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(Re)defining their place at the table: Frank discussions by adults with disabilities on contemporary self-advocacy

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Abstract

Adults with disabilities have long been at the forefront of disability advocacy in the United States. Grounded in the tenets of radical disability studies and principles of disability justice, this study explored the lived experiences of 12 adults with disabilities, including intellectual disability and developmental disabilities, with a particular focus on self-advocacy. Two focus groups were primary data sources. Three participants and one university-based researcher analyzed the data collaboratively. Iterative data collection and analysis yielded 8 primary codes and 22 subcodes. We discuss a subset of our findings, focusing on three major themes. The findings illuminated how adults with disabilities conceptualised self-advocacy expansively, including self, other, and the collective. Participants also described problems they faced advocating. Finally, adults with disabilities shared solutions to inequities at individual, group, and societal levels. This project illustrates the importance of centering adults with disabilities in research and policy with implications for future thought.

KEYWORDS
adulthood, activism, developmental disabilities, intellectual disability, self-advocacy

1 | INTRODUCTION

Individuals with disabilities[1] have long been at the forefront of disability advocacy. Since the 1960s, youth and adults with disabilities in the United States (U.S.) have been organising, demonstrating, and litigating (Pelka, 1997). At the local level, disability activists in Oregon formed the first support group focused on self-advocacy for individuals with developmental disabilities (Miller & Keys, 1996). At the national level, disability activism led to the passing of Section 504 of the Rehabilitation Act of 1973 (1973) and later, the Americans with Disabilities Act (1990). Moreover, the experiences and voices of people with disabilities have been representative of state and federal legislation (e.g., Olmstead v. L. C. and E. W, 1999). In sum, self-advocacy is a social and political activity with potentially enormous implications.

Early disability activism and the disability rights movement constituted genuine grassroots organisation and success (Patterson, 2012). Like the ways the self-advocacy movement changed ideologies, organisations and practices, it also influenced other movements. For example, the independent living movement arose in the 1970s advocating a shift away from professional-based decision-making to a focus on people with disabilities orchestrating the life course (Danforth & Connor, 2020). In the 1990s, the self-determination movement arose advocating a power shift away from the system to the individual (Pennell, 2001). Despite countless resulting achievements, disability advocacy and activism are ongoing realities as local and national legislation have not changed ideologies or abolished inequities (Zames & Fleischer, 2012). As such, inequities and injustices persist through adulthood for people with disabilities.

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[1]In this article, the term 'individuals with disabilities' includes individuals with intellectual disability, individuals with developmental disabilities, and individuals with diverse and complex support needs. Person-first language is our stylistic choice because most study participants preferred it.

Inequitable systems and processes have economic, material, political and social consequences for people with disabilities. For example, adults with disabilities in the United States have few opportunities for preferred employment, housing, and health care (Human Services Research Institute & The National Association of State Directors of Developmental Disabilities Services, 2019). Specifically, individuals with intellectual and developmental disabilities may earn only $1.57/h while the federal minimum wage is $7.25/h (gender and race not reported; Yell et al., 2017). That said, these consequences are particularly oppressive for historically marginalised individuals with intellectual disability and/or developmental disabilities. For example, women of colour with developmental disabilities are underrepresented in community-based employment settings (Hasnain & Balcazar, 2009). Yet, people with disabilities are often not considered solution generators for the inequities and injustices that impact them. Therefore, this qualitative study sought to understand the self-advocacy experiences of adults with disabilities in the United States, including problems they experience and solutions they want brought forth, as well as how self-advocacy has changed over time. Two questions guided this inquiry: How do adults with disabilities conceptualise self-advocacy and advocacy? How do local and national policies, processes and systems impact self-advocacy?

2 | LITERATURE REVIEW

Globally, scholars have studied self-advocacy focused on individuals with intellectual disability through various methods and with different goals. Some scholars used the term 'self-advocate' to identify participants but not to examine self-advocacy (e.g., Brake et al., 2012; Nonnemacher & Bambara, 2011). Others have studied individual and group perspectives on participating in self-advocacy organisations (e.g., Beart, 2005; Gilmartin & Slevin, 2010; Goodley, 1998; Tilley, 2013). We focus this review specifically on the self-advocacy experiences of individuals with disabilities, including individuals with intellectual disability.

As scholars examined self-advocacy during adulthood, their findings highlighted the complexities of self-advocacy embedded in peoples' lives. For example, Caldwell (2010) studied the stories of trailblazers in the self-advocacy movement and found that experiences enhanced leadership and self-perspectives. These findings had direct implications for supporting youth advocacy and leadership development. Scholars have also examined self-advocacy with a focus on sexuality illuminating themes of respect and communication (Owen et al., 2016) as well as the importance of personal choices and healthy relationships (Friedman et al., 2014). Recently, Ryan and Griffiths (2015) asserted how 'recognizing the importance of self-determination to the exercise of effective self-advocacy must also not be underestimated' (p. 49) as decision-making and self-awareness are inherently connected to self-advocacy. Examining specific domains of self-advocacy afforded an insight into how self-advocacy, ideologically and pragmatically, was interconnected across life activities.

Landmark et al. (2017) surveyed individuals about their self-advocacy experiences broadly revealing that most participants relied more on other individuals with disabilities and advocacy organisations than family members and individuals without disabilities in their advocacy efforts. Moreover, most study participants were members or leaders of advocacy organisations. This reality may have increased their opportunities to have an impact on policies and practices but also showed how adults with disabilities adopted 'smooth and nomadic' qualities as they were required to advocate across life spheres (Roets & Goodley, 2008, para 7). Through a life history project, Traustadóttir (2006) studied the self-advocacy experiences of one individual with multiple disabilities. This work unveiled how self-advocacy developed over time and included diverse enactments, including speaking up and resisting.

In 2010, Caldwell argued that future self-advocacy scholarship ought to include adults with intellectual and/or developmental disabilities in the research process. In fact, two study teams (Friedman et al., 2014; Owen et al., 2016) reviewed here used a participatory research method known as nominal group technique. In this technique, group discussions (and oftentimes decisions) are based on initial written responses from participants (Friedman et al., 2014). This gave the participants space and time to think about their responses (McMurray, 1994). In sum, the studies reviewed here were important to this project because they revealed how self-advocacy transverses across life domains and experiences. Notably, the reviewed studies also supported our methodological decisions regarding collaborative research (Bigby et al., 2014a, 2014b), including data collection and analysis techniques.

3 | CONCEPTUAL FRAMEWORK

This project is grounded in the tenets of radical disability studies (Withers, 2012) and principles of disability justice (Invalid, 2019). Next, we outline the affordances of combining radical disability studies and disability justice to studying self-advocacy.

We position disability as a complex social, political and cultural phenomenon (Piepzna-Samarasinha, 2018). Even though disability is natural, it is used to oppress certain bodies and minds (or bodyminds, as the body and mind are not separate) depending on the contexts (Withers, 2012) and necessitates self-advocacy and advocacy. Therefore, based on our radical context, we privilege the interests, agendas and voices of people with disabilities, particularly intellectual and/or developmental disabilities, in this study 'because to truly have liberation we must be led by those who know the most about these systems and how they work' (Berne et al., 2018, p. 227). We argue the experiences and perspectives of people with disabilities, and specifically advocacy experiences, are needed to create and critique transformative change.

In addition, disability is intersectional (Withers et al., 2019). People with disabilities have numerous identities and identity markers (e.g., cultural practices, gender, language expression, race and sexuality) that inform and are informed by their life experiences. Moreover,

many people with disabilities experience multiple intersecting oppressions (e.g., racism and sexism) in addition to and in conjunction with ableism (Berne et al., 2018). Ableism works conjointly with other oppressions to marginalise people with disabilities. That said, marginalisation and advocacy look, feel and sound different depending on race, class status, access to supports and services and so on (Bisesti & Landes, 2021; Erevelles, 2002). For example, the oppression that women of colour with intellectual disability experience is different, more complex, and harsher than their white male counterparts with intellectual disability (Goodwin, 2003). Thus, engagement in disability advocacy needs to be cross-coalitional (Collins & Bilge, 2016) and not single-issue focused. Cross-coalitional politics honours the diverse identities and (disability) cultures represented while working to eradicate inequities. Moreover, it involves power-sharing between people with disabilities and people without disabilities, or ceding power to people with disabilities. As such, radical disability studies and disability justice provide an important lens to examine how contemporary advocacy and self-advocacy are conceptualised by adults with disabilities and impacted by local and national policies, processes and systems.

4 | METHOD

This empirical study used phenomenology and collaborative research. The project was phenomenological in nature because we asked participants to reflect on their self-advocacy experiences in as much detail as possible to better understand the phenomena of contemporary self-advocacy (Bhattacharya, 2017), including if the term 'self-advocate' was still relevant. Collaborative research (Bigby et al., 2014a) provided the project with several affordances. For example, collaborative research aligned with our paradigmatic orientations. We grounded this study in interpretivist and critical paradigms (Tuck & McKenzie, 2015) asserting that knowledge is influenced by perceptions (interpretivism) and power (critical). Said differently, the perspectives and experiences of people with disabilities and their communities are impacted by power, which may be afforded to them or yielded over them. In addition, people with intellectual disability who have lived experiences with self-advocacy were part of the project from conceptualisation to data collection and analysis and then dissemination, including presentations and publications (Bigby et al., 2014a). Importantly, when three adults with disabilities who participated in the focus groups volunteered for the data analysis team—referred to as community scholars in this article—their roles were integral and equally valued throughout the process (Bigby et al., 2014b). Finally, the data analysis team (discussed later) met regularly building trust and connecting with one another and sharing power in planning and decision-making.

4.1 | Background and context

A couple of years ago, some adults with intellectual and/or developmental disabilities in the United States posed a question on a national self-advocacy organisation's social media site. They asked: Should we

identify as 'self-advocates' or 'advocates' on job applications? Around the same time, a federal government community living agency asked the national organisation a similar query. These curiosities prompted the organisation to inquire with its advisory committee members at their next national convening. The advisory committee consists of adults who identified with intellectual and/or developmental disabilities and who have extensive experiences with self-advocacy and the self-advocacy movement. That way, everyone would be in the same room and the organisation could inquire about how self-advocacy has changed over time and which terminology was most relevant. In sum, that initial question about how someone with intellectual and/or development disabilities should identify on a job application was the catalyst for this qualitative study.

It was important to the national self-advocacy organisation that they stay up to date on how individuals with intellectual and/or developmental disabilities were conceptualising self-advocacy and using certain terminology. Initially, each advisory committee member signed a release of information giving the organisation permission to record the meeting and use the recording only for internal purposes. After viewing the recording, the board of directors decided to transform the project into a research study and invited a university-based researcher (the first author) to assist them in the process. Then, the university-based researcher and the board of directors wrote a research study proposal together. The project received ethics board approval from the State University of New York at Cortland. Each advisory committee member, as a study participant, provided written consent to (a) allow the original recording to be used as project data and (b) participate in future data collection activities (i.e., completing a demographics form and participating in a focus group). No one received an incentive for participating in the focus groups. Only the data analysis team (discussed later) received monetary compensation.

4.2 | Participants

Study participants were current advisory committee members of the national self-advocacy organisation. In fact, only advisory committee members were invited to participate in the study because that was the original inclusion criteria of the first group conversation. All participants identified as individuals with intellectual and/or developmental disabilities and had extensive experiences with self-advocacy. The committee was diverse in races/ethnicities, genders and gender preferences, sexualities, disability labels, services and supports, employment statuses and geographic areas (including rural and city spaces). Also, most members received supplemental security income (SSI). As a collective, they experienced multiple intersecting oppressions and had a range of diverse and complex support needs. A total of 12 participants partook in the study (see Table 1).

4.3 | Data collection

Two focus groups were the primary data sources. The first focus group was conducted in person and led by the national self-advocacy

TABLE 1 Participant demographics

Participant	Age	Racial/ethnic identity	Gender identity	Disability identity	Focus group 1	Focus group 2
Atiya	Not reported	Not reported	Not reported	Not reported	X	
Brent	55	White/Caucasian	Man	ID, LD	X	X
Caleb	65	Black/African American	Man	MD, VI/B, epilepsy	X	X
Darius	Not reported	Not reported	Not reported	Not reported	X	
Jasmin	35	Pacific Islander	Woman	MD, ID, LD, OI	X	
Jenny	47	White/Caucasian	Woman	MD, VI/B		X
Katherine	58	White/Caucasian	Woman	MD, ID, ED, LD	X	
Linda	57	Native American, White/Caucasian	Woman	MD, HI/D, OI	X	X
Lucas	54	White/Caucasian	Man	Cerebral palsy	X	X
Nia	60	Black/African American	Woman	OI	X	X
Thomas	34	Black/African American	Man	MD, ASD, ID, LD, SLI	X	
William	62	Black/African American	Man	MD, ID, LD, VI/B	X	

Note: All names used in this manuscript are pseudonyms.

Abbreviations: ASD, autism spectrum disorder; HI/D, hearing impairment/deafness; ID, intellectual disability; MD, multiple disabilities; OI, orthopaedic impairment; SLD, specific learning disability; SLI, speech or language impairment; VI/B, vision impairment/blindness.

organisation. The participants, 11 of the 12 advisory committee members, travelled from around the country to meet and conduct organisation-related business. One person could not attend this meeting, and subsequently the first focus group, due to a scheduling conflict. The national self-advocacy organisation vetted the focus group questions amongst its board of directors (some of whom identify as adults with intellectual and/or developmental disabilities). The focus group questions and conversation were open-ended (Merriam, 2002). For example, the questions 'Does the term "self-advocate" mean anything to you? Do you identify as a self-advocate?' and 'How do you think other people view you?' prompted a range of reactions and emotions. Open-ended questioning allowed responses to reflect the nuances of firsthand experiences (Merriam, 2002). Finally, the questions were sent to the advisory committee members ahead of the meeting.

Data collection was iterative wherein the creation of the second focus group guide was informed by data generated from the first focus group, existing literature and current contextual factors (i.e., global pandemic; Bhattacharya, 2017). These open-ended questions were created by the university-based researcher. Then, the board of directors provided feedback. Questions included, 'How do we create space for individuals with disabilities in shared spaces, where individuals with disabilities are the ones in power?' and 'Do you think the self-advocacy movement needs to broaden? How? For whom?' The current context was also reflected in the focus group questions as participants discussed the new *Crip Camp* documentary, how the COVID-19 pandemic was impacting self-advocacy, and tips for including youth in self-advocacy. The second focus group took place 15 months after the first focus group. It was co-led by the board of directors and the university-based researcher but was not part of a larger organisation-related meeting or online gathering. All advisory committee members were invited to the second focus group and provided with the questions ahead of time (Friedman et al., 2014).

However, some could not attend, and the second focus group only had six participants. The second focus group was conducted online using GoToMeeting because of COVID-19 pandemic restrictions and precautions. As primary data sources, the two focus groups yielded 196 min of audio/video recorded data. After the first and second focus groups, most participants completed a demographics questionnaire.[2] Primary data collection ceased after the second focus group because the national organisation felt confident to share on social media and with federal agencies that people with disabilities were using 'advocate' and 'self-advocate' and it was up to the person to decide how they identified (Moore, 2020).

In addition, five data analysis team meetings and accompanying meeting notes were secondary data sources. The meetings were audio/video recorded on Zoom, totaling 450 min. Recording the data analysis team meetings allowed the university-based researcher to ensure the participants' views were built into the study and the interpretations of the three community scholars on the data analysis team were stronger and louder than her own (Creswell & Miller, 2000). For example, the university-based researcher listened to and watched these recordings and reviewed the notes when constructing the code book and later, the code tree. She also included the community scholars' words and ideas from these meetings to write notes that accompanied the coding process in Dedoose (discussed later). In sum, the secondary sources upheld our paradigmatic and axiological commitments to the project as a critical and collaborative endeavour.

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[2]Considering disability identification, participants selected from the 13 disability categories recognised by the Individuals with Disabilities Education Improvement Act (2004) as well as a fill in the blank option because all participants went through the United States education system as youth. While the Americans with Disabilities Act (1990) does not include learning disability, some of the participants still identified with that label.

4.4 | Accommodations

Participants were provided with accommodations prior to and during the focus groups. First, all participants were provided with focus group questions ahead of time. Like nominal group technique (Owen et al., 2016), this gave each participant a chance to process their responses over time. Additional accommodations included sign language interpreters, augmentative communication devices, onscreen captioning, and text readers. For the first focus group, participants were provided with any accommodation they needed for travel by the national self-advocacy organisation, including personnel attendants for day-to-day experiences. Additional support personnel and advisory members were on site to assist as well. For the second focus groups, participants were provided with any accommodation they needed to attend an online GoToMeeting group conversation by the national self-advocacy organisation.

4.5 | Data analysis

Data analysis held participatory elements (Kramer et al., 2011) as the data analysis team consisted of three community scholars and the abovementioned university-based researcher. All three community scholars were adults with disabilities who (a) had firsthand experiences with the topic of study, (b) had participated in the two focus groups, (c) volunteered to analyse the project data on a team with the university-based researcher when all participants were asked if they wanted to join in this aspect of the project and (d) were monetarily compensated for their time (i.e., analysing data, meeting to discuss data analysis, disseminating knowledge via presentations and publications). One community scholar identified with intellectual disability.

Initially, the data analysis team searched the first half of the first focus group transcript for key ideas (Rodwell, 1998). The university-based researcher worked with one community scholar and the other two community scholars worked on their own. The two worked as a partnership on Zoom because the community scholar asked for reading supports. The university-based researcher read the transcript line by line to the community scholar, highlighting when she wanted her to emphasise important or key ideas. The university-based researcher also took notes in the margins about what the community scholar discussed and reflected on. Then, the data analysis team met twice on Zoom and discussed excerpts as a group as the university-based researcher took notes. The team also discussed any patterns emerging from the data.

Next, the data analysis team worked in partners wherein the two community scholars who had worked individually paired up on Zoom to read through and search the second half of the first focus group transcript. The other dyad continued to work together on Zoom. Partners read this next portion of the transcript for key ideas and highlighted and made notes in the margins accordingly. The team met together on Zoom again to talk through the transcript excerpts as well as any patterns they were noticing.

Then, the university-based researcher created code categories with definitions using the language of the participants (Charmaz, 2006) and created a code book (Rodwell, 1998). The data analysis team met on Zoom so that the university-based researcher could share the code book and get feedback from the community scholars. For example, *Disability hierarchy* was one code category the group wanted changed for language accessibility. This code was eventually collapsed into two larger code categories—*How people treat people with disabilities* and *How people think about people with disabilities*.

The university-based researcher then coded the second focus group on her own as requested by the community scholars due to time commitments and responsibility load. While applying the code book, codes were collapsed and reorganised illustrating the ideological and actionable implications of the participants' narratives. For example, adults with disabilities described solutions that were ideologically- as well as action-oriented; this was salient across the two focus groups. In addition, a new COVID-19 pandemic code surfaced. Then, she shared the edited code categories and definitions with the three community scholars during another data analysis team meeting on Zoom. The new or edited codes and their definitions were conferred by the team and decided upon through consensus. As such, an iterative process through recurring meetings afforded several opportunities for the community scholars to give feedback and make necessary changes to the code book (Bhattacharya, 2017).

Next, the university-based researcher created a code tree on Dedoose that was applied across the two focus groups. Using Dedoose allowed her incorporate highlights and notes from the partner-coded transcripts as well as code fresh, unhighlighted copies of the transcripts. She also added notes as memos from the data analysis team discussions, providing a more in-depth, three-dimensional data representation. Two rounds of axial coding, wherein codes were compared, reorganised and refocused, took place (Rodwell, 1998). This resulted in 8 primary codes and 22 subcodes. The team met again to discuss the primary codes and subcodes. Finally, the team chose salient themes. Analysing the data in this way ensured community scholars' expertise and knowledge were foregrounded throughout the analysis (Stevenson, 2014).

4.6 | Trustworthiness and rigour

We employed four strategies to ensure trustworthiness. First, we used iterative data collection and analysis (Bhattacharya, 2017). For example, the second focus group guide was informed by the first focus group conversation and preliminary analysis. Further, the data analysis team worked through the data in chunks over time turning hunches into questions and returning to the data to mine for answers. Second, we stayed close to the data by using the participants' words to label and then define the code categories as much as possible (Charmaz, 2006). Said differently, quotes from the participants were used within code definitions.

Third, we used member checking (Lincoln & Guba, 1985) from the first focus group to the second group. For example, we sought

TABLE 2 Themes and subthemes

Theme	Subtheme	Definition
Defining self-advocacy: For self and others		*Conceptualising self-advocacy* was defined as 'Adults with disabilities discuss what self-advocacy is and what it means to them'.
Revealing problems: Adults with disabilities discuss self-advocacy	Ideologies impact people and self-advocacy	*How people think about people with disabilities* was defined as 'Adults with disabilities describe how individual, community, and societal ideologies impact self-advocacy'.
	Ideologies inherently impact actions	*How people treat people with disabilities* was defined as 'Adults with disabilities discuss the problematic treatment of people with disabilities'.
Generating solutions: Adults with disabilities discussion self-advocacy	Self-advocacy and cross-disability activism	*Collective action and working together, supporting one another* was defined as "Adults with disabilities discuss how people with disabilities need to work together and collaborate to cultivate and maintain power."
	People with disabilities leading the solution-generating	*Led and created by people with* disabilities was defined as 'Participants describe the importance of people with disabilities being the creators, leaders, and decision makers'.

confirmation or disconfirmation from the participants during the second focus group to inform what was discussed during the first focus group. Finally, we used investigator triangulation (Anney, 2014) by analysing data as a team. This allowed for an additional level of member checking because the data analysis team consisted primarily of project participants. As such, member checking took place during analysis. The university-based researcher brought questions to the community scholars to inform her understanding as the team coded the data. Notably, the community scholars collaboratively generated knowledge and understanding around the data that was shared during dyad and team meetings.

5 | FINDINGS

Our findings revealed how participants thought about and acted on self-advocacy. Adults with disabilities also described various problems and solutions related to self-advocacy and activism. Please refer to Table 2 for a list of the themes and subthemes we discuss next.

5.1 | Defining self-advocacy: For self and others

During focus groups, participants discussed what self-advocacy meant to them, including how they defined it. *Conceptualising self-advocacy* was defined as 'Adults with disabilities discuss what self-advocacy is and what it means to them'. Self, as an aspect of self-advocacy, was prominent during focus groups. Jasmin explained, 'self-advocacy means having a voice, having a good life and be a role model to other

self-advocates'. Here, Jasmin centered the importance of the person having an impact on their life and modelling for others. William added, 'And self-advocacy also means having the voice to say what you feel, not what somebody else has trained you to say. It is whether they like it or not. You have the right to say what you feel'. Here William expands on Jasmin's conceptualisation of self-advocacy by including that the focus is on what the person wants rather than what others want for them.

Advocating for others was another critical component of self-advocacy. Linda explained, 'First of all, my definition of self-advocacy is to advocate for yourself and for others'. Caleb affirmed and added, 'Well, we speak for ourselves. We speak for others. We're advocating for others. Sometimes people want things that we think are wrong, but it might be right for that person'. Caleb acknowledged one self-advocacy tension but noted how disagreeing did not mean ceasing self-advocacy. Linda added how self-advocacy was cyclical 'because you're opening a door', she said. Nia concurred, 'With me, I have been advocating for a while… I was so busy advocating for other people, and now I'm doing both. I'm advocating for them and myself'. As such, self-advocacy created a loop wherein what one person advocated for benefited others.

Self-advocacy as collaboration was also discussed. Nia described the importance of working together. She said, 'Self-advocacy also means we all, they've got so many types of disabilities out here that we all need to get together and work together as one'. Self-advocacy meant everyone, regardless of disability label, working together. Jasmin added, 'So, what I've kind of learned when I've worked with people like me, all of us, is we have to serve everyone else, not only some people'. In this way, advocacy was not solely about the person,

it was about collective service to one another. Caleb reiterated the strength in collective advocacy. He said, 'And then if you have a whole group like a whole state or other people advocating for the same cause, it helps'. Another important aspect of self-advocacy as collaboration occurred when the individuals with disabilities upheld the causes that other communities brought forth.

Participants thought about self-advocacy as pertaining to self, others, and the collective. This is important to note because often self-advocacy is presented as advocating solely for oneself. As the participants discussed here, self-advocacy was more complex and expansive.

5.2 | Revealing problems: Adults with disabilities discuss self-advocacy

Adults with disabilities described myriad problems related to self-advocacy. Largely, participants felt that disability was viewed through a deficit lens, and this impacted the way people with disabilities were thought of and treated as adults.

5.2.1 | Ideologies impact people and self-advocacy

How people think about people with disabilities was defined as 'Adults with disabilities describe how individual, community, and societal ideologies impact self-advocacy'. Participants shared how a person with disabilities was considered a 'cash cow', 'poor sick person' and 'not capable'. Brent expressed, 'I wish that it [disability] was more accepted in the United States and in the world'. Participants experienced a lack of acceptance. Linda added, 'Well, I think the community as a whole still doesn't recognise us as a people'. Here, adults with disabilities discussed how they were devalued and disrespected.

Participants described being perceived as dangerous. Thomas explained, 'I think a lot of times people are scared of people with disabilities being their neighbors in the community... I think society, they might say they're comfortable, and they're used to it. But a lot of times, they're not'. As a Black man with disabilities, Thomas felt like people were afraid of him and other adults with disabilities. He also discussed how the media impacted this positioning of deviance at the intersections of ableism and racism.

Adults with disabilities discussed how disability label or type determined how they were perceived. Caleb shared, 'But if a person has a hidden disability, they don't see that. And they figure they don't count'. In this way, the type of disability determined whether the person mattered. Darius and Atiya described how devaluation resonated from within disability communities too,

> Darius: Well, there's a lot of, people with physical disabilities will often say that 'My mind is fine'. So, in this way that kind of implies if you have an IDD [intellectual/developmental disability], you are not fine.

> Atiya: But I feel like that's fed to you, that's internalised ableism.
> Darius: Yeah. But I'm saying that it's a barrier to us cooperating in a greater disability rights movement when people say things like, 'My mind is fine'.

Participants described how they, as people with intellectual and/or developmental disabilities, experienced ableism from within the broader disability community. This impacted whether people with disabilities could partner across disability labels 'for a greater disability rights movement' as Darius discussed.

5.2.2 | Ideologies inherently impact actions

How people treat people with disabilities was defined as 'Adults with disabilities discuss the problematic treatment of people with disabilities'. Participants described how people with disabilities were 'left out', treated as an 'afterthought', and therefore, 'disenfranchised'. Moreover, adults with disabilities 'are not being put into leadership positions, and that's detrimental to the leadership of our community and the voice of people with disabilities', said Jenny. Instead of leadership roles, adults with disabilities were granted lesser roles even though, as Katherine expressed, 'We run the system. We know the system. We know what needs to get done, and we know what we want. The problem that I see, and I think all of us here at the table see, is that no one will listen...' Examples of being ignored were shared across participants.

Katherine added, 'I think part of the problem is that we are never called to the table for any decision, any major moment, nothing. And I think that needs to change'. Despite their extensive experience in advocacy, the participants did not have a role in discussions and actions. William added, 'Another part of when we're called to the table it's at the end of it'. If they were included, it was after ideas have been presented and decisions had been made. Moreover, as Linda stated, '...unfortunately self-advocates do not have an equal place at the table. We've been fighting for an equal place at the table. But unfortunately, we've been left out...' When adults with disabilities were called to the table, their membership was not equitable. This impacted much needed progress.

5.3 | Generating solutions: Adults with disabilities discuss self-advocacy

Adults with disabilities described numerous solutions related to self-advocacy. Their solutions disrupted the deficit-laden ideological underpinnings they experienced daily. Moreover, their solutions focused on transforming thoughts and acting.

5.3.1 | Self-advocacy and cross-disability activism

Collective action and working together, supporting one another was defined as 'Adults with disabilities discuss how people with disabilities

need to work together and collaborate to cultivate and maintain power'. Participants discussed the criticality of people with disabilities working together and building community. Atiya described why collaboration was important,

> So, there's the new school of thought where that would be us, right? We're more collaborative. We're more of people need to come together. So, I do not feel I do justice, I cannot call myself an advocate if I go in a space and only think of myself. I'm not perfect when it comes to issues for folks who are blind or folks with autism, but I can bring it up. Like, 'Hey, you don't have this person at the table'.

Here, Atiya shared what collaborative self-advocacy looked, felt, and sounded like. Collaborating with and for other people with disabilities was paramount to self-advocacy.

Working together was a solution for William too. He explained, 'The only way I think we're going to solve it is we are going to have to all come together… and fight as a whole team'. The ongoing fighting needed to be shared and held by a team, not by isolated individuals. Thomas explained, 'And I think we need to really focus on how we can bring this community back together as a nation more. Because our numbers are strong when we're together'. Cross-disability advocacy felt stronger and more sustaining to the participants than solitary work.

> Darius elaborated on cross-disability advocacy,
> And while I think that there has been a lot of cross-disability advocacy, I feel as though we still need to have a more cross-disability disability culture as opposed to something that's like you have people with physical disabilities here, deaf people here, blind people there, autistic people there, people with intellectual disabilities here, people with cerebral palsy there, Down syndrome. We need to be able to talk to each other. And if we keep separating ourselves, we are not going to get things done. Because a lot of these policies that are out there affect all of us, regardless of whether we are blind or autistic or have a mobility disability. It affects all of us. But we keep acting as though these things only affect blind people or something.

Advocating as a community across disability identities or categories was a pragmatic solution to the ongoing struggle for equity and justice. According to the participants, advocating together could carry more voices and ideas, and intrinsically be stronger and more successful.

5.3.2 | People with disabilities leading the solution-generating

Another solution focused on people with disabilities leading. *Led and created by people with* disabilities was defined as 'Participants describe

the importance of people with disabilities being the creators, leaders and decision makers'. For example, Nia explained, 'We always need to be at the center'. For policies and practices to be valid and representative, people with disabilities needed to be the focus.

Because adults with disabilities were often left out of leadership positions, including at the local and state government level, another solution orbited on increasing opportunities. Jenny explained, 'Because leadership positions are something that we have not allowed, you have to make space for people to be in leadership positions. And unless that is accounted for, and people are allowed to move into those positions, it's really not going to be [effective]'. As Jenny noted, the lack of leadership impacted the success and sustainability of self-advocacy.

The participants ensured this was not a call for handouts. Caleb explained, 'It's like open up the door, and I will get it myself. And as people with disabilities, we're saying, "Just open the door for us. You don't have to give us anything"'. Participants had been repeatedly excluded from leadership positions and were demanding opportunities. Lucas suggested one way to do this was through listening,

> When it comes to working with people that maybe do not have the same skill level that I may have or other people that I know, I find that when I'm trying to get information about different, what it is to be an advocate for them, the best way that I figured out how to do is to give them the floor. And if you can ask the right questions to give people a chance to speak up that maybe do not have that ability, I think that's the best way to go about doing it.

The participants often experienced being ignored and not listened to. Therefore, listening to people with disabilities was fundamental.

> Sharing personal stories and experiences was important to leading and creating too. Brent explained,
> Well, I just would like to say that everyone in this room has their own personal story. And I think personal stories are huge… Because you have got evidence of what you have been through. You've got a history of what you have been through… And everyone in here needs to share your own personal story… I have learned if they are not listening to you when you were younger, they are not listening to you now. I figure that my voice and other voices help that resistance.

Brent discussed the power of personal testimonies. Listening to their experiences and acting on their solutions was a key ingredient to greater equity and justice for people with disabilities.

In sum, participants described numerous problems with (i.e., deficit-laden ideas and actions) and solutions to (i.e., cross-disability activism, people with disabilities leading and creating) self-advocacy and disability activism. These problems and solutions

directly impacted people with disabilities living their most meaningful and empowered lives.

6 | DISCUSSION

The purpose of this qualitative inquiry was to learn how adults with disabilities conceptualised self-advocacy and advocacy. The team was also interested in learning how policies, processes, and systems impacted self-advocacy at local and national levels. Please refer to Table 2 for a list of the themes and subthemes we shared in our findings.

6.1 | Self-advocacy as self and collective activism

Broadly, adults with disabilities expressed how important it was for self-advocacy to be expansively theorised and pragmatically realised. For example, participants described self-advocacy as speaking up for oneself. This finding aligns with prior scholarship centering individualised self-advocacy (Aspis, 1997). Moreover, they described using self-advocacy to change policy and legislation, something that many may not consider adults with disabilities capable of doing. In addition, self-advocacy transected individualism as adults with disabilities discussed how self-advocacy meant advocating for others. This finding expands prior scholarship as participants considered the cyclical and collective nature (Shweder, 1990) of self and others within self-advocacy.

The findings also highlight how important self-advocacy continues to be for people with disabilities (Walmsley & The Central England People First History Project Team, 2014) more than half a century after the United States self-advocacy movement began. In this study, participants described having to be constantly vigilant or up to date on issues and current events as previously afforded rights and access were always at risk of being minimalised or erased. That said, the participants revealed how ableism persists in complex and nuanced ways (Burch & Sutherland, 2006; Calton, 2017). In sum, people with disabilities must fight daily against systemic and interpersonal barriers despite years of organising, demonstrating, and litigating in the United States and a radical disability studies model is necessary (Withers, 2012).

6.2 | Problematic ideologies and actions

Adults with disabilities described myriad problems they encountered related to self-advocacy. For example, they described how individual, group, and societal perceptions of disability as pathologised and medicalised were multiplicatively oppressive. Specifically, one participant, a Black man with multiple disabilities including intellectual disability, shared how community members considered him dangerous and deviant, causing him to feel unwelcomed and unsafe. Adults with disabilities also discussed devaluation and disregard. As such, student participants revealed how disability continues to be positioned as deficit and less than rather than as a complex social, political and cultural phenomenon and natural part of the human experience (Piepzna-Samarasinha, 2018; Withers, 2012). This finding aligns with prior scholarship as pathologising disability has always been a barrier for people with disabilities (Charlton, 1998) and expands this notion as participants expressed how oppression(s) also exists within and across disability communities, particularly for people with intellectual and/or developmental disabilities as Darius and Atiya described.

Participants also described how ideologies impacted actions. Adults with disabilities described being ignored and left out of decision-making processes. As a result, they were excluded and marginalised (and continue to be). This finding aligns with prior scholarship as adults with disabilities lack opportunities for meaningful employment (Butterworth et al., 2015), preferred housing (Office of Disease Prevention and Health Promotion, 2020), and accessible health care (Williamson et al., 2017). This finding adds to existing scholarship with a specific focus on the firsthand experiences of adults with disabilities grounded in the tenets of radical disability studies (Withers, 2012) and principles of disability justice (Sins Invalid, 2019).

6.3 | Promising solutions

Adults with disabilities described multiple solutions for eradicating inequities and exclusions. For example, they discussed the importance of collective action and working together. They noted a strength and resilience in collective advocacy. This cross-movement and cross-disability solidarity has been detailed by disability justice scholars (e.g., Hamraie, 2017; Wong, 2020). As such, these findings expand prior scholarship to consider the interdependence of self-advocacy as it relates to cross-disability activism.

Participants described the cruciality of people with disabilities leading change and creating solutions. Adults with disabilities discussed the need for increased leadership opportunities and the importance of being listened to. They also discussed the power of personal testimonies. This finding supports prior literature focused on the experiences of people with disabilities (Dybwad & Bersani, 1996; McCarthy, 2003). It expands this scholarship with a specific focus on leading, creating and solution-generating controlled by people with disabilities. Next, we discuss implications for thought, policy and research.

6.4 | Implications and limitations

Considering thought, one implication centers on disability devaluation and the subsequent oppression that is (re)produced through epistemic injustice (Fricker, 2007). Epistemic injustice–how marginalised groups are 'systematically excluded from shaping social meanings and generating knowledge' (Taylor, 2018, p. 4)—impacts people with disabilities. In this study, participants discussed how their social positioning

marginalised their opportunities to participate in actual knowledge-making practices, including practices that informed institutions and services as well as policies. However, people with disabilities, and particularly people with intellectual disability, must be considered epistemic agents (Taylor & McDonough, 2021)—knowledge producers and generators. Said differently, equity and justice cannot be actualised without the epistemic agency of people with intellectual disability being truly realised.

Considering policy, one implication stresses the importance of including people with disabilities in local and national policy initiatives guided by the tenets of radical disability studies (Withers, 2012) and principles of disability justice (Invalid, 2019). As the participants discussed, adults with disabilities are often not considered in theorising, designing, and evaluating policies until after the fact, if at all. Moreover, when they are included, they are not considered equals. While the United States has yet to ratify the United Nations Convention on the Rights of Persons with Disabilities (2006), the policy itself contains explicit global principles and aspirations for including people with disabilities in policy initiatives. Moreover, this guidance is grounded in the social model of disability as opposed to the deficit-laden medical model, and therefore aligns more closely with our blended framing. Including people with disabilities in policymaking as collaborative partners with epistemic agency throughout the process would ensure future policies focus on their concerns within their lived contexts (Schalock et al., 2020), remain 'in tune with the complex and radical meaning-making' (Goodley, 2005, p. 342) of modern-day self-advocacy movements, and dismantle systemic and interpersonal inequities and injustices.

The project limitations directly link to future research. The first limitation orbits on methodology. While this project held participatory elements in the analysis (Liddiard et al., 2019), much of the project was not driven by adults with disabilities. More participatory research controlled by adults with disabilities, including adults who experience intersecting oppressions, and have intellectual disability and/or diverse and complex support needs, is needed from theorisation to dissemination (Seale et al., 2015). This would ensure future scholarship was focused on the concerns of people with disabilities, grounded in their stories and lived experiences, and accessible (Kulkarni et al., 2020-2021; Miller et al., 2021). Furthermore, research led by adults with disabilities will lead to more expansive enactments of participatory scholarship broadly.

The second limitation focuses on data collection sources and types. Considering sources, all participants were connected to a national self-advocacy organisation. Yet, adults with disabilities without such networks should be included in future self-advocacy research. This would provide a more nuanced view of what self-advocacy means across adulthood. In addition, two iteratively designed focus groups were primary data sources. In general, future research ought to include interviews in combination with focus groups as well as visual (e.g., Kaley et al., 2019; Kim et al., 2021) and performance art (e.g., Cook, 2020) methods. Pairing qualitative and visual methods can reconfigure the researcher-participant power dynamic and provide participants with the opportunity to lead the narrative, telling their story in the way they want it conveyed (Leavy, 2009).

7 | CONCLUSION

Self-advocacy is an important part of life for many adults with disabilities, across disability label or type, because inequitable systems and processes have real economic, material, political, and social consequences for people with disabilities. Moreover, these inequities exist across individual, group and societal levels. Therefore, the purpose of this qualitative study was to learn how adults with disabilities conceptualised self-advocacy as well as how policies, processes, and systems impacted self-advocacy at local and national levels. Grounded in the experiences and perspectives of 12 adults with disabilities, the findings revealed how advocating for oneself, and others is imperative to self-advocacy as is collaborative, cross-disability activism. Participants also discussed multiple problems (e.g., deficit-laden ideologies and actions related to disability) as well as myriad solutions (e.g., people with disabilities leading and generating the change and listening to the lived experiences of people with disabilities) related to self-advocacy for people with disabilities. In summary, we hope this project illuminates the importance of centering the voices and experiences of adults with disabilities in future research and policy.

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