



Are People With Albinism Included In The Washington Group Questions?

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In some countries, people with albinism are automatically considered to have a disability and are also the victims of multiple forms of discrimination some very extreme [[1](http://http://[http://albinism.ohchr.org/about-albinism.html])]. Various policies, programs, and awareness raising campaigns are directed at addressing these practices. Data on people with albinism are needed to appropriately implement these policies and evaluate their impact. Since the Washington Group Short Set (WG-SS) of questions has been widely recommended as a means to gather information about people with disabilities, it is only natural to ask – do the Washington Group questions have anything to say about albinism?

To respond, we have to ask three separate, but related questions.

- Can the WG-SS identify people with albinism?
- Are people with albinism included among those identified as having a disability by the WG-SS?
- If the WG-SS can't identify people with albinism, can they be modified to do so?

The answer to the first question is no. The WG-SS does not address albinism directly and thus cannot identify people with albinism. The WG-SS only asks about difficulty seeing, hearing, walking and climbing steps, remembering and concentrating, communication, and self-care.

The answer to the second question, though, is yes, many are identified by the one or more of the Short Set questions, but maybe not all. According to the Mayo Clinic, a leading research hospital in the United States, "vision impairment is a key feature of all types of albinism."^[2] That means that a large majority of people with albinism are expected to report difficulty seeing, although for some people with albinism, eyeglasses might be sufficient to lead to a response of "no difficulty" or "some difficulty" to the vision question.

If those with albinism report vision difficulty, disaggregating SDG indicators by disability status or making estimates of patterns of overall disability prevalence will, by and large, include many people with albinism as having disability. Those that are not included will be people who don't have much difficulty seeing. This is consistent with the approach taken by the WG-SS – that is, identifying people having difficulties with basic activities that put them at risk of participation restrictions by a non-inclusive environment.

What the WG-SS does not do is identify the people who have albinism as a distinct group. People may have vision difficulties for many other reasons than albinism, and all those people are lumped together in one group by the WG-SS. In countries where albinism isn't a separate policy issue, this is not a problem. In those countries, policies are aimed at helping and monitoring people with low vision for whatever reason. Moreover, in some countries, albinism is a fairly rare event so missing a few people with albinism – for the purpose measuring gaps in outcomes between people with disabilities as a whole and people without disabilities– will not have a significant statistical effects.

However, as stated above, in some countries being able to identify people with albinism is very important. In those countries, a question can be added to the WG-SS that explicitly asks if the person has albinism. It is important, though, that this question gets asked **after** the WG-SS and not immediately before it. This is the approach Kenya has taken in a recent survey (see below). Since albinism is associated with some functional issues, it would not be desirable for respondents to think that the WG-SS questions are in any way related to albinism or any other medical condition. Responses to the WG-SS should not be influenced by any mention of disability or any medical condition associated with disability. That will undermine the approach taken by the WG-SS that focuses on activity limitations and not a medical approach to disability.

Example of Disability and Albinism Questions To BE Used in the Kenyan Census

C: Information Regarding Persons with Disability
To be asked of persons Aged 18 years and above

MAIN DISABILITY DOMAIN

Does <NAME> have difficulty...

1. Seeing, even if wearing glasses?

1= No, no difficulty

2= Yes, some difficulty

3= Yes, a lot of difficulty

4= Cannot do at all

9= DK

2. Hearing, even if using a hearing aid?

- 1= No, no difficulty
- 2= Yes, some difficulty
- 3= Yes, a lot of difficulty
- 4= Cannot do at all
- 9= DK

3. Walking or climbing steps even with assistive device?

- 1= No, no difficulty
- 2= Yes, some difficulty
- 3= Yes, a lot of difficulty
- 4= Cannot do at all
- 9= DK

4. Remembering or concentrating?

- 1= No, no difficulty
- 2= Yes, some difficulty
- 3= Yes, a lot of difficulty
- 4= Cannot do at all
- 9= DK

5. With self-care, such as 24-hour care, toileting, bathing or dressing?

- 1= No, no difficulty
- 2= Yes, some difficulty
- 3= Yes, a lot of difficulty
- 4= Cannot do at all
- 9= DK

6. Communicating using their usual (customary) language for example understanding or being understood?

- 1= No, no difficulty
- 2= Yes, some difficulty
- 3= Yes, a lot of difficulty
- 4= Cannot do at all
- 9= DK

ALBINISM

Does <NAME> have albinism?

- 1= Yes
- 2= No
- 9= DK

[1] <http://albinism.ohchr.org/about-albinism.html> [https://eur01.safelinks.protection.outlook.com/?url=http%3A%2F%2Falbinism.ohchr.org%2Fabout-albinism.html&data=02%7C01%7C%7C59261faa6d1044b705ae08d818768fbd%7C1faf88fea9984c5b93c9210a11d9a5c2%7C0%7C0%7C637286244780908629&sdata=%2BaL.%2FG4%2FWE5zr%2BcJHxs4Og%2BQeJXnb]

[2] <https://www.mayoclinic.org/diseases-conditions/albinism/symptoms-causes/syc-20369184> [https://www.mayoclinic.org/diseases-conditions/albinism/symptoms-causes/syc-20369184]

- [Learning From The Use Of The Washington Group Questions In Development And Humanitarian Programmes](http://www.washingtongroup-disability.com/wg-blog/learning-from-the-use-of-the-washington-group-questions-in-development-and-humanitarian-programmes-117/) [www.washingtongroup-disability.com/wg-blog/learning-from-the-use-of-the-washington-group-questions-in-development-and-humanitarian-programmes-117/]
- [Differences in Reported Disability Prevalence Rates: Is something wrong if I don't get 15%?](http://www.washingtongroup-disability.com/wg-blog/differences-in-reported-disability-prevalence-rates-is-something-wrong-if-i-dont-get-15-120/) [www.washingtongroup-disability.com/wg-blog/differences-in-reported-disability-prevalence-rates-is-something-wrong-if-i-dont-get-15-120/]