

The Importance of Disability Identity, Self-Advocacy, and Disability Political Participation

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Abstract

The process of developing an identity that is distinct from one's disability is an essential component of the life of a person who is disabled. Self-advocacy is closely tied to participation in disability community activism and advocacy for the aims of the disability community. Self-advocacy is a vital factor in the process of changing persons' perspectives of both themselves and their impairments. This article explores a political disability identity conceptual framework and provides recommendations for teachers to develop an understanding of disability in school focused on self-worth and pride; awareness of discrimination; common cause within the disability community; policy alternatives; and engagement in political action. The recommendations are intended to help teachers develop an understanding of disability in school focused on self-worth and pride.

Keywords: disability identity, self-advocacy, political activism, political disability identity, disability rights, teacher practices, and special education

I. Introduction

Self-advocacy is a complex combination of activities and beliefs that define an individual's worldview and disability identity. In schools, self-advocacy is often characterized as reporting disability to gain legally required accommodations (Hartman, 1993; Tilley et al., 2020) or the result of an intervention (e.g., Holzberg et al., 2019; Mazzotti et al., 2018). Mel Baggs, a handicapped writer and neurodiversity pioneer, wrote in 2019: Self-advocacy is about identifying and addressing power, respect, and equality disparities. Real self-advocacy will always upset the status quo, whether it's going through the legal system to close an institution, fighting back physically against intolerable surroundings, talking back to staff, sabotaging staff's power over disabled people's lives, being listened to when we communicate in non-standard ways, learning that it's okay to have a voice and make decisions, or passively resisting the dominance of others over our lives.

Baggs asks significant questions in the post. Why term actions or aims "self-advocacy?" Who decides? Self-advocating in systems that aren't designed for disability? How do power relations affect self-advocacy? How can self-advocacy be disabled community advocacy? The TASH (2000) Resolution on Choice states that "active efforts by individuals with severe impairments to exert control over their lives sometimes has been characterised as problem behavior." Self-advocacy, according to Baggs (2019), involves challenging the existing quo through building power in the disability community. This article discusses how school-based disability community and activism transforms, develops, and molds persons with disabilities' self-concepts.

Disability identity development—"a positive sense of self and sentiments of connection to, or solidarity with, the disability community"—has lately attracted attention in educational and other settings that serve individuals with disabilities (Dunn & Burcaw, 2013, p. 148). The self-advocacy movement began as grassroots organization by people with intellectual and developmental impairments (Anderson & Bigby, 2015; Caldwell, 2011). Hence, community involvement helps intellectual and developmental disabled individuals create disability identity, connection, and solidarity to change the world. This form of community engagement goes beyond campaigning for accommodations and involves activism and advocacy for the larger disability community to alter the status quo, as Baggs (2019) noted.

People with disabilities must see themselves as part of a larger disability community and as political identities to accomplish this change. This essay uses Putnam (2005)'s conceptual framework for political disability identification to explore the value of disability community. Self-worth, pride, discrimination, common cause, policy options, and political action are the six aspects of political disability identity that we shall study via personal experience (Putnam, 2005). Some of these characteristics, like selfworth and pride, are internal ways a person might connect to their identity, while others, like discrimination and common cause, emerge from encounters with ableist organizations that foster unity. As two white people with disabilities—Ivanova with intellectual and developmental disabilities and Carlyn with cerebral palsy and learning disabilities—we know the importance of considering identity, political engagement, and disability community together and the vital role this work plays in the lives of people with disabilities across disability labels, ages, and awareness. We co-

authored this paper in cross-disability solidarity (Sins Invalid, 2015), understanding that our racial identities influenced and favored our experiences with disability in school and further marginalized persons of color in these same frameworks. Disability is a rich, lively, intersectional, and political group with a history worth studying in school. We first examine these political identity areas via the personal experience of one co-author, Ivanova, and then propose ways to promote identification and self-advocacy in educational contexts.

Connecting Disability Identity, Self-Advocacy, and Challenging the Status Quo: Strategies and Recommendations

Ivanova's disability identity development shows the relevance of education and schooling. We encourage instructors build a positive sense of identity, membership in the disability community, and self-advocacy as well as disability community advocacy in the following section (Table 1). Teachers influence students' self-concepts and impairments, sometimes unintentionally (Moriña & Carnerero, 2020; Storey, 2007). Teachers often explain, analyze, and describe disability as "descriptively impaired," according to disability rights activist and community organizer Mia Mingus (2010). We advise intentionally developing kids as "politically disabled" to promote self-advocacy, disability community advocacy, and disability identification at their intersections (Mingus, 2010). Politically handicapped kids analyze ableism, power, and privilege and see themselves as part of a larger disability community. According to Putnam's (2005) political disability identity framework, teachers can help students develop this sense of disability by building self-worth and pride in disability, raising awareness of discrimination and common causes, and engaging in policy change and political action as a matter of social, community, and intellectual importance for people with disabilities.

Expanding Awareness of Discrimination and Common Causes to the Disability Community

Discrimination from society is a common experience among members of the disability community. This discrimination is often based on preconceived notions and larger negative messages from society about what it means to be identified as having a handicap. According to Ivanova, one of these messages is the existence of a "disability hierarchy," which refers to differential attitudes and perceptions toward disability groups depending on their proximity to able-bodiedness and neurotypicality (e.g., Sauder, 2015; Tringo, 1970). Ivanova noted that this message is especially influential in schools. While working in educational contexts that classify pupils according to the "severity" of their disabilities, teachers often participate in disability hierarchy, either implicitly or openly (Danforth & Rhodes, 1997). Ivanova's experience was that instructors contrasted the pupils who were in general education inclusion courses and those who were in self-contained classrooms. The hierarchy of disability posits intellectual disability as inherently implying ineptitude when discussing those who have this classification (Kliwer et al., 2015; Taylor, 2018). Instructors have the potential to propagate unfavourable comparisons between children with impairments, indicate that some talents or disabilities are "higher" on the hierarchy, or compare the assistance requirements and functional labels of their pupils. They may also contribute to the continuation of these comparisons by concentrating their portrayal of disability on only a few of the visible types of infirmities. Teachers should avoid discussions and explanations of disability that emphasize proximity to able-bodiedness, neurotypicality, and a broader notion of "normalcy" as the goal for students. Instead, they should work to build relationships between students who have experienced different types of disability and should focus on bringing students together.

Advocating for Policy Alternatives

Putnam (2005) notes that promoting policy alternatives begins with three fundamental assumptions: that disability is not an individual characteristic, that the disability community and experience have contributors, and that public policy shapes attitudes that condition or even try to eradicate disability itself. Ivanova's journey toward realizing that her impairment was not something she could "grow out of" or saw as a personal failing exemplifies how viewing disability as a shared, communal experience may lead to a more positive internal knowledge of oneself. Teachers may start forming this perspective in classrooms and with students by first confronting their own conceptions of disability as a fundamentally individual trait, a basic issue with unique bodies and minds that calls for action.

In fact, when people identify as having a disability and start to integrate that aspect of their identity with larger community identification, they experience higher collective and personal self-esteem (Nario-Redmond et al., 2012). This medicalized, individualized view of disability underlies much of the process of identifying disability (e.g., Evans, 2004). Challenges to the use of language connected to disabilities in educational settings are one approach to investigate this community identity. Despite research and community activism suggesting identity first language is an acceptable and even preferable phrase, many teachers and associated support providers who work with kids with disabilities are trained to exclusively use person-first language (e.g., Blaska, 1993).

It is vital to acknowledge that many people in the disability community have diverse viewpoints since disability terminology varies based on the individual. The way that different individuals handle this linguistic

issue is not binary but rather quite flexible. We utilize all of these methods interchangeably in this essay since they are both significant and grounded in unique understandings of disability identity. Discussing identity, language, and preferred words with children is something that teachers may and should do in order to show them the many ways they can choose to self-identify and to emphasize the fact that disability pride can be expressed via self- and community identification. The perception of people with disabilities as members of a community with shared experiences that can be addressed, frequently through commitment to collective and policy-level change and even through language use, changes as a result of teachers' changing views of disability as an individual characteristic.

Therefore, interacting with policy entails battling the ways in which it both strives to treat and eliminate disability. Teachers should support laws that place the blame for the "problem" of disability on inaccessible settings and try to find solutions that focus on those settings rather than the people with disabilities. This meant getting support from the community for both career and parenting, according to Ivanova. Even if structural and access restrictions are eliminated in a specific place, the lived experience of disability is still there. It is crucial to feel pride in and connected to disability in this context. Working for school settings that recognize and support all children and their identities, desires, and objectives is a necessary part of engaging in policy options.

Developing Self Worth and Pride

Critical and reflective conversation on students' feelings and views in relation to disability (and their own personal experiences), which might be one manner in which educators get their students thinking about these ideas, is one possibility. For instance, talking about their own experiences and how they relate to having a handicap (and to understanding disability more critically and more politically).

Ivanova's perspective is that a person's disability is something that is constructed by adults who do not discuss disability as a permanent or instructive part of a broader sense of identity. As a result, Ivanova developed a sense of self-hatred and a sense of self as separate from community as a result of her disability. This is not always an experience that comes along with having a handicap. In point of fact, a significant amount of the writing that has been done on the topics of self-advocacy and self-determination emphasizes the significance of having an accurate awareness of one's own handicap in order to eventually get accommodations and rights (e.g., Wehmeyer & Shogren, 2016). This is the first and most significant reason to work on developing this talent. To assist students in developing language to identify with their disability; to connect them with a broader sense of disability community solidarity and shared experience; and to counter the often medicalized, nondisabled expert, and adult-focused discourses of disability with individual personal stories and student meaning-making. As we have suggested, there are additional reasons to open these conversations: to assist students in developing language to identify with their disability; to connect them with a broader sense of disability community solidarity and shared experience. This is of utmost significance in light of the larger context of educational curricula and the media, both of which fail to acknowledge disability. According to what Stacy Milbern Park said, "If you are a wheelchair user like me, particularly if you are a person of color, a woman, or a queer person riding gender lines, who are you supposed to see yourself reflected in, Franklin D. Roosevelt or the kid from Glee?"

The use of read-aloud texts in the classroom, such as the children's book *We Walk Together*, which contains characters with a wide range of impairments and intersectional identities, is one method to initiate this dialogue. In the end, it is essential that students have agency over the messages and things that people say about them and their disability, and that they develop the skills to question those broader societal messages. These messages frequently create power dynamics and ableist environments in which disabled people are unable to be their full selves.

Encourage your kids to participate in their local disabled community as a means of developing a feeling of pride in their handicap. This is another manner in which instructors may help their pupils create a stronger sense of advocacy and identification. At the level of the school, this may take the form of establishing connections and friendships with other students who have disabilities in their self-contained or inclusive classes; joining clubs with students who have disabilities; and participating in activities such as adapted sports or programs offered by Special Olympics. Fostering connections between students with and without disabilities is the subject of a significant amount of research and discussion in the field of special education (e.g., Zambo, 2010). Our research leads us to believe that it is of equal importance to cultivate relationships amongst students who themselves have difficulties. In general, participation in extracurricular activities leads to favorable outcomes for children and teenagers with disabilities. These benefits include more engaged friendships, an increase in the number of weekly telephone calls, and invitations to participate in social events (Garza et al., 2002). Participation in extracurricular activities helped students with "severe disabilities" develop and strengthen relationships, personal interests, and a variety of skills (Carter et al., 2010; Kleinert et al., 2007; Swedeen et al., 2010). This was found in studies by Carter et al. (2010), Kleinert et al. (2007), and Swedeen et

al. (2010). A study of the activities offered by Special Olympics indicated comparable impacts on participants' social abilities and friendships (Tint et al., 2017).

Participation in disability communities and extracurricular activities with a focus on disability should not, however, come at the price of inclusion in the larger school community. The objective is not to further compartmentalize students with disabilities in the name of community building. Instead, children with disabilities should be encouraged to engage in a wide variety of these activities and to cultivate relationships with others who have shared experiences and interests in the same way.

Engagement in Political Participation

Participation in political activity is an essential component of a political disability identity that plays a vital role in lobbying on behalf of both the individual and the community. The struggle for disability rights in the 1970s has been depicted in recent popular media, as in the documentary film *Crip Camp* (LeBrecht et al., 2020), for example. Individuals with disabilities have long been politically active and involved in advocacy work, especially through groups such as TASH (Longmore & Goldberger, 2000).

Advocacy for people with disabilities covers a broad range of topics, including employment, education, and health care. Baggs (2019) broadened the definition of self-advocacy, and Ivanova's experience fighting for the closure of institutions and against segregated and abusive work settings is illustrative of this enlarged definition. This perspective recognizes and accounts for the possibility of change not just for an individual in their own unique set of circumstances, but also for the whole of a community.

There are a few key methods in which educators might inspire students to become involved in political activity of this type. First, the representation of people with disabilities in school environments has undergone a significant sea change as a result of the inclusion of disability topics in curricula, particularly in ways that demonstrate people with disabilities working toward the improvement of their local communities (Mueller, 2021). Second, educators may engage students in broader conversations about social justice or current events by bringing up concerns pertaining to the disability community, including those that were discussed previously. Viewing disability as a problem that has shaped the lives of many people throughout history and continues to impact the experiences of individuals in the present day will inevitably shape perceptions of disability as being worthy of collective action and political engagement.

This is particularly significant when considering the ways in which racism and other types of marginalization interact with disability and ableism to affect students' experiences in school as well as the subjects that are left out of the curriculum. The naming of disability as an intersectional identity and experience and the tying of it to wider histories of marginalization are essential components in the process of comprehending the history of disability and the identification of people with disabilities (Brown, n.d.). Teachers may want to explore integrating the work of handicapped people of color in their lessons, such as Leroy Moore's *Black Disabled Art History 101*, which states that "Black disabled and Deaf artists have always existed." This will help support the investigation that is being conducted (Moore, 2017, n.p.).

Apart from the inclusion of disability in the curriculum, teachers should be aware of disability along with other problems linked to education that have an influence on their students and the settings of their classrooms, and they should advocate for disability. This demands instructors to position themselves less as experts or key information producers of the disability experience and more as allies and accomplices to the community of people with disabilities. This shift in perspective is necessary in order to accomplish this goal. The participation in and awareness of disability advocacy groups, the concentration on disability-specific advocacy or broader community issues, or education-specific concerns are all potential ways in which teachers can understand their role and responsibility as allies to the community of people with disabilities.

II. Conclusion

The development of one's identity, the capacity to advocate for oneself, and the establishment of meaningful connections within one's community are all essential aspects of the disability experience. Connecting with people who have similar experiences, aspirations, and backgrounds is beneficial to the process of developing a disability identity since it helps to reinforce and deepen the process. This understanding of disability as a political community has the potential to give a crucial means of navigating ableism, stigma, and prejudice, which are all things that adolescents with disabilities confront on a daily basis. The larger disability community as a whole, as well as the objectives that it has set for itself, are strengthened when members of that group realize how closely related they are to one another.

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