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# Transcript: Podcast Series on Disability Inclusive Development: Episode 3, Let’s stop discrimination and recognize diversity. with José Viera

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

Introductory soundbite: The doctors should be trained in a way that how to deal with people with disabilities, and also with women with disabilities… To ensure that we can access the quality and inclusive health services that we deserve.

Carine: Hi this is Carine Weiss and welcome to the Medicus Mundi Switzerland Health for All Podcast. And today we talk with José Viera. He is chief executive officer at the World Blind Union since 2018 and is Permanent Representative of the Stakeholder Group of Persons with Disabilities for Sustainable Development at the UN and passionate about human rights for persons living with a disability. We will be talking not only about José’s life, but also about the persistent issue of stigma and discrimination of people living with a disability, especially with regards to accessing health care services.

## **Carine: José, thanks for being my guest at the Medicus Mundi Switzerland Health for All podcast today. Welcome to this episode.**

José: Thank you Carine, for having me with you today.

## **Carine: You have a remarkable life journey behind you and today you are the CEO of the World Blind Union, which is a global organization representing the estimated 353 million persons who are blind or partially sighted worldwide. You are one of them. How is life for you as a blind person?**

José: The answer to that very interesting question can be more than one definitely. I would say that as a person with disability, in my case being blind, I have experienced part of my life with different challenges, of course a good part of my life enjoying what I do, enjoying the life I live. But at the same time recognizing that mainly as a result of different barriers: physical, social barriers, people with disabilities are often left behind and discriminated as a result of the disability.

## **Carine: What helped you to be so successful in education and in your job?**

José: The first big pillar that helped me to achieve my personal and professional goals is my family, in particular my mother, who was always next to me supporting, but at the same time helped me to understand what my rights, my human rights, were and how to fight for the rights. Along with my family, I would say that some of the infrastructures that I have accessed allowed me to be the person who I am today. But I always like to emphasize that my personal experience may not necessarily be the case for most of the people with disabilities. In my personal life I think a combination of a strong family, a family with a big conviction of the most important thing for a person, and that is to choose the life we want to live, along with some resources available from the outside world, allowed me to be the person who I am today.

## **Carine: You are the CEO of the World Blind Union. What does the World Blind Union stand for?**

José: The World Blind Union, better known as WBU, is a union of more than 350 blind organizations around the world. You know that the disability movement in general and particularly the blind movement have been always organized around organizations of persons with disabilities. Persons who believed that the best way of securing the full inclusion of persons with disabilities was actually to create this space where persons with similar needs can get together and fight for their rights. So, one of the most interesting components of the disability rights movement in general, is this bottom to top approach, meaning that a lot of organizations of persons with disabilities around the world are working and actually providing services that governments don't usually provide to persons with disabilities, and at the same time doing it from a human rights perspective, meaning putting the person with disabilities always at the center of the action.

Well, the World Blind Union is the organization that represents through those organizations for and of the blind around the world, the interest of the 253 million blind and partially sighted people. We usually work in advocating for the rights of our community at the global level with the UN agencies, with governments, with regional entities and at the same time we always try to provide support to our national members, those blind organizations that I was speaking about, to actually advance their work at the national level.

## **Carine: Today we would like to talk about stigma and social taboos against persons with disabilities. What did you encounter in your life?**

José: There are many different ways of responding to your question, Carine. We have to recognize that there are a lot of social taboos about persons with disabilities, right from the perception that many people in society have about persons with disabilities, either when they perceive persons with disabilities as a person with less ability to do something, to perform a task, or when they perceive persons with disabilities as heroes that can do more or less everything. That is the first social negative attitude that we should change. Persons with disabilities are as anybody else in this society, meaning with chances to do what they can do based on personalities. But the important thing here is to recognize the diversity of the human beings. That means that no one is more or less capable of performing a task because that basically takes us to a kind of like a bar, like a rule that you have to follow. So, if you don't meet that rule, if you cannot be as people tell you, you should be, you are less capable and therefore you are discriminated. And on the other hand, if we recognize how diverse we are, we will then understand that everyone can bring to the society different elements that will actually strengthen the society as such.

## **Carine: What is the World Blind Union doing to reduce stigma and social taboos against persons with vision impairments? Can you give us an example?**

José: As we are a global organization, we try to advocate, I would say to kind of work, on the preconditions that need to happen for what we were discussing before. So through training, through awareness raising campaigns, through sharing information with our members, we try to promote the right of persons with disabilities in general and in particular for blind and partially sighted people. I guess many of our activities in the end are awareness raising activities and training because those are I would say the two most important instruments we have in hand to actually reduce and eliminate hopefully, the stigma and discrimination. So, training to blind leaders on how to advocate for the rights of persons with disabilities, training with government officials and other stakeholders on how to interact with persons with visual impairments, etc. are some of the activities that we carry out within the World Blind Union.

## **Carine: Let’s talk about access to healthcare services. What kind of difficulties persons with disabilities face when they access healthcare services?**

José: Thank you for your question, Carine. My answer would be based on the community that I represent, blind and partially sighted people, which I'm sure some of my answer will also be applicable to other disability groups. But it's always important to highlight that since the disability movement is so diverse, maybe some of the priorities for blind and partially sighted persons may not be for other communities. That's again how important it is to recognize diversity even within the disability movement, because something that for blind or partially sighted people can be more important than other communities, can be different when you talk to people with other type of disabilities.

But going to your question… people who are blind or partially sighted, our main challenge is access to information. The health care system is one of the systems that firstly is lacking of accessible information. And it's not just about having the possibility to read a prescription or a medical requisition. When we talk about access to information, and we have the best experience within the COVID pandemic… is the lack of accessible resources that many organizations in the field of healthcare have not taken in consideration when planning their programs including for persons with disabilities.

Access to websites, access to information about medication, access to information about procedures that happens within the health care system, even accessing the health care facilities for persons with disabilities, are some of the challenges that we face as a blind community. It is important here to highlight, Carine, that this is an issue that happens everywhere, but it can be extremely higher when we talk about low- and mid- income countries. So, for those countries, the situation for the population in general is already bad. Imagine when we talk about person with disabilities. The situation it gets even worse. So, I think that that is an important element to consider. I would also like to connect this to something that we were discussing before, Carine, and that is the social attitude to the persons with disabilities within the healthcare system. The fact that we were just talking about the challenges that we face. This idea of the perception that people in general have around persons with disabilities is also impacting the access to the health care system by persons who are blind and partially sighted.

## **Carine: As you mentioned before, there is not only the issue of access to healthcare but also the issue of being received by healthcare staff. Often healthcare staff is not trained well enough to receive people with disabilities and show behavior of stigmatization or discrimination. What is the impact of such behavior on persons living with disabilities?**

José: The impact is unbelievable. Even like, either way when we work according to a disability rights perspective, the impact is really positive and great. And you can see that there are many examples around the world where the health care providers along with persons with disabilities, their representative organizations, their communities have organized together and ensuring the highest standard of participation by persons with disabilities. They have reached excellent standards of health care services. Oppositely, when there is a disconnection between persons with disabilities, where there is a lack of perception on person with disabilities as individuals who can make our own decisions, who we must be respected. When there's a disconnection between the health care providers and the communities that basically support many of the people with disabilities especially in low-income countries, the result can be a disaster.

So, either way I think the parameters here are at least two or three. One, is we always need to remember that persons with disabilities must be at the center of the decision. The fact that many people with disabilities are prevented from making their own decisions as the starting point for a non-efficient way of providing services in the health system. The second parameter is that persons with disabilities must be respected first as individuals. So, without going into first the disability, we need to recognize that we are first persons, and as such we need to be treated as individuals with full potential, especially making their own decisions. And the third parameter is that this is a joint journey. This is not just the medical approach, where the health care provider had the right to decide the final word, the knowledge. This is a joint journey where the health care provider is one of the many and of course one of the most important pieces of this machinery, that will enable us to be more included in the society.

## **Carine: You have mentioned before that we need to accept more diversity and you also mentioned several of the solutions to overcome stigma and discrimination. But what else do you see as a solution to overcome these issues in accessing health care services?**

José: Definitely governments, especially those who have ratified the Convention on the Rights of Persons with Disabilities, must do more and more in training healthcare providers on issues related to persons with disabilities. I think we need to invest more on organizations of persons with disabilities. The organizations that represent the interest of the disability community can be at the table where health policies are discussed.

Another big element, and I think this is exactly what we are doing today, Carine, is actually to promote and to do whatever we can do in order to let the society know what the issues of person with disabilities are. So, this activity of raising awareness is definitely a very important one. And, last but not least, I would say more funding, more financial and technical resources towards inclusive health care systems will enable persons with disabilities to be more included in the society.

## **Carine: Let’s talk about multiple intersecting forms of discrimination. Because they are more and more common. What exactly does this mean for persons with disabilities?**

José: As I was saying before, you know the key word of the disability movement is diversity. And in that context, person with disabilities are also women, members of the LGTBIQ group, migrants, refugees, displaced people, people living in the rural area, people who are young, children, adults. The community of persons with disabilities is such a diverse community that any form of intersectionality with disability must be considered when we talk about health care systems. Let me give you a clear example here. The fact that as a person who is blind sometimes faces a lot of discrimination, this can get even worse if that person is a woman. Or it's a woman who is indigenous or is a woman who lives in the rural area. From making programs that are exclusively oriented to some specific groups, inclusive of person with disabilities, we are working on this intersectionality perspective. So, if we ensure that sexual and reproductive rights trainings are inclusive of personal disabilities, through making information accessible, or reading material accessible, we are definitely covering different fronts and ensuring that the intersectionality perspective is guaranteed.

## **Carine: And how can we raise the awareness of intersectionality? Because I think so many people may be talking about it, but the majority is not talking about intersectionality.**

José: The answer your question, Carine, is, it's bringing organizations of persons with disabilities to the center of the discussion. If there is something that allowed us to be where we are at as a global community of persons with disabilities, it’s the fact that we realized long time ago, the important role that organizations of persons with disabilities can play in advancing our rights. On the other hand, the areas where we see a clear lack of advancing this human rights agenda is somehow highly connected to the lack of participation of persons with disabilities.

## **Carine: How can we make sure that organizations like yours are part of the discussion?**

José: The answer is easy to formulate but harder to implement. It’s to incorporate in any of our decisions the principle of participation, the guiding principle of participation. It's key to advance this discussion. And what does that mean in practical? Well, it means that if I am in a little town and I am the public health authority, and I'm going to discuss the new program for persons with disabilities and the health care system, the guiding principle for that discussion is to ensure that I contact organization of persons with disabilities, and we bring them on board, (and this is also important), and we facilitate the participation of persons with disabilities right. And what do I mean by facilitating? Well ensuring that if I have a meeting on health care systems and invite people with disabilities, accessibility measures are in place. There's no way that we can participate as blind people if we are going to discuss a topic that is presented through a PowerPoint presentation with no description, and where other people who can see have more advantages from reading those PowerPoint presentations and making proposals, comparing to persons who are blind. And because of the lack of accessible PowerPoint presentations, we cannot comment on the proposal during the conversation. So, this is a very, very small but important first step to ensure that we can achieve a more inclusive and accessible health care system.

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

José: If we want to be successful in the long term and if we want to be sustainable, societies should recognize diversity. And by recognizing diversity, we will recognize that we are equal and that all can contribute to a society. It's just a matter of how we will ensure that we are all equally treated. And the best way of doing that is by not looking too much on the person with disability, but rather on the barriers around the person with disabilities, preventing us to participate. Let's work on the barriers. If we break those barriers, if we modify the environment, we, person with disabilities, have a lot to contribute to the society.

## **Carine: Thank you so much for this invaluable insight into your work. I wish you a lot of success with your future endeavors.**

José: Thank you so much Carine. It has been such a pleasure. Thanks for being interested in our topics, and very much looking forward to continue the conversation.

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 third 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 women and girls with disabilities and their access to healthcare.