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# Transcript: Podcast Series on Disability Inclusive Development: Episode 6, Making telehealth services inclusive for all with Andrea Pregel

This podcast season has been developed by CBM Switzerland in collaboration with Medicus Mundi Switzerland. This transcript is provided by CBM Switzerland.

**Introductory soundbite:** Over a billion people worldwide have disabilities. And a lot of us are online. Put simply telehealth is a delivery of a health service across a distance. It's important to consider the potential of telehealth as an alternative method of engaging with patients.

## **Carine:** Hi this is Carine Weiss and welcome to the Medicus Mundi Switzerland Health for All Podcast. And today I talk with Andrea Pregel, who works for Sightsavers in London as a technical lead on inclusive health. He has been working in disability inclusion, global health and inclusive education across Asia, Africa and Europe. He co-chairs the Inclusive Health Task Group on the International Disability and Development Consortium. In this episode, we will be talking about digital health, inclusion and whether digital health serves the community of persons living with disabilities. Nice to meet you Andrea and thank you for being my guest at the Medicus Mundi Switzerland Health for All podcast today. Welcome to this episode.

**Andrea:** Thanks a lot for having me.

## **Carine:** You are working for Sightsavers on inclusive health. Why did you get involved in this area of work?

**Andrea:** People with disabilities have a right to access healthcare services on an equal basis with others. This is clearly articulated in the Convention on the Rights of Persons with Disabilities, often called CRPD. But many years after the Convention entered into force, access to healthcare for people with disabilities remains a largely neglected area globally. Sightsavers is an international organization working to promote equal participation for people with disabilities in society. And disability inclusion in the health sector is one of our key areas of focus. When I joined the organization in 2016, we started working on a small pilot project in India and we now have multiple inclusive health programs across South Asian and Sub-Saharan Africa.

## **Carine:** So what are your working on currently at Sightsavers?

**Andrea:** We recently adopted our new social inclusion strategy. And one of our key goals is to consolidate and expand our work aimed at promoting access to healthcare and good health outcomes for people with disabilities in all their diversity. And we have decided to use this expression to underline how people with disabilities do not represent a homogeneous group. All individuals have their own intersectional identities and experience different types of barriers. So it is crucial to ensure development programs, including health programs, are tailored around these individual experiences, while aimed at strengthening systems overall.

## **Carine:** You are also part of the Inclusive Health Task Group of the International Disability and Development Consortium. What are the current hot topics?

**Andrea:** A few years ago, I had the opportunity to become a co-chair of the Inclusive Health Task Group at the IDDC. This has given me the opportunity to collaborate with wonderful colleagues and disability inclusion advocates from around the world. There is a lot happening in the development sector at the moment. As I mentioned earlier, disability inclusion in healthcare has been a neglected topic for many years. However, we have recently observed a shift, which is in large part due to the COVID-19 pandemic. People with disabilities have been disproportionately impacted by COVID-19 and this is largely the result of pre-existing inequalities. Health systems in most countries are not sufficiently equipped to ensure equitable access to people with disabilities. In fact, in some circumstances people with disabilities are actively discriminated against and this became apparent during the pandemic. And more development actors started to recognize disability inclusion in the health sector as a priority, not just to respond to COVID-19, but to build more inclusive equitable and resilient health systems going forward.

Last May the World Health Assembly adopted a new landmark resolution on the highest attainable standard of health for persons with disabilities, which reaffirms the principles and rights defined by the CRPD and further urges Member States to invest in the development of disability inclusive health systems and decision-making processes. And IDDC has done a lot of work to support the drafting of the resolution and we're continuing to work alongside partners to influence and support WHO and Member States to move forward with the implementation of the resolution.

## **Carine:** Let’s talk about digital health. I know that area has been evolving over the recent years, particularly also during the COVID-19 pandemic. What is your experience?

**Andrea:** With the COVID-19 pandemic we have certainly seen an increased focus on telehealth at a time when many health providers had to reduce or pause their in-person services. And with lockdowns and movement restrictions in place, and with many people in self isolation or quarantine, accessing telehealth became a crucial factor. A recent report from the World Health Organization indicated that about 61% of the countries which reported service disruptions due to COVID-19, also reported an increased utilization of telehealth services. And evidence from the US for example, indicates that the use of telehealth services was 38 times higher in February 2021 compared to February 2020, with a range of approximately 30 to 70% of health services accessed via telehealth across all specialties. Clearly the use of telehealth is not uniform across all countries and the WHO report did observe a prominent trend among high income countries. However, even among low-income countries, 42% of those who reported service disruptions, also reported using telehealth. So things are slowly improving.

## **Carine:** You have worked in Africa and Asia and digital health is not accessible for everyone, regardless of having a disability or not. What is the link between digital exclusion, poverty and health? And why is digital inclusion so important?

**Andrea:** Telehealth can play a critical role in the achievement of universal health coverage by improving access to quality and cost-effective health services for all people regardless of where they live. For example, it could play a crucial role in countries with a significant rural population. In Sub-Saharan Africa, where the doctor-patient ratio is extremely low, the use of mobile technology has increased significantly in the past decade and could represent an important factor for the expansion of telehealth services and improved access to healthcare. However, there is a risk that the increased focus on telehealth will exacerbate existing health disparities. Factors such as the absence of adequate devices, limited digital literacy and the lack of reliable internet coverage are among the key factors causing a digital divide, which disproportionately impacts older people and people from marginalized constituencies such as minority ethnic groups and people living in poverty. People with disabilities are likely to be overrepresented in these groups. As the disability prevalence increases with age, people with disabilities are more likely to live in poverty compared to the rest of the population. And for example, again, research from the US suggests that people with disabilities are 20% less likely than people without disabilities to own a computer, a smartphone or tablet, and on top of all of this, telehealth services remain largely inaccessible.

## **Carine:** You mention already the digital divide. So, what exactly are the barriers for persons with disabilities?

**Andrea:** Telehealth platforms often present a variety of barriers which prevent people with disabilities from using these services on an equal basis with others. For example, these platforms often are not compatible with screen readers or other assistive devices which are used by people who are blind or have visual impairments. Captioning, sign language interpretation, and speech to text options are often missing or not entirely adequate, which means that deaf people and people with hearing loss and people with speech difficulties are often not able to access potentially lifesaving communications. Also, many people with fine motor or movement difficulties, such as for example people with cerebral palsy or down syndrome or multiple sclerosis, often struggle when icons and navigation systems are too small or not structured in an easy way, for example when they require multiple clicks.

However, one important aspect that it is worth highlighting is that it's not just a matter of telehealth platforms being inaccessible. It's also about how telehealth is used by service providers themselves. For example, if only phone numbers are offered as a way to communicate with the health providers, a wide range of people with disabilities will be left behind. Many service providers also provide insufficient time limits to complete certain tasks such as to fill out online forms, or maybe do not have enough flexibility to accommodate people who need more time for communication, for example during the consultations.

Using plain language is another critical issue. When complex technical language is used and when text and other content are not designed with accessibility in mind. And when information is not provided in accessible formats such as easy read for example, people with intellectual or learning disabilities as well as people with neurodiverse conditions will struggle to access the services they need. And another issue is that very often, not enough information is provided on how the service can ensure safety and privacy, which can foster negative feelings and discourage the use of these services. And this can be an important barrier particularly for people who live with mental health conditions and psychosocial disabilities.

## **Carine:** Before I ask you about that advantages of using telehealth, I would like to dig a bit deeper into what you just mentioned. Because you mentioned that people with disabilities have difficulties to fill out the form on a website or they cannot use the telephone numbers which are provided on a website. Why are these websites not designed for people with a disability? Even myself, I need to confess that we have difficulties with the website with Medicus Mundi Switzerland to make this more inclusive. So what is your experience on that?

**Andrea:** Web accessibility is another important topic which of course is linked to telehealth, but actually impacts the lives of people with disabilities widely. Thankfully we have the web content accessibility guidelines which are international technical standards that should be followed by developers to make websites more accessible. And it's not just for people with visual impairments, but it's actually also for other users with disabilities. For example, there are aspects that need to be considered in relation to color blindness or the accessibility of text for people with dyslexia or the importance of structuring content in a clear logical way. So, it's important to ensure that these guidelines are followed. And of course there is a point on budgeting. It is important to ensure that accessibility is factored in at the design stage. Because when services and products such as websites and other telehealth platforms are being developed, the cost of embedding accessibility is relatively marginal. But it really goes up when accessibility is overlooked and then needs to be retrofitted.

## **Carine:** What needs to change? Is it an issue on the policy level? Is it an issue on the mindset level? Is it because we need additional funding in order to make a website more accessible? What needs to change?

**Andrea:** Well when it comes to websites in general - because we do have guidelines - those should be followed. And there is a responsibility for governments to ensure those guidelines are followed in each country. So there is probably an issue of awareness, making sure that people and developers know the existence of this guidance and they know how to use it and they actually embed it within their work. When we look at telehealth, as a starting point, the industry must take immediate action to incorporate accessibility in the design of telehealth platforms. But also, governments should create an enabling environment by adopting accessibility standards for telehealth and digital health and ensuring that accessibility becomes a precondition for the design and rollout of these services in their countries.

But you also need to intervene in the wider ecosystem. For example, reducing the digital divide and ensuring access to health insurance for people with disabilities. And finally, service providers both public and private, should invest in accessible telehealth platforms and services and should embed inclusion and accessibility in the design and delivery of these services. Because again, if the platform is accessible, but the content and the services are not, people with disabilities will still be left behind.

## **Carine:** Let’s move away from the disadvantages or the challenges. Let's talk about the advantages of using telehealth for people living with a disability

**Andrea:** Telehealth could have an incredibly positive impact on the lives of people with disabilities. For example, remote patient monitoring can improve surveillance of chronic health conditions and can contribute to improving the quality of care. Telehealth also reduces the need to travel to a facility which often comes with additional challenges and additional costs for people with disabilities. But again, in order for this to become a reality, those barriers which currently prevent people with disabilities from accessing services, must first be removed.

## **Carine:** Are there any international standards to guide digital health and accessibility?

**Andrea:** Recently the World Health Organization has been working with the International Telecommunications Union to develop effective international accessibility standards for telehealth. At IDDC we have been working closely with the WHO and ITU to provide some technical support in this area. We are engaging in a series of consultations with stakeholders in the industry and in March we co-hosted with WHO a webinar on telehealth accessibility, to promote civil society engagement on this topic and to gather inputs and perspectives from people with disabilities and their representative organizations. A draft of the standards is now being produced and WHO and ITU are planning to release the final document early next year. And the fundamental next step will then be for countries to adopt the accessibility standards for telehealth and to ensure these are used by industry and service providers.

## **Carine:** How does it look like? Is there available data on uptake of digital health services by persons with disabilities?

**Andrea:** The answer is not much. There's some data from the US suggesting that there has been an increase in the utilization of telehealth services by younger adults with disabilities in recent years. And this suggests that there is a cohort of people with disabilities who are keen to use telehealth, and which reinforces how critical it is to ensure that these platforms and services are inclusive and accessible. However, we do need more granular data on access to telehealth about people with disabilities and on the quality of their experience using these platforms and services. Most service providers do not record information on disability in their patient’s records and do not include disability in their demographic data collection systems. So this still remains an issue.

## **Carine:** Andrea, if you had one sentence, what would you wish for?

**Andrea:** Over the last decade governments multilateral agencies and other development actors have made serious commitments to ensure people with disabilities can participate in society on an equal basis with others, including in relation to access to healthcare. Now is the time to move from theory to practice. Now it's time to ensure people with disabilities are not left behind.

## **Carine:** Thank you so much for being my guest at the Medicus Mundi Switzerland podcast today. I wish you a lot of success for your future endeavors.

**Andrea:** Thanks a lot for inviting 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. Stay tuned and watch out for the next season or go back and listen to many other inspiring podcasts which we published previously.