

# CHALLENGING SOCIAL NORMS ON DISABILITY

## Making Sexual and Reproductive Health Accessible to People with Disabilities



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Despite having the same sexual and reproductive health (SRH) needs as anyone else, people with disabilities often face stigma, discrimination, and barriers that prevent them from accessing SRH information and services. How can we work to meet the SRH needs of all people, including those with disabilities? To explore this issue, Sarah V. Harlan, Partnerships Team Lead for Knowledge SUCCESS, spoke with Cynthia Bauer, the Founder and Executive Director of [Kupenda for the Children](#). Kupenda is a non-profit organization whose mission is to transform harmful beliefs surrounding disability to those that improve children's lives. Note that this interview has been edited for brevity and clarity.

*(Content warning: sexual abuse and violence against children and adults with disabilities)*

### **Sarah's Question: Can you tell us a bit about Kupenda's work?**

**Cynthia's Answer:** Kupenda's mission is to transform harmful beliefs connected to disability to those that improve lives. So many people around the world, especially in low-income countries, hold negative beliefs about disability—things like [thinking] disability is from curses or witchcraft, or making deals with genies. That creates more discrimination, abuse, and so on for families affected by disabilities.

[Listen to more about Kupenda's work.](#) (4:03)

## Q: What is your role at Kupenda?

**A:** My role is Executive Director and Founder. It morphs over time. At the beginning, I was often the one leading workshops and things on the ground. I would play my guitar and share my own personal story.



Cynthia Bauer plays her guitar, surrounded by children. Image credit: Britta Magnuson

I was born without my left hand. And even when I was born, here in the United States, my dad actually wanted to take me to a faith healer, because he thought that maybe God could sprout me a hand. He meant well... My family was very supportive of me [trying] to be and do anything that I wanted to do. When I was in Kenya doing my research in wildlife biology—which is what my actual education is—I found a school that had just started for children with disabilities. I met the person who started it, who is now my co-founder and director in Kenya, Leonard Mbonani. He’s a special needs teacher, and he introduced me to fifteen children with disabilities that were basically meeting in a storage shed at a

mainstream school. They had a variety of disabilities, mostly deafness or cerebral palsy, with a few that had some physical challenges. And I got some friends and families to pay for their school fees twenty years ago. But now, based on where we've partnered with other organizations and our methodology of advocacy, we were actually able to support 74,000 people with disabilities just last year.

## **Listen to more of Cynthia's story**

[Knowledge SUCCESS · Cynthia's Role](#)

[Read more of Cynthia's story on Kupenda's website](#)

### **Q: What are some effective ways you have found to talk to people about disability and to counter some of the myths and misinformation?**

**A:** Our workshops are one-day workshops. They're fairly low in terms of expense. We've actually had workshops in a field, under a tent, in a traditional healer's land, for example. We had someone in Sierra Leone tell us that they were trying to work with traditional healers around the subject of disability, and he said it just wasn't working. He said, "When we tell them they're wrong, they just don't want to talk to us anymore." Leonard and I both said, "Well that's the problem, to start with. You don't tell them that they're wrong, especially at the beginning." .... Proper facilitation skills mean that you're asking them questions. People remember more what they say than what you say. And so we ask a lot of questions.

We also ask [participants] how many of them have been affected by disability. And without fail, at least half of the participants have a family member with a disability. That's actually reflective of the WHO data that says that 50% of the world either has a disability or a family member with a disability. It's a lot of people, if you talk about half the world being affected.

*"50% of the world either has a disability or a family member with a disability."*

### **Hear more about Kupenda's work challenging social norms**

[Knowledge SUCCESS · Countering Myths](#)

## **Q: Can you say more about including people with disabilities in the workshops you do?**

**A:** In every workshop or training that we do, we always have a person with a disability sharing their testimony. And the feedback that we've gotten from our leaders is that the testimony from a person with a disability was one of the most effective parts of the workshop. Because at the end of the day, people with disabilities are people. I used to share my own story, but now, our programs have grown enough that we have local people that are sharing their stories of disability.

I was told that if I was born in Kenya, I might have been killed because I was born without my hand. Stigma goes along with that, and a misunderstanding of what people with disabilities can do, and are capable of. I've asked [other people with disabilities], "Which is a bigger barrier in your life—physical barriers or societal perception?" And 100% of people will say societal perception. However, very few organizations are really targeting the belief system, because I think it can be overwhelming to think about that and try to figure out what to do. I've found there are very few that are challenging the belief system that then can help with some of the physical services that are needed. But I would say even half of the families that we've encountered with children with disabilities don't even necessarily need specialized services. They might be someone just like me—missing a hand, but I never needed any special services or specialized education. I just needed people to come to a conclusion—which they come to themselves—that their child is not cursed, that their child can do more than what they expect them to do, and that they should be part of a living community.

*"I've asked 'Which is a bigger barrier in your life—physical barriers or societal perception?' And 100% of people will say societal perception."*

## **Hear more about including people with disabilities**

[Knowledge SUCCESS · Including People With Disabilities](#)

## **Q: What are some sexual and reproductive health issues faced by people with disabilities?**

**A:** For many people with disabilities, they are not viewed as sexual beings ... Even when they go to see a doctor and they're pregnant, I've heard of people saying, "How could that be?" They're not seen as fully human, or people with the

same sexual desires and ability, in most cases, to reproduce and have children. So that's one thing I've encountered—I think there's a common dehumanization and desexualization, especially of women with disabilities.

In terms of access to information around sexual and reproductive health—that's also a really challenging area. Let's say if people can't go to school—either they're not going to school because their family doesn't understand that they could be capable of it, or there aren't services to support these families with disabilities. This means they aren't getting access to the [information] about sexual and reproductive health. So we have had children that have intellectual or behavioral disabilities [who] were impregnated by someone—we're not always sure who—and they didn't even know how that happened. They didn't understand how it worked to get pregnant, because they weren't getting access to the right information. Which seems so simple, but people need to know how. There are so many different challenges.

And we unfortunately have had too many rape cases of children with disabilities, especially ones where they can't really speak, or kids that are in wheelchairs. It's just horrifying to think about why someone would even think to do that to a child. And it's a strange irony in a way, that people with disabilities are more likely to be sexually abused and raped than women without disabilities, even though they're also considered asexual.

## **Cynthia's full response to this question**

[Knowledge SUCCESS](#) · [Disability And SRH](#)

### **Q: What is the medical model versus the social model of disability?**

**A:** There's this concept [that people have] for so long that disability is a medical issue. And it's almost like you're trying to get people to be more “normal”—as opposed to the social model that says it's the society that needs to change, not the individual, so that people with disabilities can have more access. And that doesn't just mean wheelchair ramps and elevators, which are important. It also means how **society** views people.

## **Cynthia's full response to this question**

[Knowledge SUCCESS](#) · [Medical Model](#)

## **Q: What are some common themes among people with various types of disability?**

**A:** I have found that, regardless of the disability, there are some common themes that most of us that have experienced disability have encountered. I always make sure that people understand that I don't know what it's like to need access to specialized learning. I don't know what it's like to need physical accommodations and all that. But I do know what it's like to have people underestimate me. I do know what it's like to have people discriminate against me. I do know what it's like to suffer from self-esteem issues because of how the world views me. And I've noticed that that's a common theme amongst most people with disabilities. *"I don't know what it's like to need physical accommodations and all that. But I do know what it's like to have people underestimate me."*

## **Hear more about themes in social perception of people with disabilities**

[Knowledge SUCCESS · Common Themes](#)

## **Q: What solutions would you propose to address SRH needs among people with disabilities?**

**A:** In terms of the solutions around sexual and reproductive health, the role that we think is most important to play is, first of all, [connecting these kids to school, to education](#). SRH is a major component of education programs, at least in Kenya.... Also to make sure it's included in specialized learning programs. So, in terms of their education around SRH, we are trying to base that on the schools that we connect them to, where they have programs to do that. We're also talking with medical communities and community health workers to ensure that there's proper access to these services for people with disabilities. And this could be for many different medical areas, including SRH. It's important to ensure that stigma is not at the medical level. When people are coming for services, it's important to ensure [healthcare providers] would accept them. [For example,] one woman—I think she was in Pakistan, who was a wheelchair user—went to the doctor for some other condition entirely, and he just kept asking her questions about her wheelchair and her abilities. It had nothing to do with why she was there. And I think that has happened to a lot of people in terms

of pregnancy or wanting contraceptives, [people saying] “Why would you need that?” Going back to that asexualization.

But also—going back to what we talked about before with abuse of people with disabilities—people with disabilities are four times as likely to have HIV. And there is the stigma belief system that if you have sex with a virgin, that will cure you from AIDS. Therefore, there’s an assumption that a person with a disability, especially a young one, is going to be a virgin, and therefore they’re taken advantage of that way. So I just wish more people knew that people with disabilities need just the same access to SRH services as people who do not [have disabilities]. There needs to be more action in thinking about the challenges that people face with accessing appropriate services, with accessing the education that they need.

Also, this doesn’t have to do with people with disabilities in particular, but it has to do with stigma. There have been a lot of people in our workshops that believe that disability actually was caused by using contraceptives.

We do a lot of individualized counseling sessions, especially with young women who have been raped, and young women who are pregnant. Mostly we really are trying to connect them to the professionals. Our job is to ensure that the professionals dealing with sexual and reproductive health—whether it be education, clinics, so on—are accessible. For example, at a clinic, can a person in a wheelchair even get in? And will you serve them in the same way you would serve anyone else?

## **Cynthia discusses solutions to meeting the SRH needs of people with disabilities**







Cynthia Bauer (right) with a colleague in Kenya. Image credit: Julia Spruance

## **Q: Any final thoughts?**

**A:** Sometimes, you can get overwhelmed by how horrible the situation can be for people with disabilities around the world. There are so many people that are living in situations that are really abusive and harmful and lonely. I think that for all of us, if we can think of those stories of the people we know and the successes, it can help us keep going so that eventually we could reach the billion people [with disabilities worldwide]. And the only way to do it is with partnerships with people on the ground, and the communities themselves, and with people with disabilities themselves—to actually tell us how we can best come alongside them as they create solutions to be more inclusive of people with disabilities in all aspects of life.

## **Cynthia's closing thoughts for this interview**

[Knowledge SUCCESS](#) · [Final Thoughts](#)

## **Bonus Audio Content:**

[Listen to Cynthia describe the proudest moment in her career](#) (3:52)