



Intellectual Disabilities, Global Poverty and Isolation

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Good afternoon. I'd like to start with a question: how many people are there, living in developing countries, who are both poor, and have intellectual disabilities?

The answer is going to shock you, as it does me. The answer is: We do not know. No one in the world knows. We live in the information age, where people complain of TMI – too much information. Yet we have hardly any data on intellectual disabilities.

Today I'd like to talk to you about the vital importance of identifying and measuring isolation in the context of Multi-Dimensional Poverty, in a way that reflects the full reality of people with intellectual disabilities, and thereby is relevant for policy and bringing about change. And I will share with you a programme which is just beginning at the University of Oxford, on this topic.

First, the data: We have information on stock prices every hour; we have information on inflation, on labour markets, on GDP growth, and consumer prices every quarter. We have consolidated information on hundreds of economic and social indicators every year. But in developing countries, we have updated data on multidimensional poverty only once in every three to ten years. Data constraints severely hamper our ability to understand and reduce poverty in many countries.

I work with the Oxford Poverty and Human Development Initiative – OPHI – at the University of Oxford. We work on measures of multidimensional poverty. What do we mean by this? Most countries of the world define poverty by income. Yet poor people themselves define their poverty much more broadly. Multidimensional poverty measures reflect the multiple deprivations that a person suffers at the same time and present an integrated view of the situation.

Yet even if we had data on multidimensional poverty – aspects like malnutrition, child mortality, health functionings, educational achievements, housing, assets, water and sanitation, services, livelihoods and income – even if we had data on these standard dimensions of poverty more often – we would still be lacking something.

We would be blind to intellectual disability. For example, no standard surveys that are used for the Millennium Development Goals include information on intellectual disability.

Furthermore, I would submit to you, that data on intellectual disability and on poverty alone would not tell the full story of people's lives. For example, that is why we at OPHI are drawing attention to what we call the 'Missing Dimensions' of poverty data – things like violence; disempowerment, informal work; and safety at work; and shame, humiliation and isolation.



At the present time, information on these aspects of poverty is systematically overlooked by internationally comparable datasets. We need information on these aspects for their own sake. But we also need them to be able to track, analyse, and reduce the multiple disadvantages experienced by those with intellectual disabilities and their families, especially in relation to poverty, both in low-income countries, wealthy countries and everywhere in between. Poverty is poverty after all and multi-dimensional poverty is not defined by geography or economy; it is much deeper than that.

An overarching and critical component of poverty with respect to intellectual disability is isolation. What is isolation? My definition of isolation is that experience in which a person feels like they are sitting alone at the bottom of the well – no one knows their suffering; no one cares; if they call out they cannot be heard; they are invisible and outside all circles of concern.

More formally, isolation can be defined both by external and internal circumstances. Externally, it means having a small number of meaningful relationships with other people or how alone that individual may be (de Jong Gierveld and van Tilburg and Dykstra 2006). Internally, it refers to 'the distress that results from discrepancies between ideal and perceived social relationships' (Hawkley and Cacioppo 2009).

The relationship between internal and external social isolation is not direct. Being alone may trigger feelings of loneliness, and feeling isolated may result in being alone. Yet one may feel extremely lonely while being surrounded by people, family or friends, and people with few social contacts may not feel isolated at all (indeed, many people enjoy their solitude and value it). Thus, the crucial issue for the feeling of isolation is not the amount of social connections one person has but how meaningful they are.

Now you might wonder, is isolation really that important? Well, here I'd like to share with you a few facts from our research programme at Oxford, which is in its early stages.

First, isolation hurts. And this is not only a metaphor: neurological studies have now confirmed that the reaction to social pain in the brain is experienced in a similar way as the reaction to physical pain. It is a serious and common problem the effects of which can be considerable.

Recent studies have established that chronic feelings of internal social isolation trigger a series of physiological events that have an impact on health comparable to the effect of high blood pressure, lack of exercise, obesity, or smoking, and can actually accelerate the ageing process (Cacioppo and Patrick 2008). It is also a predictor of functional decline and death among individuals older than 60 years (Perissinotto, Stijacic Cenzer, and Covinsky 2012).

Second: it is not an uncommon phenomenon: at any given time, roughly 20% of people in the US alone feel sufficiently internally isolated for it to be a major source of unhappiness in their lives (Cacioppo and Patrick 2008).

Third, isolation matters to people. We now have thousands and thousands of studies of what people understand their own poverty and well-being to be, studies carried-out across the world, in rural and urban areas, among poor communities as well as citizen groups and expert groups.



In all of these consultations – whether it's Voices of the Poor, conducted in 60 countries across 60,000 poor people, or a study in the UK on how people define well-being, or the academic set of dimensions named by Nobel Laureates Amartya Sen, Joe Stiglitz and Jean-Paul Fitoussi – In all these very different contexts, one finding has come up over and over again: People name isolation as a component of their poverty. And they name social connectivity as part of their well-being. People, at the end of the day, are the true experts on poverty, and our measures of poverty should match their descriptions of it.

Fourth, isolation can be particularly pervasive among people with intellectual disabilities, and it compounds the many other kinds of disadvantages that they may experience, giving them an almost unbearable burden. Moreover, in this case, what is otherwise mainly an individual phenomenon can easily become a group phenomenon as the whole family unit is affected by isolation as consequence of this burden. Of this pain.

We need to get data about people with intellectual disabilities. But we need to get data that shows the key aspects of their lives at the same time. Only then will we be able to fully assess their well-being or poverty and better understand the connections between the different aspects affecting their lives. Moreover, we need to capture data in ALL the aspects that are relevant to them, and not only the aspects we are used to measuring. I am arguing with my work that isolation is a relevant fact for human beings in general, and can be a poignant reality for people with intellectual disabilities who are living in poverty, in particular.

We also need to gather stories too for stories have power and combined with research and measurement, we can strengthen the power of one person's story to bring about change for a community of people around the world -- policy change, behavioral change, positive, sustainable, beautiful change.

My dream is to support the vision and voice of the person who is sitting alone at the bottom of the well. But I cannot work on isolation in isolation. And I can think of no better model for inclusion and social connectedness - the opposite of isolation - than the Special Olympics movement worldwide, which to me represents a global culture of "I BELONG." And this brings me joy. In the words of the great Indian poet, Rabindranath Tagore, "I was singing alone in a corner and the melody caught your ear." The Special Olympics melody caught my ear a very long time ago and that melody let's me say, "I BELONG TOO."

I will now close by inviting others to join me in identifying, measuring and combatting isolation, not only researchers and experts, but especially those individuals with intellectual disabilities and their families around the world who suffer from isolation and its manifestation in multidimensional poverty.

A manifestation that becomes a systemic reality that hurts very much and in very many ways. In my view, isolation is a pervasive disease, one that is entirely preventable, and thus it is an injustice if we allow this to continue and don't make the commitment to act. To lift the mirror. To bring about change. Thank you very much.