After the Deluge: Leveraging Lessons from the COVID-19 Pandemic to Build the Trust of North Carolina's Disability Community

Virginia Knowlton Marcus

North Carolina's disability services infrastructure is biased toward institutional care, with inadequate funding and supply of home- and community-based services. The COVID-19 pandemic revealed dangers with this imbalance and provided the roadmap and motivation to fix it.

Introduction

The COVID-19 pandemic was devastating for people with disabilities. But it brought a groundbreaking opportunity: it allowed people across North Carolina to see first-hand the systemic problems that disabled people have protested for years. North Carolina's overreliance on institutional long-term care allowed the virus to spread like wildfire among people with disabilities and older adults residing in facilities. The state's underinvestment in home- and community-based services (HCBS), easily overlooked by non-disabled people but crucial to the success of the whole system, turned deadly.

At the heart of North Carolina's lack of a robust community service network is institutional bias. It permeates all aspects of North Carolina's health system and erodes trust. It is based on a lack of commitment to the basic notion that all people are equally valuable and that every human has the right to experience life how they see fit, in whatever setting they choose.

Trust depends on respecting and valuing each person's choices, including the fundamental choice to live, work, and play in the setting of one's choosing. To those unfamiliar with the realities of the disability community, it may seem strange to learn that many people with disabilities are not able to make such a basic choice for themselves. Too much of North Carolina's health system is built on the outdated presumption that people with disabilities would be better off, safer, and happier living in an institution rather than supported with HCBS in the community—that is, on institutional bias. While facility-based care has a role in some instances, the lack of real choice and sorely insufficient HCBS infrastructure perpetuate fear and distrust among disabled people, whose lives are diminished by these inadequacies.

History of Failures Leading to Distrust

When it comes to health care, North Carolina's disability community is rightfully distrustful. We have endured generations of mistreatment, abuse, neglect, forced treatment, discrimination, stigmatization, and isolation at the hands of health professionals. Even today, studies show that many medical professionals lack training in accommodating patients with disabilities and even shy away from treating folks with certain types of disability [1, 2]; for example, few medical offices have scales equipped to weigh individuals who use wheelchairs or adjustable exam tables, and few offer communication access, such as American Sign Language (ASL) interpreters. Many decline to treat people with substance use disabilities, and life-saving procedures are often reserved or prioritized for those without disabilities [3, 4]. Despite huge leaps in health care, distrust persists in large part due to skepticism of health professionals' attitudes about the quality and value of our lives, and their tendency to claim to know better about what we can and should do.

For decades, people with disabilities and their families in North Carolina have sought out adequate HCBS to remain healthy, happy, and safe in the community. Direct-support workers make up the engine that drives these services. Nevertheless, facilities offering institutional care routinely enjoy the lion's share of attention, support, and funding.

North Carolina advocates have been shouting from rooftops for years about the urgent need to strengthen the HCBS system, but nothing made the case quite like the COVID-19 pandemic. When the virus was at its peak, people tried to avoid congregate care settings for some of the reasons many people with disabilities historically have chosen to avoid them—concerns about conditions, heightened risk of disease transmission in close settings, increased abuse and neglect due to low staffing, and isolation from family

Electronically published May 1, 2023.

Address correspondence to Virginia Knowlton Marcus, Disability Rights North Carolina, 3724 National Dr, Suite 100, Raleigh, NC 27612 (virginia.knowltonmarcus@disabilityrightsnc.org).

N C Med J. 2023;84(3):169-171. 0029-2559/2023/84311

and loved ones. It is no wonder people sought safe community options during the pandemic; according to the National Council on Disabilities, during the first year of the pandemic, 35,000 nursing-home residents died of COVID-19, representing 42% of the total deaths in the nation [5]. And all congregate living facilities, not just nursing homes, struggled with low staffing, leading to tragic stories of abuse and neglect.

Many people in North Carolina saw for themselves during the pandemic that institutionalization did not offer the safety they were promised for themselves or their loved ones, and that the alternative of relying on HCBS was not a true option due to decades of underinvestment in community-based services. Many people without disabilities experienced for the first time how transitioning back into the community from an institution can create huge challenges, due to a lack of network adequacy in the community and immense failures in programs, such as transition services and in-reach (a process in which managed care organization (MCO) staff visit residents in congregate facilities and discuss possibilities for living in the community). In addition, people developing illnesses or disabilities and hoping to avoid institutions by staying in their own community discovered that the network of providers available to them was not up to the task. Even when health providers could be located, their availability was limited, and when appointments could be made, accessible transportation was typically not offered. Even when telehealth was made available, broadband or technology access was lacking for many. All these forms of HCBS infrastructure play an important role, and all of them failed in one way or another.

Since the 1970s, when Geraldo Rivera's exposé of the Willowbrook State School in New York revealed the horror of locking up people with intellectual disabilities against their will and isolating them for years in squalid conditions, leaders have articulated support for policies prioritizing HCBS for disabled people [6]. Hopes soared when the 1999 Supreme Court decision in *Olmstead v LC* required state actors, such as Medicaid-funded agencies and managed care entities, to provide people with disabilities the choice to receive care in the least restrictive environment suitable to meet their needs, i.e., to live in their own home or a group home with help if they chose [7].

North Carolina leaders have long touted their commitment to such integration, but articulated goals have not aligned with actual programming and resources available. A disability system that prioritizes integration would not require disabled people to live in emergency rooms for months because of a lack of accessible housing and community service providers. A mental health system that values independent living would make sure someone who wants an appointment with a psychiatrist can get one quickly, without having to check into a facility.

The list goes on, all based on the fundamental problem that North Carolina's health system is inherently biased toward institutional care, even when that is not what disabled people need or want, what produces the best outcomes, or is most cost-effective [8]. Direct support professionals (DSPs), who travel to homes to provide individual care for people with intellectual and developmental disabilities, are in woefully short supply [9, 10]. The DSP crisis is part of a nationwide health staffing problem. But North Carolina's problem cannot be shrugged off as some unavoidable nationwide phenomenon; it arises from poor planning, lack of vision, inadequate compensation, and lack of accountability of the groups tasked with providing that network. Sadly, North Carolina's Direct Care Workforce State Index is ranked 47th by PHI, the nation's leading authority on the direct care workforce [11]. This ranking is not surprising when a DSP, a pivotal health professional whose work literally saves people's lives, earns less per hour than their counterparts working in a facility. PHI encourages the creation of policy infrastructure to improve direct care jobs.

The Good News

The good news is that state policymakers and health professionals can leverage their once-in-a-lifetime experience of living through a global health pandemic to reimagine what it means to treat people with disabilities with dignity and respect. It is time, at long last, to build trust by creating robust community choice options for all people with disabilities who want to receive care in their own communities. People with intellectual and developmental disabilities need DSPs and robust care management to coordinate care, housing, and transportation. Adults with physical disabilities need durable medical equipment, home modifications, and regular medical treatment to stay in their homes and in the workforce. Children with disabilities whose parents rely on home services for activities of daily living or respite to avoid sending their child to a facility would also benefit from more options, as would older adults who need accessible transportation, medical professionals who accommodate patients with disabilities, and community day programs for enrichment. People with mental health disabilities need access to preventive mental health care and crisis management resources to avoid the trauma of an involuntary commitment, and students with disabilities need access to school psychologists for proper diagnosis and collaboration with care managers and social workers.

The timing has never been better to pivot North Carolina's health system and fully realize choice for people with disabilities; all three branches of government are positioned to collaborate in making the shift. At the executive level, new leadership at the Department of Health and Human Services (NCDHHS) is working to increase staffing and promises to prioritize the well-being and dignity of choice of people with disabilities. A new Division of Child and Family Well-Being at NCDHHS is creating momentum behind the goal of keeping families together. A recent North Carolina Superior Court ruling in *Samantha R., et al v NCDHHS* suggests judi-

cial branch recognition of the need for increased HCBS supports, such as addressing the shamefully long wait-list for the more than 16,000 people with intellectual and developmental disabilities who want services to help them stay in their community [12]. New lawsuits, such as *Timothy B., et al v Kinsley*, continue to bring attention to the child welfare system's weaknesses and the important role of the health system in supporting families with disabilities, wherever they are [13]. Finally, at the legislative branch, committee leaders and members in both chambers and across both aisles at the North Carolina General Assembly have heard the input of constituents and advocates and have expressed interest in fighting institutional bias and providing true choice to people with disabilities. Also, their generalized focus on financially conservative policies meshes well with the goal of shifting resources from unnecessarily expensive institutions to less-costly, community-based services that result in better outcomes, such as increasing the likelihood that disabled North Carolinians and their family caregivers will return to and stay in the workforce.

Conclusion

Creating trust among disabled North Carolinians is simple but requires bold reinvention premised on the notion that all lives are meaningful and that every human has the right to real choice about fundamental parts of their lives. North Carolina's health industry faces a once-in-a-lifetime opportunity to use the lessons learned during the pandemic to emerge as a national leader in eliminating institutional bias. Let's prioritize building the community services infrastructure and fix that weakest link, letting all North Carolinians live enjoyable, fulfilling lives in an appropriate setting, and in the manner and place that they choose. NCMJ

Virginia Knowlton Marcus, JD CEO, Disability Rights North Carolina, Raleigh, North Carolina.

Acknowledgments

Disclosure of interests. The author is the CEO of Disability Rights North Carolina, which is a party to two lawsuits mentioned herein: *Samantha R., et al v NCDHHS* and *Timothy B., et al v Kinsley.*

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