# Transcript of the Podcast Season on Disability Inclusive Development: Episode 1, Hannah Kuper

Why is Data and Research on Disability so Important?

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Soundbite Hannah Kuper: So unfortunately, today’s world is often not built for people with disabilities. People with disabilities around the world face really negative attitudes frequently, that the building and the infrastructure and the transport may not be accessible for people with disabilities. And people with disabilities are on average poorer.

And so for all of these different reasons, people with disabilities are being really left behind in today’s world.

If we flip that around, however, and if we make a world that’s built for people with disabilities in its center, it’ll be a world that’s better built for everybody.

Carine: Hi, this is Carine Weiss and welcome to the Medicus Mundi Switzerland Health for All Podcast. And today we talk with Hannah Kuper, Professor of Epidemiology at the London School of Hygiene and Tropical Medicine and the Director of the International Centre for Evidence in Disability. Disability affects 1 billion people globally of which 80 percent live in low- and middle-income countries. In this episode we will be talking about research, what decision makers need to know, and how we contribute to improving the wellbeing of people living with disability through science.

## **Carine: Hannah, thank you for taking part in the Medicus Mundi Switzerland Health for All podcast today. Welcome to this episode.**

Hannah: Thank you and thank you for inviting me.

## **Carine: When we hear the world ‘disability’, we tend to think of people being in a wheelchair. But what does the term disability really mean?**

Hannah: It’s absolutely right that most people think about people who are in wheelchairs, or people who are blind, or people who are deaf. But actually, disability is a lot broader than that. So, somebody has a disability if they have an underlying impairment or health condition. So, they may have a visual impairment, or they may have a condition such as schizophrenia. And that because of the environment in which they’re living and lack of support, they are not able to fully engage in the same way as everybody else. So, imagine somebody who is blind, and doesn’t have a guide dog and is not living in an area where laws support the rights of people who are blind to work. And maybe that person cannot work. So that kind of exclusion from participation is what we really mean when we talk about disability.

## **Carine: You are the director of the Centre for Evidence in Disability in London. What is the main focus of this Centre?**

Hannah: So, I am the director together with a man called Tom Shakespeare. And we work in a very complementary way. So, I am the numbers person. I work a lot about statistics and about how many people are disabled and what the kind of measurable impacts are in their lives, and what kind of interventions work to support people with disabilities. And Tom leads more on the qualitative or stories aspect. So, what people describe as being most important in their lives, the biggest impacts and their biggest needs. And all of our work pretty much is focused on disability in low- and middle-income countries and how to best support the participation and improvements of the lives of the people with disabilities in those countries.

## **Carine: Why the focus on low- and middle-income countries?**

Hannah: It’s a very good question. So, I have always worked in low- and middle-income countries and I feel very passionate about that because the gaps there are so big, and the health gaps are so big. And so, there’s a lot of need for research, but there’s also a very important need for building capacity in supporting local researchers to become the research leaders in their own field. And in the last few years with decolonizing global health, it has become even more important, and also with the COVID pandemic, where it’s become difficult to travel for people like me. So, for me there’s two reasons why I’m passionate about working in low- and middle-income countries. The one is the need and the second is the opportunities that help build strong research partners there.

## **Carine: Before we talk about research in disability, the majority of people living with a disability, live in low- and middle-income countries. Why is that?**

Hannah: Well mostly that’s because the majority of people live in low- and middle-income countries. So, it’s about 80% of people in the world, live in low- and middle-income countries and that’s where many people with disabilities will be. There is also some evidence that the prevalence – how common disability is in a population – is higher in low- and middle-income countries because of factors like lack of access to good healthcare that can prevent and treat impairments. Because people live in unsafe environments and therefore may experience more injuries and so on.

## **Carine: And what are the common problems they face?**

Hannah: Well people with disabilities face a wide range of exclusion. So almost anywhere you’ll look, you’ll find exclusion. So, children with disabilities are much less likely to go to school or to achieve well at school. Adults are less likely to be in employment, have worse health and have worse healthcare access. And a result of that people with disabilities are often poorer. But it’s absolutely not inevitable, and if people have the right supports in place, people with disabilities can work and have jobs and participate in the community, to the same extent as anybody else. So, it’s really an unnecessary exclusion that’s happening.

## **Carine: What kind of support would they need?**

Well, there are different levels of supports we can think about. So, one very important aspect is legal support and policy support, so that it becomes illegal to discriminate or exclude people with disabilities. That then different structures need to be built in a way that they’re inclusive of people with disabilities, so that schools are accessible and healthcare facilities are accessible. But also, that the personnel there: the teachers, the doctors, the nurses, are well trained to be able to meet the needs of people with disabilities. And then there may also be things in place at the kind of family level, like providing a disability allowance, to help families meet the extra cost of disability. Or helping to build support networks like organizations for persons with disabilities, to support people with disabilities to take part in the community. So, there’s not a magic bullet, there’s not just one thing that’s needed. There are lots of different things. But I know that this is a health podcast and one of my interests is in the health component and how helping to improve healthcare access and meeting the healthcare needs of people with disabilities will also help them to have a healthier life and perhaps a more independent life.

## **Carine: You are very passionate about research on disability and access to healthcare in low- and middle-income countries. What does data tell us with regards to access to healthcare for people living with a disability?**

Hannah: Well, what we know is that on average people with disability have got worse health status and that they face lots of difficulties in accessing healthcare, and when they do access healthcare it costs them more money and they often experience worse quality healthcare. And that all of these things are very problematic for people with disabilities and their families, and what the beauty is of evidence is that it can show us where the need is and what we can do. So, for instance within the UK, I’ve recently helped support analyses on people with learning disabilities and whether they’re more likely to die from COVID. And we helped with a very large-scale analysis and showed that yes, they are unfortunately more likely to die from COVID. And because of that policies in the UK were changed, so that all people with learning disabilities who are registered, were invited for vaccination. And that for me is the kind of beauty of research, is that it can show you what the evidence is, and then hopefully it can trigger an action that then helps to resolve the problem. But without that evidence, the action wouldn’t happen.

## **Carine: And why is there so little research in this area given the high number of affected people?**

Hannah: I think there’s been a lack of focus on disability because it seemed something very difficult and expensive and complicated to work with. And I think lots of other things like HIV or malaria, the end goal is elimination. This problem goes away. Whereas with disability, there will always be disability and there will always be people with disabilities. And that’s absolutely fine, there’s nothing wrong with disability. What’s wrong is that people with disabilities are excluded. And so, doing research on promoting the participation of people with disabilities has not been seen as enticing, as doing research to eliminate HIV, or eliminate leprosy. And so, I think that has been one big issue. I think the second big issue is that it’s been unclear as to who should fund it. So, a lot of the medical research is interested in prevention of conditions and not so much about improving quality. And I think a lot of the disability research has been focusing on issues such as inclusive education and inclusive livelihoods, rather than health. So, it’s been a double neglected issue. Not only is research on disability neglected, but research on disability and health is particularly neglected.

## **Carine: We will come back to this issue, but let’s talk about how do we measure actually, disability?**

Hannah: So that’s a really good question and there’s complicated ways. So, the first is basically to ask people: are you disabled? Do you consider yourself to be disabled? And that’s not a very good question because it’s quite stigmatizing and lots of people with certain conditions wouldn’t necessarily consider themselves to be disabled. They may just think I have difficulty walking or seeing because I’m old, not because I’m disabled. Then the second layer is you can ask people about functioning. And this is a very common way. So, asking people: do you have difficulties with seeing, with walking, with usual activities and so on. If people say they have a lot of difficulties in one of those domains, then they are classified as disabled. So that’s a sort of functional self-report. And that’s the most common way of being classified as disabled in kind of research. And the final way is to go out and try to measure whether people have impairments, so do they have visual impairments, do they have hearing impairments, do they have mobility impairments. And although that can be important because it shows the kind of healthcare needs that people have, it doesn’t really relate to what we consider disability, which is more on the focus on that exclusion of participation, not how much we can see on a visual impairment chart. So, the most common way of measuring disability is through self-report, asking people questions about functioning and what they can do.

## **Carine: Does everybody measure disability in the same way?**

Hannah: Traditionally, people have not measured disability in the same way and that has produced a lot of difficulty because the different kinds of ways people use make it very difficult to compare sources of data. In the last 10 years or so, there’s been a big push internationally to use what’s called the Washington Group Questions to measure disability. And the most commonly used version is six questions measuring functioning as I’d described before. So, ask whether people have difficulties in seeing, hearing, mobility, self-care, communication and remembering. And if they say they have a lot of difficulty in one of those domains then they can be classified as disabled. Now there’s still some controversy around that, for instance in that it doesn’t capture very well mental health conditions. But at the moment this is the standard of what is used. And because this is now used a lot more widely, it’s allowing a lot more comparative data to be collected.

## **Carine: We know there’s only few data on disability available globally. How do you and your Centre contribute to filling the gaps in research?**

Hannah: Well actually, since the Washington Group questions have appeared and people are more interested in disability. There’s actually now quite a lot of data. There’s one large health survey repository, so all the surveys done on health are put there, and there are over 1,800 that include measures of disability. So now the problem is less about availability of data, but more about that people have analyzed that data, and disaggregated the data, and shown how to use it. So that’s one big gap, which is slowly being filled.

Where there is still a gap is about what works. So, we now know that people with disabilities are falling behind in all sorts of ways, but what we don’t know is what interventions work to improve the inclusion and improve the lives of people with disabilities. And that’s an area where in our group we are focusing a lot. So, to do more intervention studies to see what works, but also to start using this widely available data, these 1,800 surveys, to start showing what’s known and what it means.

## **Carine: Can you give us an example of an evidence-based intervention for persons with disabilities that you are most excited about?**

Hannah: A few years ago, we were working on a project in Bangladesh about childhood disability. And one of the biggest groups was children with cerebral palsy or other severe neurological disabilities. And there were no services in place there at all. And so, ethically, we had to refer these children who were found, for services, but there weren’t many services in place. So, we decided to develop an intervention. And we worked together with the families and we developed a parent support program for children with cerebral palsy and other kind of similar conditions. And that has been used very widely. And then when the Zika epidemic hit in Brazil, the children affected by Zika showed a lot of similarities to children with cerebral palsy. And we received funding to then adapt that program for children affected by Zika and roll it out. And so that’s something that I’m really excited about where evidence was used to produce an intervention and the intervention was shown to work, and it has now been scaled up.

## **Carine: And what do decision makers or policy makers need to know when designing projects and programs for people living with disabilities? Given the already limited resources in this field.**

Hannah: I think the most important thing is to incorporate disability from the start. So, if programs are planned to be inclusive of people with disabilities from the start, that shouldn’t cost much extra. So, if you’re building a school, and you ensure that that school is physically accessible, that shouldn’t cost much more. But if you try and adapt a school afterwards to be accessible, then that can be really expensive. And I think that is true for all kinds of interventions that we may want to do. So, the importance is to plan from the start. But to plan from the start there must be awareness about disability and the people who are planning. And so, there is a responsibility I think to donors such as FCDO and USAID and the World Bank, to say, all programmes must be inclusive of people with disabilities and we need to see that in your plans rights from the start, how you’re going to do that. And that’s something that I am really interested in and have been talking with donors about. But unless you specify that it’s going to happen from the start and that it must happen, it’s unlikely to happen.

## **Carine: COVID-19 hit us hard, and it has been especially hard for women being in lockdowns, as violence has gone up. And it has been in the news. What happened to people living with a disability? What do we know about this group of people?**

Hannah: We know quite a lot about people with learning disabilities. And that’s because in lots of countries such as the UK, there will be a record in your medical records, that you have a learning disability. So, we know that people with learning disabilities unfortunately were much more likely to die from COVID. We know very little about the mortality experience of people with disabilities more broadly. There’s some suggestion of data from the UK and from South Korea, that people are more likely to die from COVID. But it has been very, very little researched. But if you look at even different groups, like people who are blind or who have hearing impairment, there’s no data at all about their risks of COVID. What my colleague Tom and others have done a lot of research on is, what the impact of COVID has been on the lives of people with disabilities. And although as you say, everybody has had a difficult time during COVID, it is clear that, that has been heightened for people with disabilities. That there’s obviously a greater vulnerability if there’s a reliance on carers, that a lot information has not been given in the right ways so that it’s accessible. But the kinds of supports that people with disabilities may have in place, to promote participation, may have been wiped away during COVID. Things like rehabilitation, things like carers, and even disability allowances may have been reduced. So, there’s been a really disproportionate impact of the pandemic in the lives of people with disabilities. And there’s evidence to show that’s lead to heightened mental health problems, and also physical declines.

## **Carine: Is it a lack of reporting, or is it simple that this group of people is left behind?**

Hannah: I think what COVID has done is it has revealed something that is happening anyway. So, people with disabilities are often left behind and this is revealed through COVID. There is also a lack of data about people with disabilities, and that’s because of difficulties in how disability is measured in routine data. So, for instance we’ve been doing a lot of work with the UK GP databases and there’s no measure there that people are disabled, so then it’s hard to see what the outcomes are for people with disabilities. But I think what COVID has done is it has magnified discrimination that has already been in place and it just shows that people have always been left behind are now also left behind during the pandemic.

## **Carine:** **In one of your talks, I heard you saying that there is a need to redefine our role in global health. What did you mean by that?**

Hannah: I have been working in global health for about 20 years, and I’ve seen a very big change, and that’s been really accelerated by COVID. So initially, people like myself from high income countries, they would go to low- and middle-income countries and help conduct research. And then come back and write it up. And then over time there’s been much a stronger shift towards capacity development supporting low- and middle-income country researchers to lead research. And that’s obviously incredibly important because it’s their country, they will know the country much better, they will be able to work much more effectively will also be able to help use the research to influence policy and practice. So that shift has already been in place. But what has happened with COVID, is it has been massively accelerated because the high-income researchers have been unable to travel for the last 18 months. So, everything has been at a distance led by low- and middle-income countries. And so that shift that was in place already has now been happening at a much-accelerated place, which is a very good thing.

## **Carine: What are your hopes and wishes for the future?**

Hannah: The International Centre for Evidence in Disability, we developed it 10 years ago, 11 years ago. And it’s been really great working there, setting it up, leading it and seeing how it’s really contributed to the debate about disability in evidence. And my hope is that there will be Centers like that in low- and middle-income countries leading research, driving forward this momentum. And that the role of organizations such as my own, will be much more supportive and technical. So, my hope is that research generation, evidence generation, will be much more led by low- and middle-income countries. But also, that the loop from evidence to informing policy and practice, will be much stronger. And that it will be much clearer why evidence is needed and how evidence really influences practice. Because as a researcher what can be very demoralizing is that if you do research and you show that there’s an issue or you show that there’s a solution, and then nothing is done about it.

## **Carine: Thank you so much for this very interesting talk, Hannah Kuper. I wish you all the best and a lot of success with your future endeavors.**

Hannah: Thank you so much for having me.

Carine: This was the Medicus Mundi Switzerland Health for All Podcast with Carine Weiss. You can listen to it on Apple Podcast, Spotify, and on our website. To spread the message, please leave a comment on our website, share and like it.

This was the first episode of the new season on disability inclusion and human rights. Stay tuned and watch out for the next episode where we will be talking about the UN Convention on the Rights of Persons with Disabilities and its implementation in and by Switzerland.