## 3 Ways Disability Allyship Can Go Off Track

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Exploring disability practices, policy, politics, and culture.

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April is Autism Acceptance Month. It's a good time to rethink not only how non-autistic or "neurotypical" people can best support autistic people — but also how non-disabled people in general can do better in supporting people with any kind of mental, developmental, or physical disability. There's no shortage of good intentions. Most people if asked would say that they at least *want* to do right by people with disabilities. But being a good disability ally requires more than goodwill.

The disabled community is well past the point of being satisfied with simple recognition or mere shows of support, as we might have been 30 years ago. We're not even looking for advocacy, if it means non-disabled people speaking *for* us, defending *their* perception of *our* rights without our full participation or consent. It's always important to do the right thing when you can, and to be counted on the side of disabled people and our needs. But it's even more important to discover and center disabled people's concerns, priorities, and preferences, even if you don't always understand or agree with them. We need allies fighting *with* us, not just advocates fighting *for* us. Fortunately, we seem to be gaining more genuine allies every year. That's worth celebrating.

Still, as more people learn about disability issues, it's important to be alert for ways that disability allies can lose their way. The following are three of the most common ways that even the best, most committed disability allies can go wrong.

# Listening to disability awareness seminars instead of disabled people.

Articles and training on disability issues and etiquette are certainly valuable. They can be especially useful for people just starting to learn disability issues. Formal training can teach the basics of how to behave towards disabled people in social situations. You can learn a bit about how everyday accessibility

problems affect disabled people. And you can start to get some rough guidelines on common questions, like whether or not to ask disabled people about their disabilities, or what terminology to use and what to avoid.

But disability awareness seminars and webinars are no substitute for listening to actual disabled people. Our individual views and preferences don't always match the standardized rules of "disability awareness." Some of us want to be left alone; others crave interaction. Some of us invite questions and are happy to explain our experiences. Others of us feel besieged with people's curiosity and want to choose when and how we will "educate" people about disability. Practical accessibility affects each disabled person differently too. Some of us are more bothered and confrontational about it than others. And we have different opinions on disability terms. Some, like the "R-word" for intellectual disability, are clearly off-limits. Others, like whether to say "person with a disability" or "disabled person," are still open to debate and personal taste. Rules and philosophies learned in advance can help, but they will only get you so far.

The worst thing you can do is lecture disabled people you meet in real life on how *we* should process our *own* experiences. Yet, this happens, a lot. It's entirely possible, even common, to meet disabled people whose views on disability are different from what you've been taught. Regardless, never tell or imply to a disabled person that you understand disability issues better than they do – even if you have reason to believe that might really be true. If you find yourself thinking that a disabled person's views on disability issues are wrongheaded or uninformed, and that it's your job to enlighten them – stop yourself. Think about it carefully, and proceed only with great caution. Or, leave it alone, and respect the opinions and choices of the disabled person you are talking to.

# 2. Assuming you have a new and essential idea, without first finding out if it's either new or essential.

At first glance, the disability field can look empty and neglected, especially to people new to the disability experience. It often seems like nobody is doing anything – that the cause of disability inclusion and liberation is starved for ideas, organization, and commitment. In some ways disability culture *is* underdeveloped and fragmented, at least compared to some other communities. But it's also easy for ableism to creep in and add the notion that disabled people need inspiration and motivation from outside, that the disabled community needs saviors to rescue them from obscurity and whip

them into shape. Even some disabled people think this way, especially when disability is new to them, or they don't have much contact with other disabled people.

In fact, the disability community is dynamic, diverse, and full of innovation. It's also easier to find than ever before. Disabled people and disability issues still aren't as visible as they should be in mainstream popular culture. But that is changing. And disability organizations exist almost everywhere, striving for change and helping meet disabled people's needs. Between affiliates of The Arc and Centers for Independent Living alone, there are hundreds of credible disability organizations in every state and nearly every county in the United States. And there are scores of national disability organizations with a wide range of mission scope, emphasis, and philosophy. The American Association of People with Disabilities is another good place to start for anyone with a disability, and anyone who wants to be an ally.

These organizations aren't always perfect. It may also take a while to find the right home for your disability work. Some people never find what exactly they are looking for, and really do have to start something new. But there are so many disability organizations doing so many things that it's impossible to say, as many still do, that there's "nothing out there" for disabled people.

Meanwhile, it's always possible for someone to come up with a truly new approach or device that could revolutionize life for disabled people. But if you have an idea for something that could help disabled people, or a way disabled people could do things better, chances are good that disabled people somewhere have thought of it and tried it before. Sometimes we've tried and it didn't work. Usually someone is already working on it, and could use your help rather than a duplicate effort.

The disabled community isn't always great at communicating our presence and promoting our work. But we are doing things. And we need *partners* even more than we need innovators or entrepreneurs. Joining an effort already underway instead of centering yourself and your own ideas can be hard. Sometimes it's a sacrifice. But it's the essence of true allyship.

### 3. Approaching disabled people like a missionary.

There are plenty of disability-related injustices problems to solve and injustices to fight. Disabled people certainly need allies. But it matters what kind.

Now more than ever, we need everyday voters to support bold plans to address major disability issues, like the Biden Administration's proposal to invest \$400 billion more in Home and Community Based Services. We always need employers who do more than superficially "comply" with disability rights laws, and actually recruit, accommodate, and nurture employees with disabilities. In our everyday lives we all need friends and partners who treat us like full human beings, each with our own personalities and priorities.

Unfortunately, it's far too easy for well-meaning non-disabled people to stray into the role of rescuer, to start thinking that you and your role in the struggle for disability rights and welfare isn't just helpful, but essential. Despite decades of progress, the traditional relationship between non-disabled and disabled people still dominates. It's a combination of championing, charity, and care. These are all nominally positive motivations. But they tend to reinforce inequality, and can quickly become oppressive. This is partly why some disability scholars talk about disabled people being in some sense "colonized." There is both a literal and theoretical connection between everyday ableism and historical colonialism.

It's possible to overstate the case, and ableism is quite different from, say, racism, or upper class condescension. They aren't the same, and shouldn't be superficially compared. But the toxic blend of superficial benevolence with underlying domination and exploitation that characterized colonial subjugation is eerily familiar to many disabled people today. Most of us at one time or another have experienced being cared for, cherished, and enthusiastically studied – *and* controlled, exploited, and mistreated ... often simultaneously, and by the same people.

While there are many specific improvements disabled people need, what we need most overall is agency and a voice. Taking more decisions out of our hands, and further drowning out our voices — even if the cause is good — doesn't help us with the fundamental problem that too many of us don't have control over our own lives, or a meaningful voice in our own affairs. So be careful not to drift into a superior position with the disabled people you are "helping." And don't let your own urgency and ego warp your approach to disabled people and the disability community.

The faults of disability allyship aren't solely in non-disabled people. Disabled people too can be self-centered and condescending, to each other and towards non-disabled people. But lack of agency and effective voice is a signature problem of the disability community. It's a problem that is more often than not perpetuated and made worse by well-meaning but unwary non-disabled

allies. In the long run, having recognized credibility and control over our lives is usually more important than short-term relief and material gains. If you want to be a disability ally, do your homework, and resolve to fight with, not for disabled people.

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