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# Transcript: Podcast Series on Disability Inclusive Development: Episode 2, Nothing about us, without us, with Mirjam Gasser and Chris Heer

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

Introductory soundbite: In 2006 the United Nations made a treaty. It is called United Nations Convention on the Rights of Persons with Disabilities. The UN CRPD talks about how countries should make sure that people with disabilities have the same rights as others.

Carine: Hi this is Carine Weiss and welcome to the Medicus Mundi Switzerland Health for All podcast. Today we talk about the inclusion of persons with disabilities in Switzerland as well as in Switzerland's international cooperation. We will hear about the Swiss disability movement, the UN Convention on the Rights of Persons with Disabilities and its implementation in and by Switzerland. I talk with Mirjam Gasser, head of advocacy of CBM and Chris Heer, self-advocate on the rights of persons with disabilities and head of equality and social policy from the organization of persons with disabilities, AGILE.ch.

## **Carine: Chris, you have been engaged in the disability movement in Switzerland over the past years and you were born with a disability. What does it mean to live with a disability in Switzerland?**

Chris: People who live in Switzerland are in general quite privileged in the sense that they can lead a life without fear of hunger, loss, or shelter or dying because of poor hygiene or lack of health care. I think that's why non-disabled people do not want to think about the possibility of becoming disabled. But by pushing this thought of disability away they also push disabled people and their everyday needs away. So we live in a reality where people like us are seldom included. This led to construction work, communication and infrastructure that lack accessibility for everyone. I was born with a very visible walking disability. This meant that from an early age on, people are staring at me or asking me intruding questions about my body, my health history, or my sex life. And the phrase: what happened to you, is the most commonly asked. It suggests that something is wrong with me or with people with disabilities and that we have to be fixed if we are living with a disability.

## **Carine: Thank you. What about you, Mirjam? You are Head of Advocacy of CBM and you advocate for the inclusion of persons with disabilities in Switzerland’s international cooperation, and you live with a wheelchair. How is life for you?**

Mirjam: As Chris said already, even today it means that I am facing barriers and discrimination on a daily basis. And to give you some examples, for example the nearest tram station from where I live isn't accessible, so I walk every day to the next one, and then not every tram is accessible, so it happens sometimes to me that a tram that is supposed to be accessible is in fact not and I have to wait another 10 or 20 minutes. Or to give you another example that is very recent. I did a certificate of advanced studies and the building wasn't accessible, so the other students had to carry me up and down the stairs. And it's actually not only dangerous but it also means that you are dependent on other people and it's very discriminating if you're not having the same access as everybody else does.

## **Carine: Do you get to travel to project areas of your organization, CBM?**

Mirjam: Yes, I do. Especially before COVID-19 of course, I traveled regularly because it is very important for me to know the situation on the ground and to talk to persons with disabilities from the Global South, and to exchange with them. So, for example in Nepal, I visited one of our projects centered around community mental health and I talked to different persons living with psychosocial disabilities as well as to government representatives, together if our local partner KOSHISH.

## **Carine: I need to confess that I did not come across the disability movement very much. It was not really on my radar and I think I shifted my thoughts and behavior when I experienced an odd situation in a train with a person in a wheelchair, and I started to think about inclusion in more details. Chris, can you tell us a bit more about the disability movement here in Switzerland? How did it start?**

Chris: It kind of started at the beginning of the 20th century. The first organizations of and for people with disabilities were founded and the first attempt of creating social security also for people with disabilities were done. In 1911 the Swiss organization of blind people was founded in Lausanne, as the first organization of people with disabilities. And 1920, after the parliament refused to instate social security insurance for people with disabilities, the today best-known organization for people with disabilities, Pro Infirmis, was founded.

After the second World War, AGILE, then named Ascio, was founded as an umbrella association of self-representing groups and organizations of people with disabilities. The main goal was the establishment of a social security insurance for people with disabilities. For this issue people with and without disabilities demonstrated in Bern, Zurich, and Geneva during the 1950s until 1960. The Swiss law about the disability insurance was enacted. This was a huge step, as now people with disabilities were socially and economically secured.

But we had to wait until the end of the 1990s until the Swiss constitution was revised, until we got our equal rights in written. After that a Swiss initiative was launched to ensure and enable disability rights also in the field of construction, communication and public transport. The law that we have today is not what was demanded, but a compromised solution from the politicians, because it shouldn't burden too much the costs on society and the economy.

## **Carine: We still have not achieved equal rights for persons with disabilities. On the international level, the UN adopted the Convention on the rights of persons with disabilities in 2006; Switzerland ratified it in 2014. The CRPD aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.**

## **Mirjam, what did you think when the CRPD was adopted?**

Mirjam: It was indeed an important moment and for me the CRPD is not just a text but when I first read the Convention, I really felt that I am now accepted as a human being like everybody else and that equal rights are now also guaranteed for us persons with disabilities.

## **Carine: Is the Convention a necessary tool, or not?**

Mirjam: Definitely, the Convention is a necessary tool. I would say mainly for three reasons:

The first one is that all the documents and decades on persons with disabilities that existed before the CRPD was adopted were not legally binding. Secondly, persons with disabilities have a long story of discrimination and high marginalization and there was a need to address this. And thirdly, there was a need to clarify and also to qualify the human rights in a context of persons with disabilities. And this is what the CRPD does.

## **Carine: The Convention puts persons with disabilities into the center but what does that mean?**

Mirjam: The CRPD recognizes that all persons with disabilities enjoy all human rights. Persons with disabilities are therefore recognized as rights holders and not anymore mere recipients of charity or persons in need. They have a right to fully and equally participate and make their own choices. If you have rights holders on the one side, then you have duty bearers on the other side of the equation, and they have obligations that they have to meet. And this is for example also for Switzerland under the CRPD.

## **Carine: Chris, you are an advocate on the rights of persons with disabilities, why did Switzerland take so about 6 years to ratify the CRPD?**

Chris: The main discussions are usually about the costs and money that has to be spent. In this discussion it is always neglected that people with disabilities also bring an additional value to the society and that they have abilities and are able to contribute to the economy, but only if they are enabled also by the rights and by the assistance that they need and when the barriers are less. Also, I think the Swiss consensual political system doesn't help. That's also why Switzerland hasn't signed yet the additional protocol which would allow people with disabilities to file a recourse to the Committee of the UN if the CRPD was not respected enough in some fields.

## **Carine: And where do we stand today with the implementation in Switzerland?**

Chris: The implementation of the CRPD is not that far implemented in Switzerland yet, but we have this disability equality rights act that I talked about before. That helped to get some public transport that is quite good, and also made a lot of progress in the last 20 years, but from my experience that's basically the main field that made constant progress. And when it comes to education and independent living and work inclusion, we are far behind.

## **Carine: Where do you see the gaps?**

Chris: I think the gaps are that often people with disabilities are not thought about, that we do not participate in the decision building. We are not represented enough in the local and also the federal parliaments. I think this is the main reason why in other fields other than public transport, it’s not getting as fast forward as we wish and as also the CRPD would want us to.

## **Carine: Mirjam, the CRPD has two articles on international cooperation. Where does Switzerland stand with regards to inclusion in its international cooperation?**

Mirjam: Switzerland is still at the beginning of its journey towards the inclusion of persons with disabilities in its international cooperation. At the moment, current strategies and policies do not give a priority to disability inclusion. For example, there isn’t a standalone policy on the inclusion of persons with disabilities in Swiss international cooperation and there are also not adequate financial and human resources that would allow for a comprehensive approach. Switzerland addresses persons with disabilities as part of “vulnerable groups”. However, actually our experience shows that if the inclusion of persons with disabilities is not mandatory and if no specific attention is paid to their situation and requirements, persons with disabilities just tend to be forgotten and they are even more left behind.

If we are now looking at international health cooperation, Switzerland does a lot in the realm of rehabilitation which is actually good and important. However, as explained beforehand, we also need to work on the structural level. With regard to health, this means for example physical access to health facilities, this means training on the inclusion of persons with disabilities of health professionals, because we need a cultural change. And it also means for example accessible communication, so sign language or easy to read.

## **Carine: One of the underlying principles of the CRPD, is the participation of persons with disabilities and their representative organizations. Chris, why is equal participation so essential for the inclusion of persons with disabilities?**

Chris: It's important that nothing about us is decided without us. So this is also the main thought of the CRPD. Nothing about us without us because only people who are affected and living the reality of a disability know the actual needs and gaps in the everyday life.

I think it's also very important that people with different disabilities are represented, because only the ones that are also affected by a specific disability know best what they need and what are the gaps in society and legislation and what are the barriers in everyday life. So people who are not affected, they can learn but they should actually learn from the people who are affected by a specific disability.

## **Carine: Mirjam, what is the difference between an organization for persons with disabilities and an organization of persons with disabilities?**

Mirjam: This distinction is actually vital because persons with disabilities themselves are the experts in the matters concerning them, and I think Chris just said it. What happened in the past and what is actually still happening today, is actually that decisions are taken for persons with disabilities, instead of them being asked, and they are being enabled to take decisions. So, an organization of persons with disabilities is an organization that is led, directed and governed by persons with disabilities and where the majority of their members are persons with disabilities themselves. And in contrast, an organization for persons with disabilities is an ally of the disability movement, supporting and empowering it but not led, directed and governed by persons with disabilities. So CBM, for example, is an organization for persons with disabilities.

## **Carine: Mirjam, in your position as head of advocacy of CBM Switzerland, you engage with disability movements globally. What do you expect the Swiss international cooperation to do with regards to the participation of persons with disabilities?**

Mirjam: So actually, organizations of persons with disabilities must actively take part in project design, implementation, monitoring and evaluation as well as in the development of strategic plans or policies. We therefore recommend that the Swiss Agency for Development and Cooperation, sets up what we call “participation forums” both at headquarter and at country level. The forums should allow for the participation of a wide range of representative organizations of persons with disabilities, and especially those that are most marginalized, such as for example women and girls with disabilities or indigenous persons with disabilities. The forums would need to ensure accessibility and the experts would need to be renumerated.

## **Carine: Chris, if you had one sentence, what message would you like to convey?**

Chris: Every person, every human being is valuable and deserves respect and love regardless of their abilities, identity or economic value.

## **Carine: And Mirjam, I know you will keep advocating for human rights. What do you wish for?**

Mirjam: My vision is an inclusive world in which all persons, with or without disabilities, or with whatever characteristic they have, can participate in life on an equal basis with others and realize their full potential.

## **Carine: And I wish you both a lot of success for advocating more and more for persons with disabilities.**

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 second 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 access to healthcare, stigma and discrimination which persons with disabilities often face.