



How can data better support disability in East Africa?

Claudia Wells: Welcome everyone. My name's Claudia Wells and I'm the Director of Data Use at Development Initiatives. I'm really pleased to welcome you all today to this podcast, where we'll be talking about how data can better support disability advocacy across East Africa. It's the 19th of April, and I am really pleased to have three fantastic speakers here with us today. We've got our lead DI analyst from East Africa, Martha Bekele, and representatives from two organisations that Development Initiatives has been working with over the past year and we've learned so much from in terms of disability inclusion. That's Edwinah Orowe, who's a global advocacy advisor at Sightsavers, and Eric Ngondi, of the United Disabled Persons of Kenya. Thank you for joining us.

So Development Initiatives has been working with Sightsavers and the United Disabled Persons of Kenya over the past year under our Inclusive Futures consortium, where we're looking to improve employment opportunities for persons with disabilities. In this podcast today, we're going to be exploring some of the key disability advocacy issues in East Africa, new data-led approaches to advocating on those issues and hopes for the future of database disability advocacy. So in this first section we'll examine East Africa as a region and set out the issues disability advocates are really trying to address. We're going to explore some personal experiences of working in the region, the concerns of persons with disabilities, and the cultural and economic factors that lead to marginalisation and exclusion.

So my first question, which is going to Eric: Can you set out the scene by telling us a little bit more about the issues facing persons with disabilities in Kenya and East Africa more broadly?

Eric Ngondi: Thank you very much, Claudia. These are robust disability movements in Kenya and indeed in East Africa. Persons with disability have come together in a united voice to mainstream their issues. However, we note that just like in [other global regions], that persons with disability have been quite disadvantaged or disproportionately affected due to many, many, many, many issues. So, for example, we are talking of inaccessible education and inaccessible healthcare, we talk of attitudinal barriers such a stigma, discrimination of persons with disabilities. You also talk of inaccessible infrastructures and looking, especially now that the world is being affected by the pandemic, persons with disability have also not been spared and our present concern is actually to do with the vaccines, we are concerned that governments actually have not prioritised persons with disabilities. This is surely an urgent issue to look at.

Claudia Wells: Thank you so much Eric, you touched on so many important issues that I think data can be really well placed to inform. Edwinah, coming to you next. You've been working with Sightsavers in Nairobi for more than five years, and you have a really strong advocacy focus; can you tell us a little bit about the advocacy landscape in East Africa and why some of the issues that Eric is mentioning are so difficult to resolve?

Edwinah Orowe: Thank you Claudia. So when I think about advocacy in Eastern Africa, I want us to think about it from the principles, the UNCRPD principles. If we do not consistently and continuously demonstrate that we understand issues of persons with disability as human rights, then it becomes challenging to ensure service delivery in health, in education, stigma and all this infrastructural exclusion that we see even in physical access to public institutions. If we don't have a health system, for example, that does not consider persons with disability in vaccine access, then it means we haven't taken that into consideration. For me, that is how we need to consider and look at how policy would be, or should be, responding to some of the issues that Eric raises. They become difficult because of, I guess perhaps, lack of data and, I don't know if I'm pre-empting the conversation, lack of data but also lack of moving from policy into implementation.

Claudia Wells: Such important issues that you raise, and that phrase is really going to stick with me, “disability rights are human rights”, and really what we must be considering is not just signing up to recognising these rights, but actually thinking about how they're implemented at the point of service delivery.

Now Martha, can I turn to you? You're leading DI's work under the Inclusive Futures consortium, and there we focus in particular on identifying and removing key barriers that prevent persons with disabilities from accessing healthcare, education and work. Could you perhaps talk to our listeners about some of those barriers, particularly with regard to employment, for disabled persons in East Africa?

Martha Bekele: Thank you, Claudia. On lack of comprehensive accessibility, you can speak of lack of proper training, starting from early age. Our education programs and the education systems in our region are not inclusive, education materials are not in accessible format, they are not in easy-to-read and -understand formats, you can even talk of lack of teacher training in responding to communication and information needs. The other barrier I see is in information technology and communication. ICT is now providing an opportunity for many to learn remotely and carry out their work remotely, but for persons with disabilities, the low accessibility of digital resources indicates that the digital divide is real and this can also be a barrier, particularly to opportunities.

Another barrier which was touched on by previous speakers was on data. As we always say, what is not counted does not count, so we need comprehensive data to inform service delivery policy programming and program interventions for, say, better access to employment opportunities. Touching again on data in Kenya's last census, 2019, disability prevalence has been reported even less because children below five years with disabilities were not counted. Now, in terms of employment, if I give you an example, a conversation we had with our partner in Kenya, the Kenya University, for instance, there is absolutely no information on how their former students with disabilities fare in the labour market and what barriers they face and the support they need.

Claudia Wells: Thank you, Martha. Now to support our work here at DI we've employed two brand-new interns, Peter in Kenya and Timothy in Uganda. They both joined the team, and both have a lived experience of seeking work as disabled persons in East Africa. Peter has recorded a short piece on his experiences for us, which we will play for you now.

Peter: Being a jobseeker in Kenya is one of the most challenging and toughest tasks and worse for persons with a disability. Jobseekers are scrambling for few and limited job opportunities available for them. Prior to sight loss, I used to depend totally on my sight and my friends for job alerts. With my disability I lost connections with my friends and I was also not sure whether I could perform without sight. This lessened my confidence and self-belief, which led me to avoid chasing new opportunities. To overcome such a challenge, I enrolled for various programs on disability inclusion and empowerment, particularly soft skills programs. This helped me to restore my confidence and self-esteem. I've struggled to secure job opportunities since I had limited professional connections. As a matter of fact, most Kenyan jobs are secured through professional connections, who knows who, because they are few and competitive.

After my surgery, I was advised to take one year resting without being involved in any heavy or excessive work, as well as avoiding exposing my sight to light from phone or computer for long hours. I was not able to pay for my rent, food and other basic needs at the urban centre. I was bankrupt. This made me disengage from my friends and relocate to a rural area, leading to more disengagement. To overcome such challenges I had to start income-generating projects, reunite and reconnect with my former friends and create new professional connections. This helped me to pay for my Internet bills and to get insights on available jobs.

One of the worst experiences I can remember as a jobseeker was feedback given to me after undergoing processes as a job applicant. After attending the interview, we were informed to go and wait for the feedback. After waiting two to three months, I followed up to know whether we were still waiting for the

feedback or not. At the reception, I was informed that successful candidates had been recruited and were already in the workplace. As I was moving out, I met one of my friends who had successfully secured the job and sadly informed me that they avoided including a person with severe disability to avoid burdening their organisation. Truly this experience left me with the bitterness which sometimes makes me anxious when there is delayed feedback.

Claudia Wells: Wow, thank you it's great to hear from Peter there talking about how his disability is not just impacted on job opportunities, but actually the lack of inclusion has meant that there has been a significant impact on his broader wellbeing. And as Peter's experience highlights, some of the challenges persons with disabilities face in East Africa but also in areas where interventions can have a positive impact. Crucially we're able to advocate for and implement positive change without good data on persons with disabilities and their needs.

This next question is for all of you: What innovative approaches have you seen bring data into advocacy, using data-led information to strengthen efforts to ensure persons with disabilities secure their fundamental rights?

Edwinah Orowe: Yes, so what for me innovation really is about is how we do it differently, how we bring in stories or use the story and listen to stories, such as those of Peter, to start to show that you can actually learn with data as you pick it up.

In 2019, Sightsavers for World Disability Day in part of December, were calling on the UN in New York to support and prioritise persons with disabilities, issues, and needs as we moved into 2020. As a result, we started running a campaign that was aiming at collecting signatures of all people, of all areas, to be able to reach out, to be able to support the voice of persons with disability so that we don't have just persons with disability talking about themselves, but also to bring in the broader community to be able to support and make a case and a profile, they need to work with and recognise persons with disability, as members of society. Therefore, we developed an app and it became clear, which does not use the Internet, but allowed us to be able to reach out to a project in as far as Northern Uganda, we would never find Internet, to be able to use that data and gather people and bring them to actually, just with an android phone, to be able to sign on an app and be able to literally participate directly. As a result, we were able to collect about 50,000 signatures from Pakistan to Kenya to Northern Uganda and in about 14 countries across Africa and Asia.

Claudia Wells: Can I ask the same question about bringing data into advocacy and data-led information to Martha?

Martha Bekele: Yes, so, Development Initiatives, DI, is supporting organisations with data to work on disabilities. DI is not an organisation of persons with disabilities, but a friend of such organisations. DI is here to support with the data and evidence, for instance, we were able to break down the 2019 census report and compare those results to the results of census 2009. We reached out to many stakeholders such as the Washington Group, UDPK, Sightsavers, to understand why there was huge variation in prevalence rate. As Edwinah said, it is one thing to have evidence and data available, but another to have the culture of use. So in order to ensure that we first get requests from organisations of persons with disabilities, who are ready to move with advocacy.

So I'll give you an example, for instance through our budget community, we were approached by a county-based organisation of persons with disabilities, and this is in Bungoma, but covering for other counties in Kenya to track how much seven national governments have spent in Kenya to include persons with disabilities in development planning and resource allocation. Now, before we started the analysis, we developed the detailed table of contents, which was refined by UDPK, and when we were done with the analysis we went back to UDPK for review of the report so that we speak the same language, so to speak, and also for UDPK to help us strengthen the product and the key messaging. The preliminary key findings were presented at World Disability Day by our partner who initially asked for these products, and our partner in Bungoma managed to present to the Governor of Bungoma and good promises, not only for more resource allocation consideration, but also the establishment of disability directorates in the county.

Claudia Wells: Thank you so much Martha, and I couldn't agree with you more on the importance of data. Perhaps though finally I can turn to Eric to see whether you have any thoughts about bringing data into advocacy?

Eric Ngondi: As the United Disabled Persons of Kenya, how have we been innovative? So we've really moved ahead in trying to work with the national statistic organisations; for example, in Kenya we have the Kenya Bureau of Statistics and other development partners in the field of statistics and data, and I can mention that the organisations of persons with disability, together now with the partners, have come up with a technical working group on the statistical data for persons with disability. So generally persons with disability are on board on this technical working group, and this is a consortium where by now the issues of persons with disability will take a fore. I can also mention that regarding innovation, we know that our National Council of Persons with Disability have actually implemented a portal for persons with disability in area of employment, whereby now the artificial intelligence is about to match their capacities with the employers out there.

Claudia Wells: Thank you so much Eric, and some really great examples about not just improving the data but improving the process around that data to ensure that it's inclusive as well, and that's another issue that we've learned so much about here from both of your organisations, UDPK and Sightsavers, over the past year, and ensuring that our methodology is inclusive and our analysis is inclusive, as well as the data itself.

Some really positive stories about how data and data-led approaches can really strengthen the movements to change both in East Africa and elsewhere, but there's also a lot of work to be done in terms of expanding the data that we have available and ensuring that decision-makers are able to use it before we'll see the changes that we want.

Eric and Edwinah, looking to the future, how do you see things being different for persons with disabilities in East Africa in 10 years' time? And from the point of view of your own organisations, how can better data help empower your action to get us there? Eric if I could come back to you first.

Eric Ngondi: Looking ahead, I see a strong collaboration with the government agencies and also development partners and non-state actors with close engagement of course of OPD's, Organizations of Persons with Disabilities, so that's one. Two, looking forward I see a time whereby the issues of persons with disabilities are actually integrated in the government systems by the agencies that actually use and implement issues of data; and lastly, I look forward to whereby we do not continually focus on disability data in the area of census only, but also in administrative issues. So, for example, whereby data will be used in terms of implementation, in terms of monitoring and also in terms of evaluation, just as part by the United Nations Conventions of Rights, rights of persons with disabilities and also in the SDGs.

Claudia Wells: Thank you so much Eric, and it's great that you see a real growing role for data to help really empower action. Edwinah, perhaps I could come to you from the point of view of Sightsavers, with the same question: how do you see things being different, and how can data help empower your action to get us there?

Edwinah Orowe: I think, like Eric, for me at the core of stigma and discrimination is data. I say data because data can socialise our society's differences. If I look at the role of the Central Kenya National Bureau of Statistics, if I talk about Kenya, but more Central Bureau of Statistics across East Africa, to start to look at data and gather back data and be in a position where they encourage everyday use of that data. To have that data is one thing, but to encourage and excite everyday use across the different public service ministries. So if you think about Ministry of Education, how are we using data? If you think about education, if you think

about Ministry of Health, if you think about in energy, in, you know, agriculture, where and how are we using data? When we start to get the ministers to the Central Bureau of Statistics, not just to say, "This is the data," but also encourage use of that data, then ministries in their everyday actions will start to socialise communities' differences. You can imagine this data, working with persons with disability is actually about this. And when we start to do that, then we start to challenge social norms by simply going back in saying, "These are the practical ways of using data to inform, how different ministries respond to issues that impact persons with disability."

Remember the first, the very initial at the start of my conversation, I said actually it's about policy and programmes that are linked to that, these programmes are actually the role of different line ministries that should be using that data to make that decision. So yes, ministers and Central Bureau statistics in 10 years, we should be able to play an active role in re-socialising people around using data and thereby challenging deep-rooted issues such a stigma and discrimination because, for me, I think that is the heaviest issue with most impact, the actions that followed, because it involves individuals and culture, etc.

Then secondly, in going back, then we start to get together better data, what are we going to do with that? Better data allows us to start conversations and sustain conversations, for example, we are looking at inclusive data. How many persons with disabilities are accessing some of the health services that we produce? This is the data that you want to start, we want to use to initiate a conversation with the ministries.

These are the issues that I imagine, I expect other people to do the same with education, we are gathering data, what is the transition? What are the experiences of children with disabilities transitioning into education? Again, looking at this data, how do we use it to start and sustain conversations? Thereby continuously learning and continuously building on the on the on the legacy, on the data landscape, which is really the essence of making sure that ultimately, we are able to ensure we have responsive services and policies that actually are in line with the realities of persons with disabilities, thank you.

Claudia Wells: Thank you so much Edwinah, so many important and rich points there about how data can really ensure that that voice is brought to all levels of government across all ministries.

Martha, we've heard a bit today about what better data could mean for advocacy and the future of inclusion in East Africa. In closing, perhaps you could share what you consider to be the most important data gaps that need to be addressed in the region?

Martha Bekele: There are encouraging steps being taken around us. For instance, in Kenya, the Ministry of Labour and Social Protection of the Government of Kenya drafted action plans for inclusive data charter deliberately focusing on disability as a theme. This we think will help Kenya address major data gaps. That being said, the most important data gaps that we think need to be addressed for the region, and this is based on our experience in Kenya and in Uganda, are firstly the need to have reliable and up-to-date data, so this is on data availability, but as Edwinah said earlier, we need to also talk about data use, and I can't agree more. Where data availability is one step in the right direction, we need to use data and have the culture of everyday data use.

Secondly, where data exists, one has to consult multiple sources in different places. You have surveys, census, administrative data and then government data. Therefore, we need a central repository to bring these data sources in an internal possible manner. The first step should be a national indicator framework, this is just a mapping of the data statistics that are required and where they can be sourced from. Because building such a framework exposes that publications and gaps and should also record something about the quality of data. Another thing is, once we have a national indicator framework, or a central data dictionary in place, one can then look pragmatically at what is possible in starting to actually join up different systems.

And lastly, on data gaps, I would want to mention issues on official data. That is data collected by non-government stakeholders and used for programme designs and interventions. However, there are no standardised tools and approaches that are being used to collect this unofficial data.

Claudia Wells: Thank you so much, Martha. So much to reflect on there, and it makes me think of the quote from the UK's ex-national statistician John Pullinger. He said, "Good data makes it intolerable to do nothing," and that's absolutely why it's imperative for us to improve the data ecosystem on persons with disabilities.

So it's been really interesting today to listen and hear all of your perspectives, and of course Peter's as well, and I'd just like to reiterate that we're so pleased to be working in partnership with Sightsavers and UDPK and the other members of the Inclusive Futures consortium as an organisation.

Broad partnerships like this bring together different organisations, really allow them to benefit from each other's perspective and expertise, and help us work in a way that's inclusive, effective and sustainable. So thank you very much, thank you to everyone who's listening, and thank you especially to Edwinah, to Martha and to Eric.