



Difficulties in coping, or disabled?

How to measure the difference

Disability surveys provide important information to national government which helps in the planning and development of policies and related services. Yet, disability can be defined in a number of ways, writes MARGIE SCHNEIDER. The way it is defined in surveys is crucial in determining how and what we measure.

WHO IS DISABLED? The elderly gentleman who walks with two sticks because of two hip replacements? The 16 year old with Down's syndrome? The 26 year old with moderately severe cerebral palsy who struggles to walk and communicate? The homeless person who mumbles to himself? The person with a mood disorder? The child with recurring middle ear infections and loss of hearing?

If we say disability is a physical or visible impairment, the last three people are not disabled. If we say it is when a person experiences disadvantage and discrimination in various aspects of life, then maybe the last two people are not disabled. If it is defined as when a person is born with a disability, then only the second and third of

our people are disabled. And if we say disability is about having difficulties in doing various activities, such as hearing, walking, learning, communicating or interacting with others, then all our people have difficulties or are disabled.

Not only is the definition of disability important, the wording used in surveys plays a significant role in how people respond to questions on disability.

Disability is seen as something that is physical (and sometimes mental), permanent, and for which nothing can be done. Difficulties, on the other hand, are usually less severe than disability and can be managed and solutions found, as expressed by a range of disabled and non-disabled South Africans.

Internationally there is a move towards asking questions about difficulties people have because of an underlying health condition. This move away from asking about disabilities has important effects on how people respond to questions.

South Africans who are wheelchair users, blind, deaf, or suffer from a serious mental illness like schizophrenia respond that they have difficulties and that they are disabled. People who are older, living with HIV/AIDS or who have a chronic illness, report having difficulties but state categorically that they are not disabled. And young adults indicate a few instances of having some difficulties but state categorically that they are not disabled.

The response options that are provided for a question also have an important influence on how people will respond to questions. If the options are 'yes' or 'no', people are less likely, for example, to respond yes to the question 'Do you have difficulty walking?' unless they feel the problem is serious enough to warrant such a response. Otherwise they will respond with no. So a no response incorporates 'I have some difficulty but I am not sure it is severe enough to say yes!' If more than two response options are given (for example, no difficulty, some difficulty, a lot of difficulty or unable to do), the person is more open to use the 'some' and 'a lot' options.

This approach allows for a more nuanced understanding of population functioning when using these questions in a census or national survey. The results can be categorised into those people who have some difficulty doing one or more activities, those who have a lot of difficulty and those who are unable to do one or more activities. This gives three points on the continuum of functioning that can be used for different purposes. For example, people who are unable to do one or more activities are most likely to be those requiring technical and personal support. This group together with those with a lot of difficulty are most likely to be the sector of the population eligible for the disability grant.

We are moving to a better understanding of disability statistics as obtained in surveys, therefore, and are able to start incorporating these questions in surveys to allow for analyses that include disability in an integrated manner.

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