

DISABILITY AND IDENTITY: WE NEED TO DO BETTER

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By Carli Friedman | CQL Director Research

cfriedman@thecouncil.org

For the past year I've been conducting in-person focus groups with people with intellectual and developmental disabilities (IDD) for a research project. As part of this research project, my team and I have been supporting the participants with IDD to complete standard demographic questionnaires which ask people about their background – gender, race, disability, education, employment, etc.

The more people with IDD we supported to answer these questions, the more I was struck by the fact that the overwhelming majority of people with IDD we worked with had no clue what disabilities they had; many also did not know what race they were. In fact, research indicates that this phenomenon is not uncommon

– many people with IDD do not know what intellectual disability means, or if, or why, they are in this category (Beart, 2005; Davis & Jenkins, 1997). This trend says a lot more about how we support people with IDD, than it does about people with IDD themselves. In this Capstone article, I discuss why this is a problematic phenomenon and what we can do to course correct.



CONTRIBUTING TO SHAME AND STIGMA

It is easy to understand how well-meaning people and organizations may avoid talking about disability with someone with IDD because they believe it will prevent people with IDD from becoming aware of stigma. Indeed, there is a long history of pejorative and stigmatizing language, such as the R-word, being used to marginalize, oppress, and segregate people with IDD. However, not talking to people with IDD about their race or disability underestimates their ability to understand these identities, and by failing to talk about disability – by distancing from disability and trying to shield people from it – organizations are actually doing the reverse of what they intend. They are making it seem like something shameful that should be avoided and are actually furthering stigma.

Our avoidance of talking about disability with people with IDD is problematic because it is based on ableist assumptions that disability is negative and should be avoided; doing so not only serves to reinforce stigma – it becomes something shameful that should not be talked about – but also justifies and reinforces difference. One would not give a second thought to identifying a person from another social minority group, such as a man or person of color, so what is wrong with identifying someone as a person with a disability?

THE IMPORTANCE OF IDENTITY AND COMMUNITY

Avoiding talking about disability or race with people with IDD denies people their identities as well as denies them community, and the sense of belonging which can come with both. Disabled scholar Tom Shakespeare describes, “identity is an aspect of the stories we tell ourselves, to others... Previously there was a limited range of narrative devices and themes available to people with impairment; now, new stories are being told, and we are creating ourselves for ourselves, rather than relying on the traditional narratives of biomedical intervention or rehabilitation, of misery, decline and death. Doing it for ourselves, perhaps we can reconcile tensions and produce alternative, happier endings” (Young & Quibell, 2000, p. 761).

How can you be proud of who you are if you do not know what that is? Everyone has multiple identities; while certain identities may be more important to each of us than others, they are part of who we are. Believing disability is negative (whether that is done consciously or not) and therefore not talking about it with the people we support does them a disservice.

Autistic disability rights advocate Lydia X. Z. Brown explains, “When I say that I am ‘disabled,’ I am not putting myself down, insulting myself, suggesting that something is wrong with me, or making a negative statement about myself. I am staking a claim in an identity that is important to who I am as a person. I am recognizing that my mind/body function atypically, and that because of this, I am constantly forced by mainstream

“It is important for me to define who I am, and **being disabled** is an important part of how I define myself.”

social/cultural attitudes and the laws and policies that enforce them to choose between being othered (and then discriminated against or outright harmed) or accepting the idea that I must hide who I am by passing as an abled person. By calling myself disabled, I am rejecting the idea that it is wrong to have a mind/body like mine. When I say that I am ‘disabled,’ I am not reducing myself to my disability, just as I am not reducing myself to my gender or my race when I say that I am genderqueer or that I am Asian. Being disabled is one part, albeit an important part, of my multifaceted identity. Each of these parts overlaps with each other, blurs into each other, and intersects with each other; they are not separated or disparate. It is important for me to define who I am, and being disabled is an important part of how I define myself” (Brown, 2013).

Disability rights activist Jax Jacki Brown reinforces, “disability is not a source of shame... and being able to use the word unites people with disabilities as a minority, a community, and enables them to mobilise and advocate on issues of importance. This idea is not new, the recontextualisation of disabled from a derogatory term to one of power and connection has its origins in the disability rights movement of the 1970’s” (Brown, 2016).

WHAT WE CAN DO ABOUT IT: PROMOTING IDENTITY, COMMUNITY, AND EMPOWERMENT

I am not saying that we should tell people how to identify or what language they should use to describe themselves – those decisions are up to each person. I am also not denying that stigma can have consequences for people with IDD. However, we are all obligated to work to reduce stigma and ableism; trying to sweep disability under the rug by not talking about it is not the way to do so. Instead, here are some places we can start to promote identity and empowerment amongst those people with IDD we support:

Providers, supporters, and allies: Let's educate ourselves

One of the best ways to not accidentally reinforce stereotypes and stigma is to educate ourselves about disability, identity, and community, particularly with resources made by people with IDD and people with other disabilities. Not only will our knowledge about disability identity and community grow as a result, but by doing so we will also be better equipped to support people with IDD to explore their identities and communities.

Have honest and real conversations about disability with the people with IDD you support

When the people with IDD I was working with for my research project did not know about their identities, it was evident nobody was having conversations with them about disability or their other identities. Organizations should be having regular conversations with the people with IDD they support about identity and disability. In fact, research suggests that as people with disabilities develop a sense of self, not only does their internalized ableism reduce, but their sense of disability community and pride also increases (Onken & Slaten, 2000). As they are the experts on this topic, these conversations should be guided by resources created by people with IDD themselves and moderated by experienced self-advocates.



Photo Credit: Disabled And Here

Support people to interact with their various communities

Identity does not exclusively happen in the classroom – it's part of the real world. While having discussions is a fantastic place to start, people should also be supported to interact with their various communities if they want to. When doing so, it's important to remember that disability doesn't exist in a vacuum – all people have multiple and interacting identities.

Support the self-advocacy movement

Participation in the self-advocacy movement can be liberatory. Not only can it serve as a form of community, the self-advocacy movement also draws particular attention to stigma, identity, self-determination, and empowerment. The self-advocacy movement allows people with IDD to “demonstrate the self-determination they encompass even while constantly encountering society's discrimination and oppression. The self-advocacy movement is a productive vehicle to gain... agency” (Spassiani & Friedman, 2014, p. 334). Equip a self-advocacy group to be successful, and remember, self-advocacy is a movement, not a program.

Celebrate disability pride

Finally, work to empower people and celebrate disability pride. There are many ways to celebrate disability pride, including by learning about disability history, attending a disability pride parade, commemorating disability rights leaders, and interacting with disability art, among others!

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