Lessons in Self-advocacy: What I Would Tell My Younger Self

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Abstract

Self-advocacy represents a constant process of self-discovery. This involves both trusting your instincts, while at the same time questioning previously held beliefs. The process of self-discovery involved in advocating for oneself can at times be extremely isolating. Finding a community of like-minded people with whom to work alongside is the key in my view to finding fulfillment while traveling the often-uneven path to becoming a self-advocate. This essay details my journey of becoming a self-advocate. I often resisted along the way, but now I find that being an advocate in ways of my own choosing brings me positive energy and happiness. I hope this article inspires others who feel isolated as I once did to realize that the difficult journey of advocacy can lead to community and fulfillment.

I come to this writing as a self-identified person with a disability who keenly understands what it means to be treated as less than fully human. This is an essay about the difficult work of being an advocate while staying true to yourself and what you believe as a person, including how you want advocacy to look. There is no one right way to "do" the work of advocacy and this essay explores some of my experiences from early childhood through an academic career path.

From an early age, I have had to be familiar with what advocacy means. My earliest memory of being in K-12 education is having surgery in first grade and not having an accessible restroom which was indoors and out of the elements. As a person with cerebral palsy, my family advocated for me for as long as I can remember. They saw my potential and knew what I could do, if given the opportunity educationally. I am forever grateful for what my family did for me, but I also saw and understood the costs of their advocacy – not only financially, but emotionally and in terms of family dynamics. Even though my family was advocating *for* me, I often felt my voice was left out of the equation. If my opinion was requested, I often felt like what I said was disregarded in favor of what my parents thought was best. Ultimately, they did many things right because I have gone on to earn a PhD and I am eternally grateful for their advocacy. However, it also led to persistent trauma which shapes how I advocate to this day.

When I got to college, I started to make a conscious effort to find my own community and my own voice. Unsurprisingly, I have found community with people who shared the experience of knowing what it is like to live as a person with a disability and advocate for yourself, or try to advocate for yourself, in a world and political climate which most often tries to silence our voices. "Providing on-campus opportunities for students with disabilities to interact with one another… [could allow them the opportunity to] participate in the co-construction of more inclusive campus environments" (Maconi, Green & Bingham 2019, 189). Here, the authors point out the importance of sharing disability experience and the lived knowledge which comes with it in order to construct, from both a theoretical and practical perspective, campuses which are truly both accessible to and inclusive of stakeholders with disabilities. The concept of co-creation of knowledge became the central theme of my dissertation work and related research agenda. The only way to "do the work" of disability advocacy, in my experience, is in community with others who share similar experiences. This work is difficult but entirely

possible if we commit to the messy process of disability advocacy. This includes the willingness and ability to adapt, as needed, in a world and academic environment where "worth" is based in ideas of productivity, which are themselves problematically tied to ideas of "normalcy" and "normal bodies" (Labaree, 1997; Dolmage, 2017; Davis, 1995). Fundamentally, disability advocacy, as I understand it, is connected to subverting or flipping on their head ideas of which bodies and experiences are considered "normal" or "typical" (Jaulus, 2025).

Claiming Voice and Self-Advocacy

There is a significant history of the silencing or tokenizing of people with disabilities, for example our inclusion in freak shows and other spectacles geared toward the public (Craton, 2009; Bone 2017). Through my own experiences, I have learned a couple of very valuable lessons. Nothing worth doing and worth fighting for is done alone. Find a community of people who share your own lived experience, or at least some element thereof, and integrate yourself into that community. Even when advocacy may fail or a goal is not reached, the existence of a community behind you is what matters.

Institutional leadership --be they institutions of higher education or preK-12 educations --will ultimately make their own decisions for their own reasons, usually financially motivated and disregarding or putting to the side the human cost of those decisions. Ultimately, if you work in community with other like-minded people, you can hopefully build something of meaning, whether it is within or outside any institution that you may be a part of.

Returning to the question I posed at the beginning of this piece: What would I tell my younger self? - advocacy, in whatever form it takes, is never easy, but if you choose the people who advocate alongside you, it can be meaningful, and the bonds of community that you build and cultivate are more important than the result of your actual advocacy.

It is very easy when you are being advocated for -- against institutions which do not so much see you as a person, but as a financial burden -- to feel very alone and isolated. Even as I have grown older and have a community behind me, those feelings of isolation do sometimes rear their ugly head. But ultimately what I would tell my younger self is that things will get better. You have to go through the hard times to get to the other side. I would also advocate finding the community that will be your purpose. I hope there are people reading this who are in the situation I was in all those years ago. Just know that it does get better and something of meaning will come out of this situation which often feels hopeless. Advocacy is messy, but community is what matters.

Creating Communities of Care

There are many historical examples of people with disabilities advocating for ourselves to bring about the change we want to see. Two of the most prominent are the deinstitutionalization/communitization movement and the work of "the Rolling Quads" at the University of California, Berkeley. The Berkeley deinstitutionalization movement fought to close institutions for people with disabilities. Among the most famous (or infamous) institutions for people with disabilities was the Willowbrook State School in Staten Island, New York. The deinstitutionalization movement further advocated for community-based living for people with disabilities with the services they required not only to survive but to thrive. Importantly, this work continues within communities of people with disabilities. As disability studies scholar and performance artist Leah Lakshmi Piepzna-Samarasinha (2018) points out,

> Collective access is revolutionary love without charity, … How do we learn to do this love work of collective care that lifts us instead of

> abandons us, that grapples with all the deep ways in which care is complicated? This is an essay about care--about the ways sick and disabled people attempt to get the care and support we need, on our own terms, with autonomy and dignity… to create networks of care by and for us. It's about our attempts to get what we need to love and live, interdependently, in the world and in our homes, without primarily relying on the state… This is about some of the ways we are attempting to dream ways to access care deeply, in a way where we are in control, joyful, building community (pg. 33).

The key lesson for me from within Piepzna-Samarasinha's (2018) argument is the emphasis on interdependence and community care. Put another way, "Disability justice activists are engaged in building an understanding of disability that is more complex, whole and interconnected than what we have previously found" (Mingus, 2009). Too often, when we discuss disability issues, we talk about them in the framework and through the lens of independence. Independence is incredibly valuable where it is possible for people with disabilities. We should be allowed to do what we can for ourselves without offers of charity or unsolicited help. However, interdependence and communal ties are what make our lives, as people with disabilities, more full and complete. The Rolling Quads, who advocated and eventually were successful in creating the nation's first disabled students' program at the University of California (Berkeley), serve as a perfect example of the power of communal bonds and the possibilities/opportunities which these bonds can create.[1]

As just one example of the power of community to engender positive social change, during the 2020-21 Academic Year, I was part of a group of six students, some with disabilities and some without. Together, we created an accessibility map that was added to the existing Arizona State University website campus map[2]. The layer showed the most accessible routes to campus buildings, as well as accessible restrooms and elevators. The creation of the accessibility layer would not have been possible without both the work we did together and the support of institutional stakeholders at ASU, particularly in the areas of facilities management and map design. The main takeaway from this example is that it is often easier to accomplish your advocacy goals with institutional support rather than being opposed to institutional stakeholders.

Conclusions

The key takeaways from my story and the authors I have included here are that the work of advocacy and care for one another is complex and difficult. This work can lead to intragroup conflict, and this is something people doing the work of advocacy must be prepared to address. Conflicts and opposing viewpoints will arise naturally. However, for advocacy to reach its full potential and be successful, in whichever form that success may take, it must be done as communal labor, based upon love and respect for one another and our points of view. When you are in disability circles, you should question frameworks which rely too much on independence-based solutions and not enough on a communal understanding of shared, lived experience. This is not to say that the experience of people with disabilities is in any way monolithic or the same, but as people living and attempting to survive and thrive under the label of disability, there is a shared element of our experience, whether our disabilities are different from one another or not.

[1] For a deeper examination of the deinstitutionalization movement in the United States, including the Rolling Quads, see e.g., Ben-Moshe, Chapman & Carey eds. 2014; Ben-Moshe 2020; Williamson, Bess. 2018.

[2] Prior to our creation of the accessibility layer, the campus map only included a description of accessible parking places.

The most important lesson is to truly listen before offering solutions. Any advocate must understand the experiences of the people that we are working with or alongside, before attempting to advocate. Listen first; act second. I know listening first can be extremely difficult, especially in situations which feel important or deeply personal, but for advocacy to be successful, we must understand the perspectives of all parties involved in a particular situation. Also, as people with disabilities, trying to advocate for ourselves we may very well encounter institutions and frameworks we find problematic, for example, ableism, or the privileging of able-bodiedness and able-mindedness (Dolmage 2017). These frameworks represent barriers to advocacy and to ultimately building the world we want to see as people with disabilities, but interdependence and collective action can serve as critical forms of resistance to those institutions and ways of knowing which seek to silence the voices of people with disabilities.

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