of difficulty

4) Cannot do at all / Unable to do

7) Don't know

9) Refused

LEARNING AND APPLYING KNOWLEDGE

Children aged 1 year<=x<=5 years

12) Compared with children of the same age does [he/she] have difficulty learning "to do things"? Would you say…..[*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged 6 years<=x<12 years (6 years<=x<9 years)

13) Compared with children of the same age does [he/she] have difficulty learning to read or to write or to calculate? Would you say…. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged x>=12 years (x>=9 years)

14) Compared with children of the same age does [he/she] have difficulty reading or writing or calculating? Would you say….. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

RELATIONSHIPS

Children aged x<=3 years

15) Compared with children of the same age does [he/she] have difficulty relating to parents and relatives? Would you say….[*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged 4 years<=x<12 years

16) Compared with children of the same age does [he/she] have difficulty relating to others children such as friends or classmates? Would you say …..[*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Children aged x>=13 years

17) Compared with children of the same age does [he/she] have difficulty in making friends? Would you say…. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

PLAYING

Children aged x<12 years

18) Compared with children of the same age does [he/she] have difficulty playing alone or with others? Would you say…. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Reference

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