

Inside the OUTcomes: A Rehabilitation Research Podcast

Intro Episode 9: Inclusive Disaster Planning

SHARON PARMET, HOST:

On this episode of Inside the outcomes, I'll talk with Dawn Skaggs, director of emergency disaster and climate resilience at the World Institute on Disability. Dawn has more than 25 years of experience helping organizations, corporations and government agencies ensure that people with disabilities are included in disaster planning, response recovery and resilience efforts, and that their strengths and needs are considered and included every step of the way. Welcome to the podcast Dawn.

DAWN:

Thank you, Sharon, it's really nice to be here. I appreciate the invitation.

SHARON:

We'll get right into it. Can you explain to us what does the World Institute on Disability do and who does it serve?

DAWN:

Thanks, Sharon. The World Institute on Disability is actually the oldest continually disability led organization in the US, founded 40 years ago by Judy Heumann, Joan Leon, and Ed Roberts. And it has a global mission to serve and provide opportunities for the 1.3 billion people with a disability around the world. We have several key focus areas of our work. We do a lot of work in research and policy, that direct practice and implementation. And within that strategy, we work with global community inclusion, accessibility and universal design, and disaster, emergency and climate resilience.

SHARON:

And that's where you fit in, right?

DAWN:

Exactly. Yeah.

SHARON:

So tell me a little bit about, tell me a little bit more about what you do there?

DAWN:

Well, interestingly, the emergency disaster and climate resilience domain at WID seems to have tentacles into almost everything we do. Because when we're looking at global community inclusion, or accessibility, design, all of the things that happen in a disaster are an exacerbation and a magnification of what happens in daily living.

So when we're talking about the emergency disaster and climate resilience work, that really is focused on the full spectrum of what we call the lifespan of a disaster, which is before during, after and then mitigation of a disaster. So it has a reach into almost everything we do. And as a domain that really directs what we're doing, because we are working within pre disaster planning, preparations, response, recovery and mitigation. So pretty much every aspect of daily living has a component of what we do.

SHARON:

How do you exactly work with different communities around the globe to ensure that disaster planning and response and recovery does include people with disabilities?

DAWN:

Sure, we are, we are driven by our mission to build communities from the grassroots. And so in doing that, we connect with partners and other disability led organizations around the world. Often, we make those connections in the in a response phase, when a disability led organization might be part of a community that has been impacted by a natural or manmade disaster. And they are looking for assistance. One of the projects that we one of the programs I'm sorry that we run is the Global Alliance for Disaster Resource Acceleration. The acronym is GADRA. And GADRA is an alliance of three disability led organizations that really founded this effort to identify that disability led organizations within the disaster lifecycle seem to be missing out in the conversations and response and humanitarian aid, often very often doesn't include that local disability led organization. The result is that those organizations know where the actual needs are in their disability community. They know the strengths of their disability community, but they are not part of the broader humanitarian aid effort. So that's a significant contributor to why people with disabilities often are disproportionately impacted by a disaster.

We know that statistically, people with disabilities are two to four times more likely to die or be injured in a disaster than their community members. And as a result, the disability led organization really has an important role in bridging that gap between the disability community and the broader humanitarian aid effort. So what we do in GADRA, is connect with those local disability led organizations who know their community, who have themselves been impacted by a disaster, and who are themselves people with disabilities, and connect them with partners, resources, funders, advocates, or other types of supports, in response to their requests.

In a disaster, those requests will run the gamut between continuity of operations, how they maintain their organization in the face of a disaster, how they might pivot from being impacted in a disaster. And they're irregular services, to adding on emergency response work to their regular services. They also might need support in resourcing disability equipment or supplies. Or having a voice at the table to be able to speak for and advocate for, and raise awareness to the needs of that local disability community.

A really great example might be a deaf community who has been impacted by a disaster unless the humanitarian aid efforts include that effective communication and acts and ASL interpretation or interpretation. And whatever the local language is, the deaf community doesn't even hear the opportunity to get services. So that's one of the ways that we spearhead a global reach to supporting disability led organizations in a disaster and their communities, wherever they are.

We can't be everywhere. So we do it through a virtual emergency operation center. That is a virtual hub of communication that connects that local organization to a global network of resources.

SHARON:

Can you give me an example of a GADRA partnership that responded to a disaster?

DAWN:

Absolutely, we are actually currently responding to multiple disasters simultaneously, which is another really robust feature of this strategy. We are currently supporting the efforts in Hawaii.

To respond to the fires, a local disability led organization created a hub of communication to really spearhead that coordination for all of the responders to that island. We are working and have been working for the last two years since the Russian invasion of Ukraine with a disability led organization in Ukraine, who has responded to the need for people with disabilities to evacuate from hotspots of conflict to safe zones within the country or to evacuate to other countries. And the complexities of that really resulted in many humanitarian aid organizations. Feeling like there was a barrier that there was it was too large of a lift, where with this collaborative prep practice, the disability led organization brought their subject matter expertise to that evacuation process and networked with other disability organizations to ensure that there was accessible transportation that there was accessible housing that medications and personal assistance services were provided throughout that entire experience.

We are also working with our response to the earthquake in Syria, where we have connected them with multiple disability led organizations in those countries, to partners that are providing durable medical equipment and supplies directly to the disability led organizations, literally containers of supplies that are traveling across the ocean, and being received by those local disability led organizations to fill the gap of that disability specific need that was not being met otherwise.

And most recently, we have just activated our emergency operations center to Morocco, and Libya, in response to disability outreach there.

The important takeaway is that what we do with each disaster is different. Because we don't have a set process of response that we bring, we come to the conversation, and are responsive to the expressed needs of that disability led organization, because those needs are going to be unique. And so what we do each time is slightly different, and is always led by the experts within that community. Because as we know, with every disaster response, people come and they go, and the real robust capacity building needs to happen at that local level with the community members who are going to be there long after everybody else leaves.

SHARON:

So when you form these partnerships around the world to respond to immediate disasters that are happening, when you leave, it's not like you leave and there's nothing left behind these organizations that you've worked with, I'm sure have learned from you just as much as you've learned from them. And what I'm hearing is that they go forward and can build in building resilience, and also work on disaster response plans for the next one. Is that right?

DAWN:

Yes. And I'm really glad you asked that, Sharon, because the added value to this strategy is that because we never actually go, we never actually leave. All of our disability led organizations that we have engaged with, through GADRA, we still have ongoing relationships with and so that it's creating a community of practice around the world, where the disability led organizations actually have the support through GADRA.

To pivot in the disaster and take advantage of the disaster as a fresh start to renew advocacy in a stronger way, with a more effective voice, or in a different way, and engage.

As I mentioned, many of them have not worked in emergency response before that was not part of their scope of services. But moving forward from the disaster, they then are connected to local agencies, local services to policy makers and decision makers to move their community through that short and long term recovery process to build forward better and more inclusively and more accessibly, and grit. So really, we never actually leave. We continue to grow a network of partners around the world. And the additional added value that we have seen organically developing is that disability led organizations then become aware of each other. And there becomes an opportunity for combined advocacy, and for mentorship and for collaborative work moving forward and really, really strengthening those organizations and overall inclusive advocacy and accessibility mission for years to come.

SHARON:

What happens in disaster response when people with disabilities aren't included and aren't, their needs aren't taken into consideration what happens then?

DAWN:

I'm really glad you asked Sharon, because that's the entire reason for the existence of GADRA.

In 2020, we did a global outreach to disability led organizations and asked them, Do you feel that you are included in the disaster planning preparations and response? And across the board their answer was no, there is no effective implementable plan for people with disabilities to be included. And that was the driving force. And so as a result, we have we have really identified, what are some of the ramifications and how do we avoid those barriers.

Some of those ramifications are that people with disabilities are potentially institutionalized. We see very frequently in disasters, part of the established plan for people who are determined to be better placed in an institution by some type of your triage strategy do not ever get out of an institution. People with disabilities are the least likely of all population demographics, to ever return to their baseline state of community living after a disaster unless we intentionally center the disability community in that planning and response process. The other thing that needs to happen beforehand, before we begin planning, there needs to be an establishment of those relationships between disability led organizations in the community, and some of the other community agencies who will ultimately respond.

Without that, before the planning, relationship and equitable planning partnerships, we will see that people plan based on what they know. And if you don't have disability expertise at the planning table, not as a special speaker or us one

time trainer, but as a true equitable partner, who's bringing a very specific subject matter expertise to your planning process, then that plan does not include people with disabilities.

And then we see the statistics that people are disproportionately impacted, that they are not able to participate that services and programs are not accessible. That there is no plan or training or knowledge on how evacuations can be inclusive how sheltering in place strategies can be inclusive. An example of that was seen very clearly, multiple examples of that were seen very clearly in COVID, when some of our personal protective processes that were put in place, such as masking and social distancing, actually proved to be very challenging for people with disabilities and made them more vulnerable in other ways. People who relied on facial expressions and lip reading, were not able to communicate effectively, people who relied on personal assistance services to maintain their independence, couldn't have that person come to continue that service and were at risk of institutionalization. Once institutionalized, people with disabilities have a much higher likelihood of becoming ill becoming, having multiple additional disabilities, that compound what they originally were living in the community with, and have a higher likelihood of perishing. And so the ramifications and the outcomes when we don't include people with disabilities are incredibly significant and literally are affecting whether people live or die.

On the flip side, Sharon, if we do include people with disabilities in that process throughout as equitable partners, what we see is that by centering people with disabilities in that planning process, through a strategy of universal design and universal access, we plan to include people with disabilities as part of the human experience. What happens is that we then, very frequently, also provide a more comprehensive, more accessible, more inclusive strategy for multiple other demographics in our communities. So, the benefits are magnified, as are some of the negative outcomes based on whether we do that inclusive planning and response or not.

You can't layer it on, you can't have separate processes for the disability community. But when you do universal design as your first strategy, and then fill in where you have not quite met your goals with accommodations and accessible supports and functional needs support services, then you are actually reaching the diversity of the community.

SHARON:

Well, thank you so much, Dawn, for being on the podcast. This has been a great conversation.

DAWN:

Thank you, Sharon. It's really been a pleasure and an honor to be invited to join you today.

SHARON:

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host Sharon Parmet signing off. I hope you'll join us for the next episode.