

Research on Disability and Development: Some Thoughts from the North

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Abstract

Disability research, both in the global North and the South is recent, evolving and increasingly influencing policy and practice at both national and global levels. It is time – actually far past time – that we ask critically about who is setting the agenda, who is funding, (and not funding) the issues and how we will develop the next generation of disability leaders in research from the South. But while we are carrying on this important dialogue within the ranks of disability research and advocacy, I argue we also need to look beyond the disability field and disability networks. Disability must become a key component in international development work at all levels – from the MDGs to local household surveys, if people with disabilities are truly to be reached and adequately represented. There is a pressing need for more research – both disability-specific and disability research as a component of larger work in poverty reduction, education, health, civic involvement and other key development objectives, if we hope to make a difference to the lives of persons with disabilities. Moreover, it is important that there be an increase in South-South dialogue to share new ideas and practices being developed in Africa and elsewhere in the South. It is also important to realize that there are many ideas and practices being developed in the global South from which those in the global North can learn. It is imperative then that researchers in disability from the global South take a leadership role in discussions and decisions about what should be studied and what information needs to be prioritized from the outset. The issue then becomes how to change the system to ensure that this is in fact, the case.

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Introduction

In this talk I have been invited to raise a series of questions related to the support and development of research that has implications for disabled communities, populations and individuals in Africa. Let me set out to briefly discuss four questions:

- 1) what are we researching?
- 2) how are we using the research?
- 3) who is doing the research? and finally,
- 4) how can we see disability research in a broader context?

Given the time limitations for this talk and the complexity of these issues themselves, I will endeavour only to raise some questions here. I will not try to answer them all (and indeed, do not know if I could answer them all myself) – but I hope to contribute to a dialogue that is already starting regarding many of these issues.

Let me take each of these questions in turn:

I. What are we researching?

Research on disability, especially beyond the bounds of traditional disability/health/rehabilitation research, is still in its infancy worldwide. This means that even in the best of circumstances, research on persons with disabilities and disabled communities, for the most part, is only thirty years old. And within the past thirty years, such disability research, even in the wealthiest countries, has been significantly underfunded, often shuttled from one discipline to another within the academic realm and most importantly, all too often, marginalized or not applied to pursue programmes, policies and laws that have relevance to the lives and well-being of persons with disabilities themselves.

With the new UN Convention on the Rights of Persons with Disabilities, attention is now being focused by policy makers and governments at local, national and international levels, on persons with disabilities outside of the traditional research realms. Education, health, development and legal systems are beginning to be re-examined in light of the Convention. Just as importantly – a synergy is taking place between the Convention and the MDGs. For these reasons, I think that as a research community – both within and beyond Africa - the following factors need to be seriously considered:

- Research should make a difference: I would argue that there are many types of research from the most applied to broadly theoretical. I appreciate the need for theoretical approaches – as they say, there is nothing as useful as a good theory. But whether theoretical or applied, I think that we have an obligation to pursue research that has outcomes that make a difference and wherever possible, cause trouble. Currently – and into the foreseeable future, there will be limited time, funding and expertise available for research on disability in particular and more broadly, for global health and development. We should be strategic in prioritizing what information is needed for what purposes - which does not mean that a researcher should restrict himself or herself to a specific realm or topic, but only that they should ask themselves why they are doing the research in the first place, before they set out. (I would add that the possibility of funding or publication should not be the determining factors here).

- We need to recognize that there are different levels of research: Research is often discussed as though it were a ‘black box’ – with some sort of undifferentiated activities going on within. In fact, there are all sorts of research, and research can be divided into activities that generate answers to all sorts of questions. As such, it is sometimes useful to think about research as either being:
 - Short term- answering specific/applied questions to generate information that can be used for policy or programming either immediately or in the foreseeable future;
 - Medium term – answering questions that may be specific to a particular population or situation, but that also has longer term implications. Such research can generate insights or hypotheses that can be useful beyond the specific situation;
 - Long term – setting out to address a broad issue or theoretical concern with the idea that the findings may not have an immediate benefit, but can contribute in the longer term to our overall understanding of, and approaches to, disability, equity and/or the human condition.

Now, I do not think that these can be separated into completely different categories. Sometimes it is the broad questions that yield interesting insights into something specific. Alternatively, a very small study or a singular observation may result in a new theory or insight. (Our world would be a very different place if Darwin had not noticed differences in finches’ beaks). I point this out here, because there is often a discussion at meetings such as this, about relevance of research to disability issues. I note that we do not have similar discussions when it comes to research on women’s health or poverty alleviation efforts. In these fields, both theory and practice inform each other and the populations under consideration are considered important enough to warrant a broad spectrum of research and analysis. I would argue that disability issues are no less important. The well-being of people with disability deserves as much and as sophisticated research as all other groups.

- We must be careful not to reinvent the wheel: It is important with limited resources and limited numbers of researchers that we do not reinvent the wheel – duplicate research that has already been done. This does not mean that no research should ever be repeated. Indeed, good science requires that we repeat studies to ensure that the findings are consistent. However, there is a difference between this and not doing our homework. Often – or at least too often for my tastes, people set off to do research without doing a good literature search to see what has already been done in their region or on the subject they are studying – not only in their own countries, but throughout the global South as well as in developed countries. Just because a subject has not been broached in a major northern journal does not mean that no one has been concerned about the issue or done research on the topic. And too often, people who have done excellent studies –in the global North and especially in the global South, have been slow about publishing their results or putting their results on the web, so fellow researchers can cite their work and benefit from their insights. I understand publishing is a complex undertaking and there are often significant barriers to publication when one is based in an institution, DPO or NGO that has limited support and resources. But increasingly, through the web, through professional networks and links to colleagues around the world, it is possible to broadly disseminate information. If you have taken the time and trouble to do a study or collect information, you should share it as widely as you can. If you find the results of your research interesting or insightful, I strongly suspect, other people will as well.

- Who is answerable to whom: This is an on-going issue and one that I will not be able to answer here. There are a number of different ways of prioritizing research objectives and funding, deciding who should be doing this research and identifying how this research should tie into broader discussions of policy development and programming. At the end of the day, good research is research that makes a difference in the lives of people with disabilities in the homes, communities and societies in which they live. This means that disability advocates scholars and policy makers should be at the table whenever such discussions are underway and such decisions are being made. These constituencies need to talk to each other – and they need to have such discussions within their ranks on a regular basis as well.
- *Disability-specific* research verses *Disability-Inclusive* research: Another issue to consider when we are discussing disability research is the difference between disability-specific and disability inclusive research. Both are needed. Disability-specific research is research that sets out to answer a question or raise an issue related to persons with disabilities. This research is important. No less important – and often overlooked, is the need to ensure that people with disabilities and disability-relevant questions are built into general health, development and census studies.

We are beginning to make some progress with the United Nations’ Washington Group on Disability Statistics. But each year, millions – indeed, billions of dollars are poured into research related to global health or international development issues – with the specific intention that these findings make a difference in the health and well-being of the populations being studied. Be it a study of childhood immunization rates, benefits of the new community initiative on rice farming or women’s voting patterns, there should be a disability component – just as there is now a gender component – in all this work. This is an arena in which DPOs can, and should be, major players. DPOs should be monitoring what is being done beyond the disability realm at the local, national and international levels, in international development, global health and local and national governance realms – staying informed and pressing those collecting data or initiating programs within these realms to ensure a disability component in all their work. NGOs working on disability issues should also be involved in pushing for such inclusion. Again, both disability-specific and disability-inclusive research is needed, and often they can inform each other – (and of course us).

- Unanticipated results: One last thought on research. Research means asking questions and seeking answers – however, sometimes the answers you get are not the ones you set out to find. Indeed, sometimes, they are exactly opposite of what you anticipate or hope to find. This is how science works. Moreover, if you get unanticipated results, this may be a good thing. With limited resources, it is imperative that we do not provide services that are not needed or initiate or promulgate policies that are not effective. It is better to find out something does not work or that people in the community are not doing what you expect and reallocate time, energy and resources elsewhere. Research should help identify these sorts of things.

2. How are we using the research?

- Alignment – Advocacy should be aligned with research and both should be aligned with policy development. All three should then be aligned with monitoring and evaluation efforts. We should want to know what works, how it

works and then advocate for the resources, policies and programs to enable it to work. Monitoring and evaluation then follows how these things work over time – because unfortunately, nothing stays fixed. Even if a system works perfectly, advocates, policy makers and researchers need to ensure that it continues to provide the support, services and rights it was designed to address. What this means in practice, is that all sectors should be in touch with each other and stay informed about the latest ideas, policies and practices – researchers should know what DPOs are advocating for, advocates should know what the latest research findings are to inform what they are asking for – (and what additional things they should be discussing) – and everyone should be informed enough about what is found through monitoring and evaluation to understand what works, what does not work and how things change over time. This does not mean that everyone needs to have the same level of expertise, but there should be an effort to stay informed about the latest general thinking, studies and policies in the other arenas, and systems put in place to link the various groups in order to keep everyone in the loop.

3. Who is doing the Research?

- Levels of Research – There are different types of research and different levels of research. The issue often is not to train people to do all types of research but to train them to know where their limits are and who they need to ask for help for things that they are weak at doing. So for example, collecting information at the household or grassroots level can be done by many, but a smaller number of people are able to analyze large sets of data. As a qualitative researcher myself, I rarely try to analyze statistical data – I know my limits - and I seek out statisticians when I need that level of analysis. Again, no one can do everything.
- Who is collecting the information? Again, there is an important discussion underway about who is collecting information – DPOs and people with disabilities, professionals who may or may not be disabled, and teams of disabled and able-bodied researchers. I would argue that we need any and all of these. Again, similar debates are not going on in fields like women’s health or poverty reduction.

Having said this, there is a good deal of discussion these days about how much education is needed especially at the grassroots level, in order to ask questions and collect ‘data.’ I would suggest that people in disability research look at the wealth of data and methodology from the field of ‘oral history’ and community development – where people without much education – often without any education – have produced remarkable findings. And some of these individuals then go on to acquire more education and expertise. This has usually been done by working in collaboration with researchers and policy makers.

- Which leads into a larger question of why the debate about who is being funded to do what types of research or carrying out what programs, is going on in the first place? I would argue that one of the reasons we are debating who should be studying what and who should be funded, is because disability research has been so poorly funded and has been such a low priority, that disability advocates and researchers are left fighting for scraps.

We are asking the wrong question – the question is not why one group or another gets a piece of ‘the pie’ – but rather ‘*why is the pie so small?*’ Billions of dollars are poured into global health and international development efforts annually –

where is disability in this mix? Why can the Gates or Rockefeller or Ford Foundations continue to have a history of never or rarely funding disability issues? I argue strongly that we need to expand the focus and reframe the current questions regarding funding and support both for research and action.

- Finally, we need to make a real commitment to train bright young disabled people to be the next generation of leaders and researchers in disability. And just as importantly, to train other young people with disabilities to be the next generation of leaders in medicine, law, engineering, education and the humanities. Just because a student is disabled does not mean that he or she needs to go into disability studies or advocacy. Only when a young disabled boy or girl can dream about becoming anything they want to be can we talk about real equality.

4. How should we see disability research in a broader context?

Since I have been asked to provide a perspective from 'the North' – let me conclude with a few remarks to my African colleagues that I have not heard talked about much at this conference yet today:

- South-South Cooperation – Wherever I go in the world, people in disability research and advocacy are looking to Africa. Africa is famous for its leadership in disability advocacy, in policy development – (whether or not it actually always plays out on the ground as it is envisioned in planning sessions) and for its diversity of creative ideas, insights and programs. In the same vein, ideas, insights and strategies that advocates and researchers are working on in Peru or Thailand or Mongolia, may spark new approaches and insights here. There is a great deal of attention to North-South dialogue, but I would argue that South – South dialogue is equally important and all too often overlooked in the current discussions.
- South-North Dialogue - Along the same lines, there is a large – and certainly an important discussion about North/South dialogue relating to funding, priority setting, who is doing the research and so forth. Because my fellow speakers will be discussing this issue at greater length, I will not repeat it here.

But do not overlook the fact that there is much that you in the South have to teach the North. Many of the ideas, insights and innovations developed here in Africa relating to people with disabilities and their rights, support from and for family and community, the importance of social networks and inclusion – many things – need to be shared with the North. There is much that the rest of the world can learn from you. Do not be shy. Do not be deferential. You have much to be proud of and much to teach.

- I would suggest – indeed, I insist - that we need to start thinking in broader and longer terms. What will disability advocacy, policy and programming look like a decade from now? Two decades from now? And what *research* should we be planning and putting in place now to support these things into the future.
- Finally, many of the issues that are coming up time and again concerning research and the links between research, policy and programming here in sub-Saharan Africa, are not unique to Africa. Limited funding, the need to sustain interest and involvement, what to research and how to interpret and integrate research into action, are issues faced by the disability community in Latin America, Asia, North America and Europe.

Furthermore, I would argue strongly that the issues now faced by disability researchers and advocates today, are issues that have confronted most social movements over time. The integration of women into international development is an example of another movement which has confronted similar problems of resources, participation, and representation. There is a large and growing amount of work on social movements – and much of this work could inform current and future discussions about where disability research is today and where it might go in future.

We do not have the answers to all these things, but we have both the right and the obligation to at least raise relevant questions. And that is called research.