

Factual – Measured - Critical

Day of Reckoning

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Life is hard for us disabled people in rich countries. Imagine what it's like for our counterparts in the developing world. Healthcare is hard to come by. Children don't get to school. Only 15% of people have the wheelchairs they need. Not to mention the prejudice and stigma that mean that disabled women can't find a husband, and that people don't believe that disabled people can work. Having an impairment means that you are more likely to be socially excluded, and to die young.

So you'd expect international aid programmes to prioritise disability. But you'd be mistaken. The UN's Millennium Development Goals (MDGs) did not mention disabled people (1). And too often, disability is left out of poverty reduction plans. Trying to stop polio or build schools seems simpler and quicker than tackling the complex problem of disability.

That's why the United Nations High Level Meeting on Disability on September 23 was so significant (2). The world's leaders gathered before the UN General Assembly, to discuss how to include disability in the new set of development targets that will replace the MDGs after 2015. It was a once-in-a-lifetime opportunity to get it right. If it leads to disability-inclusive goals which are specific and measurable, this could mean that barriers are removed and investments made to empower disabled people.

Although it was very exciting to be a fringe participant in this meeting, I still felt sceptical about such a gathering of politicians, remembering the English proverb "Fine words butter no parsnips". Although the UN Convention on the Rights of Persons with Disabilities arrived in 2006, it has had only had a minor impact so far on the misery that the majority of the world's billion disabled people experience (3). But the Convention was certainly a big stride in the right direction. And if all the fine speeches from September 23 are acted on in the months to come, life for disabled people could begin to go better in poor countries, just as it has over recent decades in the developed world.

But if we are to get beyond slogans and promises and drill down to specific, measurable goals, then we are going to need to know something about how disabled people are doing compared to everyone else. And here there is a problem. Very little is known about how many disabled children are out of school, compared to nondisabled children, how many disabled people are poor, how many die young, and so forth. Without the figures, then the comparisons and the priority-setting becomes much harder.

I was one of the authors and editors of the World Report on Disability, published by the World Health Organization and the World Bank on June 9, 2011 (4). The headlines reporting this milestone all mentioned the new global prevalence figure. From analysis of the WHO World Health Survey, the team had come up with the figure of one billion people, 15% of the world's population, being affected by disability. Previously, WHO and the rest of the UN system had estimated that 10% of the population had disabilities. In many developing countries, the official prevalence estimates remain under 5%. So how could we justify 15%?

To understand that, you need to remember that disability is a social category. Of course, the category is made up of real people with real health conditions – spinal cord injury and achondroplasia (dwarfism) in my case. But there is debate about exactly who the category

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covers. For example, what about people who have short sight and wear spectacles? They are unlikely to be considered as disabled people. What about people with intellectual impairments or mental health conditions? Usually they would be included. Debates rage about people with HIV/AIDs and other chronic illnesses like diabetes. The answer is not just to say that anyone who identifies as disabled is disabled. Because disability is a stigmatized identity, many people with the condition would prefer not to be associated with it. For example, UK research by the former Disability Rights Commission found that only half of disabled people actually identified as disabled.

From one perspective, everyone is impaired to some extent. Sometime in their life, most people are impaired to a great extent – imagine breaking your leg or having a serious illness. So disability is a universal condition. But it affects people more or less significantly. In other words, it is on a continuum.

This conception was what the World Report on Disability prevalence estimate was based on. Many surveys in developing countries adopt the “headcount” method: go to a sample of households and ask them if they have any family member with a disability. People think: blind? Deaf? Paralysed? Mentally ill? Intellectually impaired? And then they tick the box. But this leaves out lots of people who have difficulties in functioning which are not commonly thought of as disabilities. For example, someone may have dementia or arthritis or depression, which interferes with their daily life. This is why prevalence estimates in developing countries are commonly far too low.

The World Health Survey asked respondents a series of 8 (or 16) questions. These included areas of functioning such as mobility, communication etc. The tens of thousands of participants said how much they were restricted in those areas. This produced a series of scales. Some complex calculations were done to combine all these scales to give each participant a score on a continuum. The next stage was to decide a cut-off point. This is always the key issue in disability statistics. In reality, disability is not black and white, it's shades of grey. But for purposes of a single prevalence estimate – or for allocating benefits or parking badges or anything else – then a dividing line between disabled and nondisabled has to be chosen.

The way that the WHO team did this was to think about health conditions that everyone would agree were disabilities, for example, depression or paraplegia. By seeing what individuals who had those conditions “scored” on the survey, it was possible to find a reasonable cut off – 40. Using this cut off led to the figure of 1 billion disabled people, which in turn was a politically powerful statistic which increased awareness of disability as a significant issue for both development and for human rights.

We found that some governments were very anxious about the new figure. They asked whether this meant they had to give welfare benefits to this bigger number of people. We explained that the billion represented people who were entitled to have their rights protected, for example in education or employment. They also represented people who were entitled to access, for example in transport or information. But the number of people with very significant disability, who would rely on welfare benefits, complex rehabilitation interventions or assistance services was much smaller, about 110-190 million adults, for example.

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The global prevalence figure moves the debate forward, and ensures that disabled people have a higher profile. But it still leaves us with a problem in comparative statistics. The complex questions and mathematics that the prevalence estimates relied on are not practical for a basic survey of health or educational participation. So we need something simpler to enable researchers to disaggregate disabled from nondisabled people. Here, there is another tool available. The Washington Group are a network of statisticians and demographers working with the United Nations (5). They have come up with a simple set of six questions which give a “quick and dirty” estimate of who is disabled and who is not disabled. It is not unreasonable to ask researchers to add this question set to their population surveys. And this enables us to see how well disabled people are doing.

So now we have the global figure, and we also have a simple method of disaggregation. However, disability activists by this point will be getting anxious. This is because a human rights approach to disability stresses that disability does not just emerge from the consequences of a health condition. Instead, it is produced by the interaction of the health condition with the context. In other words, people are disabled by society, not just by their bodies. The absence of a ramp, or an elevator, or braille information, or a sign language interpreter is what disables people who use wheelchairs or are blind or are deaf. So it is important to research environmental barriers, not just impairments or functioning limitations. The new WHO model disability survey, which is currently being piloted, does just that (6).

To conclude, disability is a significant sociological issue. It shows that questions of power and meaning are unavoidable. Disability is not just a biological phenomenon, it is a matter of definition. And in a world where the majority of disabled people are poor and excluded, then getting the measurement right – both of health condition and of environmental barriers – is absolutely vital if we are to succeed in improving people’s lives. “What gets measured, gets done” is one of the favourite phrases of WHO Director General Dr Margaret Chan. If the Getpost-2015 development goals are to result in progress for disabled people, we had better get the measurement right too.

References:

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