Why Not the “New Flexible”? The Argument for Not Returning to “Normal” After COVID-19

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Keywords: COVID-19, disability, accessibility, inclusion, health equity

<https://doi.org/10.52017/001c.28332>

Rehabilitation Counselors and Educators Journal

Vol. 11, Issue 1, 2022

The COVID-19 pandemic has had a disparate impact across demographic groups, resulting in BIPOC and disabled people experiencing transmission, hospitalization, and death at higher rates than White and non-disabled populations. However, responses within the pandemic created new avenues for access to people with disabilities, including telehealth, work from home opportunities, and virtual participation, which were the very solutions and accommodations they have been requesting, but denied, for years. The call for a “return to normal” is steeped in ableist thinking. Society was made aware of the inequities for disabled people throughout the pandemic, and flexible solutions must be retained and refined to continue the access provided during this time. As a start to a discourse on reflection and action, the authors suggest four areas to target for change toward health equity: (a) messaging and communication, (b) accessibility, (c) addressing attitudinal barriers, and (d) seeking and using the input of disabled people. The following presents an overview of each factor and action steps, with resources to guide them.

Author note: Although APA style conventions and professional discourse support the use of person-first language in academic writing about disability, both person-first and identity-first language was used throughout this paper. One of the authors identifies as disabled, and we chose to use both out of respect for the disabled community about whom we speak.

Johnston, 2020). However, people with disabilities are not new to the arena of health disparities. Krahn and colleagues (2015) analyzed population-level differences in health outcomes for people with significant disabilities (12% of the U.S. population), and surmised the disparities were related to a history of avoidable disadvantages not primarily caused by the underlying disability. Disabled people know all too well that granting entry to services or care does not guarantee it will be accessible or equitable.

In the aftermath of Hurricane Katrina in 2005, federal agencies like the CDC and the Federal Emergency Management Agency (FEMA) recognized people with disabilities were not considered intentionally in their plans for disaster preparedness and emergency services. In recent years, FEMA has highlighted to local governments the importance of including people with disabilities in the planning, integration, and implementation of emergency response programs, though consistent guidelines for this are lacking (Sabatello et al., 2020). Such responses, however, are typically envisaged for time-limited situations, like hurricanes, flooding, and tornadoes. In these events, the acute crisis may last up to several days, though much of the recovery efforts continue past the turmoil and danger of the storm. The COVID-19 pandemic has created scenarios not considered in these plans. The recommended “personal support network” model to address the needs of people with disabilities

Introduction

At the time of this writing, the COVID-19 pandemic has claimed the lives of over 650,000 U.S. citizens (Centers for Disease Control and Prevention (CDC), 2021), though the impact has been disparate across demographic groups in the early and later waves of the pandemic. Poverty, resource scarcity, and living in carceral systems resulted in BIPOC and disabled people experiencing transmission, hospitalization, and death at higher rates than White and non-disabled populations (Nerlich et al., 2021; Purlang, 2021). The pandemic presented acute bioethical conundrums in intensive care units of hospitals, which further endangered and minimized the lives of disabled and BIPOC populations, and hasty decisions to move educational and work settings to remote spaces further widened the access gap (Nerlich &

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during crises and disasters is not sustainable or actionable in many cases (Sabatello et al., 2020). Stay-at-home and social distancing orders limit contact with family members, service providers, and personal care attendants.

As the pandemic wages on, the situation has worsened for the disability community, affecting everything from the routine to life-saving treatment. Throughout the pandemic, people who typically used food and grocery delivery services pre-pandemic found themselves in weeks-long queues for an appointment. Information about public health precautions and available programs was not always transmitted in formats that people with disabilities could receive or comprehend. Most contact with the outside world—employment, education, health care, counseling, recovery meetings—was transitioned to remote or virtual options. While this increased opportunities for care, technology and access to broadband internet service was not universally available. Even with technology, limitations imposed by disability often created a digital literacy divide (Piven et al., 2020). Given the overrepresentation of people with disabilities in lower-wage, hourly work, many found themselves either laid off with little support or deemed an “essential worker”, creating a paradox of priorities: choose between economic survival or personal health. The treatment of people with disabilities in acute healthcare environments—or worse, the withholding of treatment—was reflective of the devaluation of the quality of a disabled life (Kendall et al., 2020; Mello et al., 2020). When vaccines became available to protect against the virus, the criteria for priority distribution and the location of administration sites were not universally designed with disabled people in mind, and many younger disabled people were not prioritized to receive the vaccine early, despite living with health conditions that make them more vulnerable to severe cases of COVID-19.

In some ways, disabled people were primed for the restrictions and isolation posed by the pandemic through their personal experiences with lack of inclusion. Therefore, it is not surprising they were often better equipped to cope with the uncertainties because of history with overcoming inaccessibility, ableism, inadequate health care, and social disadvantages (Purlang, 2021). The irony of the pandemic is that adjustments framed in society’s response to it, such as telehealth, work from home opportunities, and virtual participation, were the very solutions and accommodations disabled people have been requesting, but denied, for years. The pandemic created conditions of urgency that brought to life flexible choices, virtual services, and information sharing no longer encumbered by bureaucracy or limited thinking. Because *everyone* needed these changes, the historical “hard no’s” quickly turned into “we could make that happen,” a sentiment disabled people have been waiting to hear most of their lives.

The reality of the COVID-19 pandemic is that it magnified systemic inequities for marginalized communities, including BIPOC, the elderly, those living in poverty and/or in congregate settings, and people with disabilities (Gray et al., 2020), though these identities are not mutually exclusive. It is not a social condition we can now “unsee.” Society needs to respond with a conscientious examination of our current and future structures through an anti-ableist lens to

enhance access for people with disabilities, while considering their intersectional needs. This includes policymakers, public health officials, counseling and human service professionals, and ordinary citizens. The lasting effect of our response to the pandemic should be an evolution of lessons learned: what was broken, and what was fixed; what barriers were removed, and what added to hardship; and what should be integrated into an inclusive and accessible solution. This confluence creates conditions for substantial and sustainable equity for people with disabilities; however, it requires not a return to normal, but a harnessing of momentum and embracing of flexibility.

Creating the “New Flexible”

The U.S. is now a year and a half removed from the initial surge of the pandemic; though far from over, media headlines, political discourse, and casual conversations all echo a sentiment of a return to “normal.” However, a return to pre-pandemic ways of life presents risks to people with disabilities, from relaxing safety precautions that protect the immunocompromised to recalling employees from their remote workspaces to returning to inaccessible, in-person events. Disabled activists are sounding the alarm on the dangers of returning to the pre-pandemic status quo (Ruiz-Grossman, 2021). The ideals of normal, such as health, access, and inclusion, were a privilege belonging to those with resources and without disability. Lack of considerations for people with disabilities are rooted in ableism—prejudice and discrimination towards disabled people based on the belief that typical abilities are superior (Ravishankar, 2020). Examples of ableism are deeply ingrained within the language, physical structures, attitudes, and policies of society (Maria R. Palacios’ (2017) poem “Naming Ableism” provides nuanced, first-person examples of everyday experiences for those unfamiliar with its manifestations). The pandemic brought different experiences of ableism: healthcare systems prioritized treatment; people became resistant to lockdowns and masks, at the expense of vulnerable citizens, for fear of slowing the economy; and symptomatic COVID patients were transferred to nursing homes to receive care, spurring outbreaks among institutional residents (Purlang, 2021). These experiences moved ableism from being insidious to highly evident:

After Covid, it’s much harder for us to hold to the comforting illusion that ableism is mostly unintentional and benign. Sometimes, in specific everyday encounters ableism truly is harmless, or merely annoying. But the last year has vividly reminded us that ableism can be harmful – and in a crisis, even deadly. (Purlang, 2021, para. 23)

The pandemic and society’s response to it set in motion two circumstances: (1) systemic inequities for marginalized populations that could no longer be ignored, and (2) adaptations and accommodations allowed for *all people* changed how disabled people experienced the world. This is not to suggest that all solutions during the pandemic created equity for people with disabilities. Remote learning, complex websites to schedule vaccine appointments, and rapidly changing public health information were difficult for many

people with disabilities to navigate, both from a comprehension and accessibility standpoint. But many other barriers were removed, such as the requirement of physical presence for attending appointments, working, and applying for services. Whether these solutions and adaptations represented the removal of a longstanding barrier or the creation of a new one, the pendulum has been set in motion.

Newton’s cradle is a good representation of the current situation. For the unfamiliar, Newton’s cradle is the contraption of metal spheres suspended by threads between two parallel horizontal bars, often found on the desks or bookshelves in executives’ offices. Its operation demonstrates principles of energy, momentum, and elasticity. The purpose here is not to assert any expertise in physics (the depiction of these aspects is meant only to emphasize the point), but one of the factors in play when a person sets the balls on the cradle in motion is elasticity. Elasticity is the ability of an object to deform (change shape) and return to its original shape without losing energy (Schulz, 2021). Though not perceptible, the metal ball changes shape as the energy is transferred. It demonstrates flexibility and moves forward. Similarly, society changed and adapted to continue to move during the pandemic. The law of conservation of energy states that energy cannot be created or destroyed; it transfers and changes forms (Schulz, 2021). In essence, the pendulum (society’s ability to adapt and accommodate) was set in motion, providing energy and momentum for change. This shift allowed individuals and systems to recognize the potential value of including people with disabilities, and how not including their voices or anticipating their needs was detrimental to society. The goal now is to harness what we have learned, so it cannot be destroyed.

Despite the prevalence of the privileged ideal of “returning to normal,” this is not needed or desired; rather, a new-found flexibility and a push for real change in society, as well as our systems and professions, should be the preferred outcome. Professionals should be at the forefront of resisting a return to normal, as it has “not worked in the past, has proven harmful, and will not be any better in the future” (Schormans et al., 2021, p. 88). Going back to normal means we accept the structural inequalities and inequities the pandemic revealed. Coordinated and expedited efforts to change systems are rarely seen, though it was possible during the pandemic, opening up opportunities to accommodate their long-term adoption for a continuum of services (Kendall et al., 2020). This can build capacity to serve people with disabilities more broadly and withstand future crises.

Responding to the Social Determinants of Health

The social determinants of health (SDOH) can be viewed as a focal point for addressing inequity for people with disabilities. SDOH are “conditions in the environments where people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (Centers for Disease Control and Prevention, n.d., para. 1). Modifiable factors within society that can reduce disparities and improve quality of life for people with disabilities include: (a) economic stability, such as income, employment, and removal of debt; (b) education,

such as literacy, higher education, and vocational training; (c) neighborhood and built environment, such as housing and transportation; (d) food, such as hunger and access to healthy food; (e) community and social context, such as support systems, community engagement, and discrimination; and (f) health care, such as health coverage and provider cultural competency (Peters, 2021). These factors speak to the targets for addressing disparities, both longstanding and those created by the pandemic; though, they do not represent tangible actions. As a start to the discourse on reflection and action, the authors suggest four areas to target for change: (a) messaging and communication, (b) accessibility, (c) addressing attitudinal barriers, and (d) seeking and using the input of disabled people. These do not represent novel concepts, as they have been the targets of advocacy for the disability community and of professional service within rehabilitation counseling for a century. However, an awakening to the needs of disabled people magnified by the pandemic provides a tipping point to begin dialogue about tangible interprofessional and systemic solutions. The following presents an overview of each factor and action steps, with resources to guide them.

Messaging and Communication

Bedrock guidelines for effective health communication include knowing and resonating with the correct audience, providing the right information, and assuring information is easy to understand (Agency for Toxic Substances and Disease Registry, 2018). However, communication about prevention and care may not reach people with disabilities because the delivery is not accessible or its dissemination depends upon community organizations and providers who themselves lack resources (Kendall et al., 2020). The following guidelines and suggestions should be considered when designing and implementing communication strategies for diverse populations. First, targeted messaging about community resources and services is key to effective communication. For example, messaging that is effective in a predominantly White suburb may be ineffective, and perhaps offensive, for individuals living in a more diverse urban setting. One size does not fit all in communication strategies. Second, messaging that comes from community members is more salient than messaging from outside experts. It is important to know who the respected leaders or “champions” in the community are and to collaborate with them. Third, often health communication focuses on individual change (e.g., behavioral change) rather than systems or structural change. To affect lasting change, messaging should include information about how to make change at both the individual and systems levels. And, fourth, messaging that incorporates societal or community values, including personal narratives, may be more effective than messaging that includes only fact-based information (Institute of Medicine, 2015).

As such, health information is interpreted as more relevant if it is tailored to a given audience (Kreuter & Wray, 2003). From the perspective of accessibility, this should include considering the literacy level of the target audience, designing information in multiple formats (e.g., Spanish, Braille, pictorial), and disseminating through accessible

means (e.g., closed captioning, ASL interpretation, alternative text on pictures). Communication cannot be heavily reliant on one mode of delivery, such as cable news or social media, as individuals may not have access to these media. From a more practical standpoint, tailoring the message includes considerations of representation. This should include pictures of people with disabilities, but often this can be limited to only include visible, physical disability. Another way to address representation is to include accessibility information beyond physical access, such as information on accommodations that would benefit people who are Deaf, blind, and neurodivergent.

Suggestion Action Steps

- Information should be accessible and presented in plain language. The University Centers for Excellence in Developmental Disabilities (University Centers for Excellence in Developmental Disabilities, n.d.) provides a set of tips, tools, and resources related to plain language messaging. The Centers for Disease Control and Prevention (n.d.) also recently released a page on “COVID-19 Materials for People with Intellectual and Developmental Disabilities and Care Providers” to overcome some of the challenges to communicating complex pandemic information to this community. All information, in both English and Spanish, is provided in the format of a social story, poster, interactive social story, and video. These forms of media can be duplicated for other health messaging and social communication campaigns targeting the disability community.
- Health information, especially during disaster crises and the pandemic, can change rapidly. To reach a larger audience of disabled people with up-to-date information, advocacy organizations at the state and local levels should coordinate efforts to develop, disseminate, and evaluate the impact of communication materials for the disability community (Boyle et al., 2020).
- With digital communication as a primary medium of disseminating health information to the population, content developers should strive for inclusive and accessible practices. Alex Chen (n.d.), a product designer with expertise in accessibility and usability, created a friendly introduction to digital accessibility based on WCAG 2.1 (Web Content Accessibility Guidelines). Rooted in Rights (n.d.), based in Seattle, is a team of disabled video producers, editors, and digital organizers. They have a goal of sharing authentic accessible stories, creating accessible content, and fighting for change for the disability community by providing a web-based primer for digital accessibility. Both of these creators have actionable resources to increase digital accessibility.
- Language used in messaging should be considered carefully. Say the word *disability* or *disabled*. Avoid euphemisms such as differently-abled, disABLED, physically challenged, dis/abled, handicapable, or special needs. These terms, and others, can be invalidating, disempowering, and offensive. Ladau (n.d.) wrote a

blog for The Center for Disability Rights addressing disability euphemisms. The National Center on Disability and Journalism (2021) provided updates to their “Disability Style Guide” to offer guidance to journalists and other communicators covering disability issues.

Accessibility

To keep the pendulum swinging, the limitations of framing accessibility as compliance must be acknowledged. The Americans with Disabilities Act (ADA) and its 2008 amendments (ADAAA, Georgetown Law Library, n.d.), were intended to prohibit discrimination in the public sector, including medical services, employment, transportation, schools, communications, governmental activities, and privately-owned places open to the public (Evans et al., 2017). The specific guidelines and compliance mindset of disability is a by-product of the medical model of disability, which situates disability within the individual and views them as the root of the problem to be cured, treated, or normalized (Shakespeare, 2016). Due to lack of enforcement of the ADA, people can decide to not comply with the law until a complaint is filed, preventing widespread change. This sends the message that people with disabilities are *less than*, and not as valuable as people without disabilities. Mere compliance does not promise equity and accessibility for all: “The current state of the law allows for separate but equal, but usually results in simply unequal” (Wentz et al., 2011, para. 55). This separation brings the country a long way from the promise of the ADA and reveals that, in fact, disability law can often be placed directly in the way of a just world for people with disabilities (Dolmage, 2017).

In addition, the ADA does not offer flexibility. For example, there are several guidelines for accessible bathrooms within the ADA; though, those guidelines often benefit people with physical disabilities (e.g., wheelchair users). However, what is considered accessible for a wheelchair user may be inaccessible for a little person or a blind person, creating an inequitable, discriminatory environment inconsistent with the very purpose of the ADA (Saia, 2019). Society must move beyond approaching accessibility as the bare minimum, the completion of a checklist, or a retroactive approach to removing barriers. The goal must be equity and a shift toward universal design (UD) as the ideal solution. Developed by Ronald Mace (1985), the seven principles of UD include: (1) equitable use, (2) flexibility in use, (3) simple and intuitive use, (4) perceptible information, (5) tolerance for error, (6) low physical effort, and (7) size and space for approach and use. Universal design seeks to bring the benefits of more usable, flexible, healthier, welcoming settings to everyone, and can also improve mental wellness and quality of life (Eisenberg & Maisel, 2021). This progressive approach goes beyond tailoring the environment to marginal groups; it is a form of hope, and a manner of trying (Dolmage, 2017).

People might struggle to find positives in a global pandemic, but for most disabled people the silver lining is increased access. Advocates can only hope this taste of disabled life is “a learning experience for everyone that will carry over into the post-pandemic world. Maybe it will fi-

nally add some urgency to the decades-long push to make life more accessible and sustainable for disabled people” (Purlang, 2021, para. 26). Post-pandemic, it is vital to continue to meet people where they are at, prioritize flexible options, and challenge practices that intentionally or unintentionally exclude disabled people.

Suggested Action Steps

- In a universally-designed society, disability would be eliminated (Preiser & Ostroff, 2001). Policymakers and administrators should commit to assessing and implementing the principles of universal design in work, healthcare, education, and community settings. Academics should use the principles of universal design to create all aspects of their courses proactively, to reduce or eliminate the need for an individualized accommodation, creating a more inclusive learning environment (Dolmage, 2017).
- Sins Invalid (2019) provides a comprehensive list of access suggestions for public events and mobilizations when including disabled people in spaces and conversations. The information available in their primer should be used as a template for accessibility.
- The National Center on Health, Physical Activity and Disability (n.d.) has compiled information and interactive tools into their “Inclusive Community Health Implementation Package” (iCHIP), to help community health practitioners, organizations, and coalitions enhance inclusion of people with disabilities. Guidance is provided on leadership, communication, policy, programming, planning, assessment, and training. These should be used to guide the assessment of existing structures and practices, and the adoption of more inclusive community health practices.

Addressing Attitudinal Barriers

Attitudinal barriers for disabled people are often heightened across healthcare settings with little knowledge, awareness, or training related to disability. Disabled people often fear disclosing their experiences to medical professionals out of fear of mistreatment or not being believed (Schormans et al., 2021). Disability can often be seen as a failure of healthcare systems to fix or prevent disabling conditions; viewing it as a mistake or failure feeds negative perceptions of disability and its effect on quality of life (Gaventa et al., 2021). COVID-19 exacerbated the ableist practices that continue to devalue the lives of disabled people and repeatedly called into question the quality of life for people with disabilities in healthcare settings (Nerlich et al., 2021).

At the start of the pandemic, Alabama explicitly recommended that patients with intellectual and developmental disabilities be viewed as ineligible for ventilators (Fink, 2020). To further illustrate ableism in health care, Michael Hickson, a 46-year-old Black man living with quadriplegia, contracted COVID-19 and lost his life because he was denied lifesaving treatment. According to his wife, doctors at St. David’s South Austin Medical Center in Texas decided, based on their biases toward his disability and race, that

he had a lower quality of life. ADAPT of Texas, a disability rights group in Austin, and the National Council on Independent Living filed complaints to ask the Office for Civil Rights to open an investigation into Hickson’s death (Shapiro, 2020). Activist Imani Barbarin (2021) stated this about attitudes toward disabled people amid the pandemic: “None of what we have experienced during this pandemic is surprising. Why would Americans change their behavior to save the disabled and elderly if we’re presented as disposable to begin with?” (para. 21). Responses to COVID-19 have triggered strenuous advocacy by disabled groups and opinion leaders with disabilities around the world, highlighting issues of equitable worth, the disposability of people with disabilities, and the stereotypical assumptions faced by the disability community (Kendall et al., 2020).

Sources of Bias

When operating under the medical model, bias is inherent in health care. Haque & Stein (2020) highlighted four biases prevalent in clinical decisions regarding people with disabilities: (a) *ineffectual bias*, where people with disabilities are seen as having lower agency and competence, leading to greater paternalism; (b) *fragility bias*, where people with disabilities are perceived as suffering more and experiencing more severe symptoms, and care should be withdrawn earlier; (c) *friendliness bias*: where people with disabilities are seen as possessing greater warmth and trustworthiness, leading to the presumption they would want to give up their own life to save others when resources are scarce; and (d) *catastrophe bias*: where clinicians project more catastrophe on those with disabilities resulting in less perceived quality of life, leading to lesser tendency to initiate treatment and greater tendency to withdraw it. Reform in crisis policymaking in health care should be led in partnership with public health officials and disability advocacy organizations to incorporate the perspectives of people with disabilities. Beyond that, healthcare systems and providers need to integrate professional training on appropriate, disability-competent care, to address not only structural and economic barriers to care, but communication and provider attitudes that affect the quality of care on a daily basis (Peters, 2021). The American Rehabilitation Counseling Association (ARCA) guidelines for disability-related competencies for counselors (Chapin et al., 2018) can be used as a starting point in this effort.

Suggested Action Steps

- Health equity is a nuanced topic, but there is danger in rooting solutions in the medical model. Bioethical decisions and allocation of resources during crises are linked to perceptions of quality of life, which often rely on actuarial models within healthcare systems (Nerlich et al., 2021). Discourse on this topic should be informed and led by disabled people (see Scully, 2008, 2020; Stramondo, 2016, 2021). Professor Scully’s (n.d.) faculty page highlights other works on the issue.
- Ethical medical decision-making is driven several principles: (a) *efficiency* to maximize benefits; (b) *utility* to promote the greatest benefit; (c) *fairness*, re-

ardless of personal characteristics; (d) *priority*, or serving those with the greatest need; and (e) *liberty*, or imposing the least amount of harm (Kendall et al., 2020). During times of disaster or crisis—when the goal of health care shifts from saving individuals to saving as many lives as possible—these values can be interpreted subjectively, inadvertently leading to inequity. The burden should not fall on the individual clinician to weigh decisions about providing or withholding care; crisis care protocols should be established with an eye toward protecting disadvantaged groups from discrimination and lower standards of care.

- Mello and colleagues (2020) provided six recommendations for policy development to respect disability and improve crisis standards of care: (1) eliminate categorical exclusions based on disability or diagnosis; (2) do not use perceived quality of life; (3) use hospital survival and near-term/immediate survival rather than long-term life expectancy to base decisions; (4) patients who present with personal ventilators should not have them reallocated to other patients; (5) designate triage officers trained in disability rights and decision-making to objectively assess patients individually; and (6) include disability rights advocates in policy development and dissemination. These should be considered guideposts for a national assessment of healthcare crisis response protocols.
- Haque and Stein (2020) asserted “disparities arise from how we see one another and the degree to which we see dignity in one another as fully and equally human and as bearers of human rights” (p. 288). They argue for a shift in viewing the healthcare needs of disabled people from a lens of dignity, equality, and disability-based human rights, rather than a lens of bias and burden. This requires medical professionals to challenge ideas, ask questions, and change practices fueled by ableist thinking, misconceptions, and stereotypes. Training should be developed for healthcare and service providers around topics of disability to avoid stereotypical decisions that deny dignity and equity, either under the pressure of a crisis or for the routine provision of care. The “Including People with Disabilities: Public Health Workforce Competencies” from Disability in Public Health (n.d.) can be used as a model for training development. Shakespeare (2018), Nario-Redmond (2020), and Ladau (2021) are all strong general resources for a starting point to understanding disability, ableism, and societal structures that support it.

Seeking and Using the Input of Disabled People

The most important stakeholder group and voice in a revision of equity and accessibility is the disability community. The Disability Rights Movement was a response to policymakers enacting laws without the input of disabled voices, and professionals championing disability causes rather than playing a supporting role. More recently, the Disability Justice Movement has emerged to counteract pri-

oritizing the most privileged of the disability community, working to center the voices of BIPOC and LGBTQ+ disabled people (Sins Invalid, 2019). Disabled people have spent decades advocating for access to health care, options, and medical professionals with a progressive understanding of disability. In 2017, hundreds of disabled people gathered in Washington D.C. to protest cuts to Medicaid that would have been detrimental to the community (ADAPT, 2017).

The leadership of disabled people in advocacy for inclusion and accessibility is vital, but should not be relegated to an exclusionary activity when partnership can be beneficial and supportive. Autistic activist Erin Ekins (2020) shared, “Disabled people often have no choice but to become advocates and activists in order to survive and get what they need, and that is not sustainable.” The disability community can benefit from the social and political capital professional advocates can provide in support of their agenda. Advocacy is an important and valued activity, both professionally and personally. Following the pandemic, the focus of advocacy should be to reduce the burden placed on disabled people, expand reach to include broader stakeholders, and work towards systematic change. This aligns with the American Counseling Association (ACA) Advocacy Competencies, which call for advocacy on *behalf* of clients and advocacy in client *partnership* within individual, community, and public arenas (Toporek & Daniels, 2018).

To remain consistent with the mantra *nothing about us without us*, the voices and experiences of disabled people should be prioritized. This includes all disabled people, rather than one group, to dismantle the hierarchy that often surrounds the disability community. Sins Invalid (2019) provided guidance on committing to and achieving mixed ability organizing. It is important to recognize that lifting disabled voices is only possible through listening, learning, examining, and seeking feedback, without policing or invalidating the disability experience. Representation of disabled people in research and on task forces should not be token, and their input should be acted upon. Authentic representation would be the inclusion of disability rights advocates in policy development and dissemination, including emergency response plans, revisions to community-based services, protocols on prioritization of lifesaving medical treatments, and guidance on the provision of remote education and health care (Piven et al., 2020). *Nothing about us without us* suggests “a sea of change in the way disability oppression is conceived and resisted” (Charlton, 1998, p. 17). Ladau (2021) described its meaning clearly:

Many in the disability community use the slogan *Nothing about us without us* as a bold reminder of the fact that we’re the ones who must be in charge of every aspect of our lives. All too often, people with disabilities are relegated to the sidelines in conversations about issues that directly affect us—everything from individual circumstances to major policy decisions...as always, disabled people are the experts on our own lives. So please, don’t speak for us, about us, or over us. Speak to us and with us. (p. 143-144)

Suggested Action Steps

- The National Council on Independent Living (2021) recently published an accessible toolkit for passing the “Real Emergency Access for Aging and Disability Inclusion (REAAID) for Disasters Act” and the “Disaster Relief Medicaid Act (DRMA).” Passage of both will ensure disabled leadership is sought, included, and amplified in disaster preparation. Professional and community advocacy should be directed toward bringing these pieces of legislation into existence.
- In crafting policy and changing systems to address the needs of the disability community, both trauma-informed (Bowen & Murshid, 2016; Carter & Blanch, 2019) and intersectionality (Hankivsky et al., 2014) frameworks should be used to capture their complex and dynamic needs. Disability rights and disability justice are necessary frameworks for considering crisis standards of care (Guidry-Grimes et al., 2020).
- Academic and community researchers should employ collaborative methods (e.g., participatory action research, focus groups; Patton, 2014) and creative techniques (e.g., Photovoice; Budig et al., 2018) to enable participation of and accessibility for disabled people to lend their voices.
- Stakeholder engagement, including but not limited to policymakers, businesses, professional organizations, community members, and advocacy organizations, can elevate systemic change, as long as the process is relative to the wants, needs, and impact of involved parties (Heiden & Saia, 2020). Engaging with the disability community requires allyship. As Ladau (2021) stated, “I believe acknowledging the process of allyship, and not the end result, is a helpful way to empower it” (p.143). Seek out and learn from the voices of disabled people. Ladau (2021), Wong (2020), and Sins Invalid (2019) all elevate the experiences of disabled people, and provide resources, websites, and social media links to follow others.

Conclusion

The discourse presented here is meant to serve as an entry point for post-pandemic dialogue and action toward inclusion and accessibility for people with disabilities. Messaging and communication, accessibility, addressing attitudinal barriers, and seeking and using the input of disabled people are practical and tangible targets for change. Our suggestions align with Krahn and colleagues (2015) who suggested improved access to healthcare and human services, increased data to support decision-making, strengthened health and human services workforce capacity, explicit inclusion of disability in public health programs, and increased emergency preparedness as the cornerstones of research and policy directions to address health inequities. While the focus here is mostly on public health and healthcare arenas, this can be adopted to other causes and practices, like VR service delivery, campaigns and voting rights, and P-12 education.

The hope is the ideas and resources shared here will be parlayed into projects, partnerships, and guidance toward maintaining and improving solutions created during the pandemic. “Returning to normal” is an ableist sentiment professionals should actively resist. The pendulum has swung, but we need to make sure it never becomes still; instead of a return to normal, we need drive for perpetual motion and flexibility. Schormans and colleagues (2021) captured this best:

We have also heard the talk and wondered as to whether the pandemic might be a watershed moment, an awakening and a reckoning. The idea that by having disrupted so-called ‘normal’ ways of being and doing – more specifically, disrupting what many with privilege understand to be ‘normal’ – the pandemic offers an opportunity to work towards ‘real’ change, to address the inequities that have become so visible and, we hope, harder to ignore. (p. 84)

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