Expecting Difference: Reorienting Disability Strategy for Jail Decarceration

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SAFETY+JUSTICE CHALLENGE

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ACCESS LIVING

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Finally, we dedicate this paper to the few scholars, activists, and writers who have committed their energy to understanding carceral systems in the context of disability. We hope this paper will encourage the engagement of many more people at this intersection.

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Key Terminology

As a general practice, Access Living makes reference to both person-first and identity-first disability language. Person-first language, such as “person with Down syndrome,” is preferred by those who may not see their disability as a core part of their identity or who are referring to a specific disability type. Identity-first language is preferred by those who see disability as a core part of their identity. Access Living uses both in recognition of the mosaic of language preferences among people with disabilities.

In this paper, we also use certain core terms or phrases defined as follows:

- **Ableism:** Discrimination against people based on disability. Like other forms of bias, ableism works through social stigma, exclusion, and formal structures. Ableism coexists and is connected to racism, sexism, homophobia, and other forms of bias.
- **Cross-disability:** A term intended to convey inclusion of all disability types.
- **Disability:** In this paper, we use the definition of disability under the Americans with Disabilities Act (ADA). A person with a disability is someone who:
    - has a physical or mental impairment that substantially limits one or more major life activities,
    - has a history or record of such an impairment (such as cancer that is in remission), or
    - is perceived by others as having such an impairment (such as a person who has scars from a severe burn).[1]
- **Disability justice:** A cross-disability framework that values access, self-determination, and an expectation of difference in disability, identity, and culture. The disability justice framework was developed by multiply marginalized disabled people of color. [2,3]

- **Disability rights:** The body of federal, state and local laws that protect against disability discrimination.
- **Medical model of disability:** A model that views disability as a defect within a person's body. The medical model assumes that people with disabilities have a lower quality of life and need medical care to achieve a higher quality of life.[4]
- **Neurodivergent:** Having a mind that functions differently from what society deems "normal" minds.[5] Neurodivergence is an umbrella nonmedical term that includes but is not limited to autism, learning disabilities, ADHD, Tourette's, and intellectual disabilities. Acquired neurodivergence can be the result of a brain-altering event and can include the effects of traumatic brain injury, stroke, and drug use, for example.[6]
- **Neurodiversity:** The biological fact that no two brains are alike.[7] Neurodiversity is used to speak about a group of people who have different kinds of minds.[8]
- **Neurotypical:** Having a mind perceived as "normal."[9]
- **Section 504 of the Rehabilitation Act of 1973:** A law that prohibits disability discrimination against any qualified individual in any federally funded program or activity.[10]
- **Social model of disability:** A model that views disability as the result of a person's functional limitations confronting inaccessible social barriers. The solution to this tension is to fix society, not the person.[11]

Executive Summary

Among disabled people in jails, certain groups require disability access that cannot be readily addressed by generalist understandings of "ADA compliance" or by disability as a medical condition. Consequently, failure to fully consider disability dynamics within jails and reentry can lead to negative health impacts, decreased jail safety, and recidivism. It is time to see disability not as a checklist of disability rights compliance tasks, but as a breakthrough lens that can advance the work of making all communities safer, and thus to support all people to achieve their true potential.

As a type of nonprofit service and advocacy organization known as a Center for Independent Living, led by and for people with all kinds of disabilities, Access Living has spent more than forty years changing society so that everyone, disabled or not, can thrive. In the last six years, with the support of the MacArthur Safety and Justice Challenge, we have sought to intentionally rethink disability strategies for decarceration[12] through reducing the use of jails. We have done this through the lived experience of our staff, as well as through rooting our work in relationships with all kinds of people with disabilities, including those who are system-involved.

This report reviews problems faced by specific under-addressed disability groups whose experiences highlight systems failures. We then identify systemic gaps created by a misalignment of philosophic approaches toward people with disabilities. The report benefits from the insights of system-impacted Access Living community members with disabilities over the years, some of whose anecdotal observations are shared in this paper. We then highlight disability-centered strategies from both jail- and community-based disability programs that offer disability justice-oriented pathways to reducing jail use and over-incarceration of people with disabilities.

Beyond ADA Compliance and the Medical Model

Because the criminal system is a legal system, disability tends to be regarded by most criminal system stakeholders as a matter of compliance with federal and state disability rights law, particularly the Americans with Disabilities Act (ADA). This "ADA compliance" mindset can lead to a narrow focus on the accessibility of physical infrastructure rather than programmatic and digital accessibility. It can also create inflexibility in problem-solving for disability access that does not involve the physical environment, such as for chronic illness or cognitive disability.

In tandem with the legal compliance mindset toward disability, jail settings engage heavily with the medical model of disability. Under the medical model, the root of disability is within the person's own body; the assumption is that with medical intervention, the person's condition will improve or be cured, and thus they will have a higher quality of life.[13] If a person in jail is labeled as having a permanent health condition, and basic physical environment adjustments do not meet their needs, the person is often sent to the hospital ward for the duration of their jail stay. In the case of those with mental illness and/or behavioral issues, they may alternatively be sent to solitary confinement as the alternative "medical" setting. In other words, the medical model spurs segregation, thus intensifying incarceration.

The legal and medical approaches neither create space for innovation toward care, nor do they decarcerate anyone. By contrast, the social model of disability understands disability as the tension between a person's functional limitations and social barriers. From this standpoint, disability discrimination must be addressed by removing social barriers.[14] Accessibility must involve the lived experience of people with disabilities. The social model is where we may begin to see creative problem-solving and new pathways of thinking.

To illustrate with an example: let's say a person with a disability is dealing with inaccessible jail conditions. Under the medical model, a person with a disability might have to deal with an inaccessible jail because the problem is their medical condition. Under the legal approach, the problem is rooted in a jail's lack of compliance with disability rights law standards. Under the social model, the problem is twofold: that the jail was never designed for all people, and that community inaccessibility forces the person inside.

The social model of disability should also be used in conjunction with our understanding of racism. As we know, jails hold a disproportionate number of Black and brown people.[15] However, the lived experiences of disabled people of color who are system-involved remain to be fully understood at this time, especially where a person of color may have an undiagnosed disability or does not identify as having a disability or being disabled. The effects of poor access to social determinants of health are always exacerbated for disabled people of color. And yet if we can find ways to support disabled people of color,[16] we suspect we will find ways to advance decarceration overall.

Understanding the social model with an overlay of racism and other forms of bias leads us to the disability justice framework. As defined by multiply-marginalized disabled people of color, disability justice is grounded not just in access but also self-determination and an expectation of difference. However, this approach is diametrically opposed to what society expects of the carceral system: that it is where one's freedom is taken away, that all those incarcerated are just a number, and that anyone who is disabled is invisible. Philosophically, the expectation of difference holds potentially the most transformative strategy for decarceration. We will explore this in subsequent sections of this paper.

Policy and community solutions toward reducing the incarceration of people with disabilities, however, face one major problem: data. Change investors and policymakers tend to demand data to begin any reforms. However, disability data remains an emerging field. To be clear, disability data does not mean healthcare data that refers to specific kinds of medical conditions. Instead, disability data looks at areas of experience and functional limitation. The American Community Survey uses only six disability questions:

- Is this person deaf or does he/she have serious difficulty hearing?
- Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

- Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?
- Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
- Does this person have serious difficulty walking or climbing stairs?
- Does this person have difficulty dressing or bathing?[17]

These kinds of questions deal more with the access needs that people have on a daily basis rather than the form of accommodation they may need. Additionally, the questions are not used consistently, and they are not used on the official regular U.S. Census. Other types of data collected tend to focus on a yes/no inquiry as to whether a person has a disability. None of these methods truly account for a person who may not have a diagnosis yet or who may not fully understand their own disability parameters. They are also not necessarily cross-indexed with other demographic categories, such as race or gender.

Taking together the social model approach to disability access problems, the inclusion of a disability justice overlay, and the growing work on disability data, the remaining component we find essential to transform the disability strategy for decarceration is to learn from the lived experiences of disabled people currently in or returned from jails and prison.

Spotlight: Under-Addressed Disability Groups in Jails

To date, certain disability categories are well investigated by criminal system stakeholders, particularly people with mental health issues or serious mental illness (SMI). Among people in U.S. prisons and jails, 40% are people with disabilities, with the most common types being cognitive (30%), ambulatory (10%), and vision and hearing (10%), respectively.[18] However, focusing on some less-examined disability areas may improve overall accessibility, as we will see in the following sections on youth with disabilities, neurodivergent people, and people who need personal care.

The deep disability disparity among incarcerated youth

65–70%

65–70% of youth in juvenile detention have disabilities

75%

At least 75% of youth in the system have experienced traumatic victimization

4.3%

But....nationwide, only 4.3% of ALL students have a disability

A. Youth with Disabilities

Disability is a fact of life in the juvenile system. Nearly a quarter of people incarcerated as adults report being in special education in their youth.[19] Some are captured in the system with no diagnosis or only a partially understood diagnosis. Even if they have a diagnosis, they may not understand what that means, nor may they identify with the phrase "person with a disability" or the term "disabled." Many have already experienced school suspension; indeed, schools are more than twice as likely to suspend students with disabilities,[20] especially Black students with disabilities.[21]

For those in contact with the special education system, they may have Individualized Education Plans (IEPs) for a modified curriculum or 504 plans for modifying the school environment. However, this documentation is not usually shared with detention staff, who may struggle with figuring out reasonable modifications or accommodations for youth with disabilities. The youth may also arrive with shame about their disability and a need to appear as "normal" as their peers. In general, they do not yet have effective skills to advocate for their access needs.

As of 2022, 27,600 young people under 18 were held in youth detention facilities across the United States.[22] According to the National Disability Rights Network:

> Prevalence studies have found that 65–70 percent of youth in the justice system meet the criteria for a disability, a rate that is more than three times higher than that of the general population. Additionally, at least 75 percent of youth in the juvenile justice system have experienced traumatic victimization, leaving them at-risk for mental health disorders such as posttraumatic stress syndrome.[23]

By comparison, around 4.3% of all students in the United States have a disability.[24] Thus, students with disabilities are egregiously overrepresented in the criminal system, and many later go on to be system-involved as adults. In fact, people with disabilities overall are almost 44% more likely to be arrested by age 28 than people without a disability; for Black disabled persons, that rises to an astonishing 55%.[25]

In the last six years, people who were incarcerated as youth have anecdotally shared with Access Living[26] that, while in juvenile detention, the first thing they experienced was a stressful transition to a new environment. Sensory input decreases because one may not hear other youth, and may not have access to a community space. While loneliness increases, educational stimulation is low for those who have longer stays. Boredom and anxiety may set in. A student with a disability considered to be a negative influence on others may be segregated away from their peers. Because the juvenile system is rooted in adultism, young people are expected to act like adults, but they are children, often from significantly under-resourced communities.

There may be no readily present adult who can provide context on what the youth with a disability may need. In custody, one is a ward of the state, not of their guardian or parent. The people who know a young person on the outside may not even know exactly where they are on the inside. The detention staff may not contact the school social worker, or the child services case manager if the youth is in foster care. Youth in detention have also been historically at higher risk of physical, emotional, and sexual abuse from staff and fellow youth.[27] Our community members shared that in addition, theft and bullying are common because facilities may be understaffed.

For those discharged to a group or foster home, disability issues grow more complex. They may be assigned to live in a place they don't know, with people they don't know or trust. It may be in a dangerous neighborhood. The young person may not look like the other kids in the foster house. They do not have any of their own possessions, and they are at high risk of neglect and abuse. They may be hungry if the refrigerator is kept under lock and key or if the other youth steal their food. Shame may prevent them from seeking help at school. Returning disabled youth who do not go to foster care often experience housing instability and high rates of homelessness.[28]

B. Neurodivergent People

While the average stakeholder is well aware of the prevalence of mental health problems among those held in jails, neurodiversity is far less recognized or acknowledged. Neurodiversity refers to the fact that many people's brains simply function in ways that are different from social expectations. Neurodivergent minds exist along a dizzying and multidimensional spectrum in terms of not only cognition but also sensory processing, language expression, and motor skills. While many people are born with neurodivergent minds (such as those with autism, intellectual developmental disability, learning disability, or ADHD), many persons in jails may have acquired a neurodivergent mind through brain-altering events or conditions, such as a traumatic brain injury, a stroke, or the effects of certain medications or substance abuse.

Simply having a neurodivergent mind does not automatically equate to having mental illness, as many neurotypical persons also have mental illness. However, some neurodivergent people may also have mental illness, either innate or acquired. Often, the stress of living as a neurodivergent person in a neurotypical world can cause some kinds of mental health issues, such as anxiety or depression. At any rate, neurodivergence among people in both state and federal prison is relatively common: In 2016, a national study found that 23% reported having a cognitive disability.[29] In the same study, 24% reported having been told they have ADHD, and nearly a quarter reported having been in special education.

Neurodiversity among incarcerated adults

23%

23% of people in state and federal prisons reported having a cognitive disability

24%

24% reported having been told they have ADHD

25%

Almost 25% reported having received special education services

For criminal system stakeholders, the critical first step is to recognize that neurodivergence exists and that a one-size-fits-all, compliance-based approach very often tends to do more harm to all involved. It can be challenging for staff to get a full sense of someone's neurodivergence, particularly for short-term jail stays and particularly if staff have no training on neurodivergence. It's also challenging to get a full sense of how many neurodivergent people are in jails, given that neurodiversity covers many, many disability categories that may or may not be documented in data.

What is incarceration like for neurodivergent people? First, consider how people feel, see, hear, and understand an environment where it feels like anything one does can be punished. According to the organization Revolving Doors, which is based in the United Kingdom:

> A sensory overload can be interpreted as aggression or public disorder, resulting in arrest. Behaviors in court can be interpreted as aloof or unremorseful, with our lived experience members feeling like [their behaviors] may have contributed to a guilty verdict or harsher sentence. Written license conditions aren't understood, resulting in breach. The lights and noise of the prison [or jail] environment can cause distress, interpreted as non-compliance with the regime. Drug, alcohol and mental health services often do not tailor their support to meet the needs of neurodivergent people, resulting in relapses or a lack of engagement.[30]

A certain baseline of uncertainty always exists in our understanding of how other people mentally experience their jail conditions. It's not always easy to tell if a person has difficulty with subtlety and needs literal communication. What one person regards as "specific" instructions may not be specific enough for another. Rules may be difficult to follow if they are not contextualized. A person with memory issues may easily forget orders once issued. Some people may not have the cognitive or emotional wherewithal to deal with jail staff commands or expectations.

Access Living community members who identify as neurodivergent and system impacted have shared with us that pent-up frustration and anxiety had a negative effect on their cognitive capacity. When they did not know what their court dates were, or when the release date might be, the uncertainty was physically and mentally maddening. The neurodivergent person may want to get clarity about their situation by asking questions, but in a jail setting, questions may not be allowed. As the stress built, clarity receded.

Incarcerated neurodivergent people tend to be at high risk of bullying or abuse, both by cellmates and by jail staff. Those who rely on others to understand or communicate can become vulnerable precisely because of their need for support. They may become targets because people sense they may not be as quick to comprehend others. They may experience people who act as wolves in sheep's clothing toward them. Name-calling is common: stupid, retard, slow, and so forth. They may not know how to react in a way that doesn't end up with being handcuffed and sent to segregation, or being medicated to control their behavior.

Our community members also shared with us that hygiene issues can result in problems for some neurodivergent people who need cues or direction to stay clean. This can be exacerbated if they also have mental illness. If someone does not brush their teeth, wash their hair, clean their clothes, or use soap appropriately, they face potentially serious conflict with cellmates and social rejection by their peers as a whole. They may be shuttled from one cell to another which can create physical altercations and put them at risk of being sent to segregation.

However, it's also possible for staff or cellmates to step up when a neurodivergent need is plain. Our community members recalled multiple instances of detainees assisting one another with disability needs. Sometimes staffers or cellmates may be familiar with neurodivergence due to having outside family members with autism, brain injury, or ADHD. They may adapt programs or communication using their lived experience. However, these informal opportunities for support are not common, and it is a lucky circumstance if a neurodivergent person finds an ally who can support their access needs.

C. People with Disabilities Who Need Personal Care

In jails, people with disabilities who require help with personal care are a small percentage of incarcerated persons overall, but their circumstances create some unique vulnerabilities. While we mentioned that some neurodivergent people may need cues or direction to deal with personal care tasks, here we look more broadly at the physical disabilities that can make it difficult for one to care for oneself.

The late Dean Westwood offered a graphic tutorial on his physical needs as an incarcerated person with quadriplegia in three separate state prisons:

> While I was confined to the infirmary, they were aware of the medications I needed due to my disability, but they withheld them from me. They denied me a medication that keeps my bladder sphincter closed, so I don't urinate

> on myself… They denied me the medication that keeps my body from locking up in terrible muscle spasms… I was repeatedly harmed by inmate orderlies required to provide my assistance but [who] had no training… At the third institution, I was confined to a dorm-like infirmary where I was assaulted by nondisabled inmates. I again was not allowed access to the yard… It became apparent to me that I was being punished and damaged not because of my crime but because of my physical disability.[31]

An Access Living Voices of Reentry interviewee, a wheelchair user who managed to keep his customized chair with him, described his experience as follows:

> You need a permit for everything in the system, for everything. I mean, if you want a lower bunk, even for my wheelchair, I needed a ticket for my own wheelchair to have it and then to prove that it was mine… I'm like, trust me, you guys don't own any wheelchairs that look like this in here. I needed new tires while I was in there. And I fought for six months to get that… I had to pay for it. I had to pay for the tires myself. I had to pay for them to, you know, get them sent in and everything… if I want to go take a shower [in the] medical wing, because I don't want to be, you know, in a public area because of the wheelchair or whatever, don't be bogus, you know, because I'm in there for an hour and you want to be out in 20 minutes… Medical attention, as far as being in a wheelchair, forget it. You know, if it wasn't for friends that I got lucky enough to be in there with that were in the gang with me back in the day that you know, would take care of me, I don't know what they would have did to me, you know.[32]

Some people in this category may be born with their disability, whereas others may acquire disability later in life due to traumatic events, illness, or aging. Outside of jails and prisons, billions of dollars per year are spent on home- and community-based services that ensure that people with physical disabilities get personal care when they need it. The people who provide this community care may be family, a certified nursing assistant, a home care worker, or a personal attendant. Most people with this level of disability are heavily involved with the public benefits system.

However, jail detention is a massive disruption to any support system that a person with physical disabilities may have built in the community. They may rely on federal and/or state disability benefits and programs, including home services. Like Dean, they may need specific medications to manage physical functions. They may rely on durable medical equipment (DME) like a walker or rollator, or customized rehabilitation technology (CRT) like a power wheelchair or custom manual chair. On the inside, DME and CRT devices may be taken away due to concerns that components could be made into weapons. The disabled person may rely on catheters that need to be changed regularly or braces that may or may not be in good condition. Perhaps they may need someone to help with incontinence or colon care. They may have skin conditions requiring specific kinds of salves or exfoliants that need to be applied by someone else.

Within jail, people who need personal care have three options. One is to go without, and deal with whatever consequences may come later. A second choice is to rely on fellow inmates. And a third is admittance to the infirmary with assigned inmate orderlies, who may be neither trained nor trustworthy. One of our Voices of Reentry interviewees shared what it was like needing care after contracting MRSA and meningitis while incarcerated:

> I had a trach in my throat. They tried to get in contact with my family because they wanted to unplug the plug, because I was having no brain activity. They put me back in prison in the health care unit. They didn't have the nurses taking care of me. They got another inmate to move into the room with me, with no, you know, degree or nothing, to take care of me, because they didn't have the time or whatever. I couldn't even sit up in a bed on my own. She had to do everything, literally everything for me. The prison was paying her $8 a month to take care of me, like changing Pampers, bathing, feeding, everything, changing my tubes, everything.[33]

Our community members noted that people with personal care needs face other unique vulnerabilities. If a jail has a program that allows some inmates to serve as aides to others, the person with a disability is at the mercy of whether the aide is truly helpful or not. Because of the hypermasculine culture in carceral settings, it may very well be that someone will resist being sent to the hospital ward by any means necessary since it creates an appearance of weakness. Accessible cells also tend to be on the first floor in jails, right off the day rooms where there is a multistory pod setup. These are the easiest cells for others to enter; the most secure cells tend to be the ones higher up.

Despite these difficulties and many others, dealing with personal care needs is one area in which, rarely, some cellmates may be helpful. Within the cell, the cellmate may be an important support for the disabled person, and care can be provided out of sight of the rest of the jail, to a certain degree.

A Cross-Disability Lens on Systemic Barriers in Jail

As in civilian communities, it is very common for people in jail to have more than one disability. There are also certain common systemic problems experienced by most, if not all, disabled people in jails. We describe these common problems from what we term a cross-disability lens, looking across all disability types. Furthermore, there can be a distinct difference between (1) what people with disabilities experience as systemic barriers to surviving jail time and (2) the security systems that corrections staff believe need to be in place. From the correctional standpoint, public safety and the security of the jail are paramount. In this section, we highlight sample cross-disability systemic barriers experienced by disabled people in jails.

Lack of Disability Competency. Understanding how to meaningfully engage with people with disabilities is a lifelong learning process. Training about disability language and disability etiquette is simply one piece of disability competency; another equally important piece is understanding the legal requirements and the full range of reasonable accommodations available for people with disabilities. Arriving at deep disability competency requires constant, ongoing exposure to people with different kinds of disabilities. When disability competency is not in place among jail stakeholders, it means that opportunities to address root needs and supports will be missed. Far too often, lack of disability competency involves misapplied security or health solutions that only exacerbate frustration among all involved.

Discontinuity of Access Flags. Records across the jail cycle may be siloed according to which entity owns which records. Police have their own records, jails have theirs, the jail's medical wing may have a separate set of records, attorneys and the courts have their records, probation has a different record system, and the various organizations providing reentry services may have their own documentation. The closest thing to a document that is used in every instance is the charge sheet. With so many recordkeeping systems involved, it's exhausting to contemplate how access needs must be flagged as the disabled person moves between systems.

Use of Legalese and Officialese. The meaning of legalese and "official" language in signage and paperwork across the jail system may be difficult for most laypeople to fully grasp, let alone people with disabilities that involve reading, cognition, vision, mental health, and more. At a minimum, signage and instructions within jails need to be easily understood at an elementary school reading level. Ensuring that the language is literal can also make an important difference in access for neurodivergent people. The inaccessibility of legalese and officialese only exacerbates pent-up stress and anger among disabled detainees.

Inaccessible Probation and Reentry. The current one-size-fits-all, cookie-cutter model of probation is, in fact, an ill fit for people with disabilities. The compliance-based probation system, especially without disability support on release, means that violation will be almost inevitable for disabled people. According to the American Civil Liberties Union (ACLU):

> Such individuals regularly face heightened barriers to understanding and complying with supervision rules, effectively communicating with supervision authorities and other stakeholders, getting to required appointments, obtaining and maintaining employment, participating in required treatment programs, abstaining from drugs and alcohol, and adhering to electronic monitoring requirements. Given other forms of structural discrimination, these barriers are particularly high for people with disabilities who are Black and Brown, LGBTQ, and/or experiencing homelessness or poverty.[34]

Reentry programs present a different but very related accessibility problem. They tend to offer a combination of resources for education, job training, and housing assistance. However, based on anecdotal evidence gathered from our Diversion and Reentry Council and Voices of Reentry interviewees,[35] the reentry resources they knew about did not provide disability accommodations such as tutors, American Sign Language interpreters, or physically accessible offices. Available housing is generally not accessible for people who have physical access needs.[36] Ironically, reentry organizations that receive government funding are required under the Americans with Disability Act to be reasonably accessible, but somehow, this may not be enforced. Thus, in returning to the community, people with disabilities face another massive challenge as they navigate reentry resources.[37] Inaccessible reentry is not reentry at all.

Electronic Monitoring. Electronic monitoring (EM) poses significant barriers for people with disabilities as well as for system-involved people who provide care to others. Since EM relies on strict rules such as curfews and geographic limits, people with disabilities on EM often experience barriers of movement that make it nearly impossible to attend to medical appointments, therapy, and other care needs. While it is possible to get approval from one's probation officer for such outings, approval can take time and does not address urgent needs. For some neurodivergent people and people with mental illness, the isolation caused by EM can also exacerbate their disability symptoms, and they may violate the EM parameters, risking going to jail again.

Hierarchical Jail Operational Protocols. Following a hierarchical command-based operational protocol presumes that orders will be followed, and that going outside the orders will be punished. However, the greater strategic disability barrier in a compliance-based hierarchy is the lack of organizational flexibility to address or de-escalate individual access needs. It also creates an inability to cooperate with other systems, such as the courts or probation. It is possible within a hierarchical system to create compliance-based protocols for disability reasonable accommodations, but only to the extent of having a limited menu of accommodations that are easily achievable, and squeezed in only as secondary to security protocol. This approach is simply not enough to manage the needs of people whose disabilities are highly individualized, complex, invisible, and/or who need constant support for access. The strategic organizational challenge for jails is that in fact, there are a lot of people in this disability category, not just a few.

Learning from Disability-Led Community Innovation

> Without comparisons to make, the mind does not know how to proceed.
>
> —Alexis de Tocqueville, Democracy in America

As a disability-led organization serving people with disabilities in the city of Chicago since 1980, over time we have developed practices and services that we believe can translate to supporting people with disabilities who become impacted by the criminal legal system and incarceration. Our approach uses the social model of disability, folding in both disability rights and disability justice practices. Access Living is part of a national network of organizations federally designated as Centers for Independent Living (CILs).[38] Under Title VII of the Rehabilitation Act of 1973 (as amended),.[39] CILs are required to provide peer support, independent living services, advocacy, information and referral, and a fifth core service called "transition." In this case, transition means both transitioning low-income disabled people out of nursing homes as well as supporting young people with disabilities in transitioning to postsecondary education or work after high school. Key practices from the cumulative experience of CILs can offer possible pathways for decarcerating jails.

Shifting How We Talk About Disability. Disability language has evolved a great deal since CILs were created in 1973. Today, CILs usually reference people with disabilities (person-first language) or disabled people (identity-first language).[40] CILs also follow the lead of an individual's own words to describe themselves as a person with a disability. In the last ten years, there has been increased discussion about how to describe someone who may not want to say that they have a disability. This is particularly important in Black communities, undisputedly both the hardest hit by mass incarceration[41] as well as sustaining the highest disability rates.[42]

Sami Schalk, the author of Black Disability Politics (2022),[43] explores how Black individuals navigate, identify, and resist societal definitions of disability using an intersectional lens. Schalk acknowledges that some Black individuals may be reluctant to claim disability as an identity due to the compounded stigma of being both Black and disabled. The additional label of disability is potentially fraught with further discrimination, marginalization, and harm. Similarly, medical and psychiatric systems have historically pathologized Blackness.[44] The mental health condition that uniquely categorized enslaved Black people as “mentally ill” through diagnoses like so-called drapetomania — which labeled the desire to escape slavery as a disorder[45] — may influence some Black people’s contemporary resistance to embracing disability as an identity.

Given this dynamic, reflecting the language that people prefer to use about their disability is probably the best way to start a conversation about access needs. Start by discussing someone’s specific condition, such as diabetes or visual impairment. They may not want to frame their condition as a disability, seeing it as a sign of weakness. Over time and with peer support, people may decide to shift how they talk about themselves and their disability.

Disability Peer Support and Empowerment. In reentry work, peer support can be a powerful factor in reducing recidivism for system-impacted people. CILs have found that people with disabilities who receive peer support from other disabled people also tend to have the most success in sustaining their lives in the community. As in reentry, disability peer support is about listening to one another, offering advice, and often figuring out how to deal with major life changes.

What is different about disability peer support, however, is that after becoming more comfortable with talking about one’s disability, the conversations turn toward teaching one another how to become the best advocate possible for your own access needs, and sometimes the discussion even extends to access needs on a broader scale. CILs often offer individual or group peer support sessions where people can learn about their disability civil rights and how to deal with the government systems that often provide key supports and services. Some programs may offer workshops targeted to specific groups of disabled people, such as those who want to move out of nursing homes.

Disability self-advocacy conversations can cover everything from finding and fighting for affordable, accessible housing; finding a job and requesting reasonable accommodations; planning finances and dealing with the “disability tax” of paying for disability-related supplies and services; parenting and being in a relationship as a person with a disability; navigating healthcare; and always—always—dealing with transportation issues. How does one describe what one needs? What does one do when someone says no? For disabled people who have been incarcerated, these conversations can also carry the overlay of reentry problems interpreted through a disability lens, such as finding accessible housing while being on a state registry.

Creating Person-Centered Plans. Every person with a disability who comes to a service provider for assistance goes through an intake process to determine their needs and goals. Some people need a relatively light level of support, but those who need more intensive life planning may go through a process known as person-centered planning. Mainstream person-centered planning is today a fairly standard element of many government and healthcare programs. This version of person-centered planning offers a person with a disability various options of services and supports to choose from, contingent on complying with various accountability measures. This version of person-centered planning can unfortunately replicate institutional practices that hinder a disabled person’s ability to thrive.

However, there is a deeper approach to person-centered planning that aligns more effectively with the goals of decarceration. This approach is more commonly practiced in certain areas of developmental disability services. As conceived in the 1970s by John and Connie Lyle O’Brien for people with intellectual/developmental disabilities,[46] person-centered planning is a facilitated process that involves gathering the person with a disability and their circle of support to have a conversation about that person’s needs and how to meet their goals. This plan is not about compliance, gatekeeping, or accountability, and it does not have a fixed end. It is a living process that centers on the person with a disability providing direction on how to live their own life.

The benefit of the O’Briens’ person-centered approach is that the disabled person feels they “own” it and that they have support for navigating their life. Most importantly, it does not rely on gatekeeping or expectations that certain things will happen on a set timeline.[47] The approach is based on consent and cooperation, not compliance. In an ideal world, every returning person should have access to a person-centered plan.

Spotlight: Best Practices

The examples shared in this section demonstrate commitment to a realigned disability approach that sets the social model of disability as its core framework, bolstered by disability rights and disability justice approaches. We believe that these programs offer potential roadmaps for more effective jail decarceration.

Community Reintegration Programs at CILs. Every CIL conducts the work of getting low-income people with disabilities out of nursing homes and into their own homes in the community. Unfortunately, an extended nursing home stay can cause many people to lose their apartments and their homes. This can be very similar to losing one's home due to jail detention since many people don't have the finances to pay rent and bills while in jail. Deinstitutionalization is the disability-specific version of decarceration. Access Living conducts this work as a contractor under the Colbert and Williams consent decrees in Cook County, Illinois.[48]

CIL community reintegration is typically for nursing home residents who have stays of 90 days or more, which is considered long-stay. A successful transition involves preparing a resident with the skills necessary for community living, working with a service and housing coordinator to ensure that supports and an accessible home are in place, establishing transportation and social networks, securing housing vouchers and sometimes programs like Meals on Wheels, and most importantly, peer support.

Nationally, the most visible proven program for deinstitutionalization has been Money Follows the Person,[49] administered by the Centers for Medicare and Medicaid Services. Although the process for nursing home transition is logistically complex, under Money Follows the Person, states transitioned 107,128 people with disabilities out of nursing homes and other congregate settings between 2008 and 2020.[50]

Alliance of Disability Advocates North Carolina (ADA NC) Reentry Program. In recent years, ADA NC took the lessons learned from deinstitutionalization and developed an entire program focused on returning people with disabilities. The ADA NC Reentry Program[51] focuses on peer support from system-impacted disabled people of color on its staff, along with the development of Individualized Reentry Plans (IRP), which focus on the specific needs and circumstances of each person.

IRPs have proven to be effective at helping people with disabilities transition from incarceration and remain in their communities.

In the Reentry Program, the services provided by ADA NC include housing, employment, benefits, mental health and substance abuse resources, travel training, independent living skills, vital records, and driver's license restoration resources. Due to the nature of the ADA NC grant, those served must have an intellectual/developmental disability and/or a traumatic brain injury (or suspected traumatic brain injury).[52] ADA North Carolina is a sister CIL in the national CIL network.

Juvenile Court Referral to Protection and Advocacy Services. Ensuring that system-involved youth with disabilities have a disability-informed advocate can make a huge difference. Protection and Advocacy Agencies (P&As)[53] are the federally mandated legal advocacy organizations that protect disability rights in every state. Among other powers, they have access to the records and facilities necessary to investigate abuse or neglect or to monitor the treatment and safety of people with disabilities. Since their establishment in 1975, this has given P&As a front-line role in observing the problems facing system-impacted disabled people.[54]

Based on the problems they documented in protecting the rights of young people with disabilities, the P&As in four states piloted a juvenile court project[55] in which they received referrals of youth with disabilities who came into contact with the juvenile detention system. The states involved in the pilot were Texas, South Carolina, New Mexico, and Kentucky. Hundreds of young people with disabilities were referred to the P&As to connect with service support and legal advocacy. The referral project was more successful in some states than others due to state-specific system barriers, but overall, the pilot showed that support from experienced disability advocates could keep youth with disabilities out of the system.

Revolving Doors Neurodiversity Forum. Revolving Doors has worked with frequently system-impacted persons in the United Kingdom (UK) since 1993.[56] In recent years, Revolving Doors has established a Neurodiversity Forum comprised of system-impacted persons who identify as neurodivergent. Forum members' leadership and lived experience drive their activities with Revolving Doors. The Forum's sharing of lived experience among members led to providing guidance to the UK's Ministry of Justice on their first Neurodiversity Action Plan, published in 2022.[57]

The Action Plan then led to the creation of Neurodiversity Support Managers (NSMs) in every UK prison. The NSMs work to identify and support incarcerated neurodivergent people in prison with appropriate education and training for their reentry. The NSMs also train correctional staff on neurodiversity and have conducted over 180,000 screenings for neurodiversity since 2021.[58] The UK government has estimated that up to half of all those in its prisons are neurodivergent.[59] Thus, the disability-informed strategy of addressing the needs of neurodivergent people in prison is a critical piece of improving public safety.

Recommendations

We believe that reorienting the philosophy behind the disability strategy of U.S. jails can lead to decreased use of jails. Based on our review of how philosophical realignment has successfully created change for people with disabilities, we recommend certain overall strategic actions for stakeholders of U.S. jails. These actions focus on what can be done beyond ADA compliance and are centered on the social model of disability, with disability rights and disability justice approaches.

- A. Establish jail entry as the starting point for reentry
- B. Develop disability self-advocacy programs led by people with disabilities, specifically for those in jail with disabilities
- C. Using the O'Brien person-centered planning approach as a model, coordinate planning meetings for returning people with disabilities
- D. Review jail programmatic offerings for accessibility and formulate action plans for improvement, including establishing a process for reasonable accommodations
- E. Provide an opportunity to show proof of disability, such as school documentation of disability or medical documentation of disability
- F. Allow transferring of access needs flags across data systems through a standard form that travels with the person across systems, as a charge sheet does

- G. End electronic monitoring
- H. Train corrections officers, public defenders, and adult probation officers on disability competency and addressing access needs
- I. Expand research on disability status among all groups in jail/probation populations

Regarding the three specific disability groups we discussed earlier in this paper, we offer the following additional recommendations:

Youth with disabilities:

- A. Consider court referral of youth with disabilities to the state's Protection and Advocacy Agency
- B. Designate a team of detention staff who to identify and coordinate disability supports with families
- C. Develop and implement disability mentoring programs for youth with disabilities and their families

Neurodivergent people:

- A. Develop a team and screening process to screen for hard-to-identify disabilities, in each jail
- B. Establish plain language standards for written signage and materials for those in jails, including for when they go to court
- C. Consider establishing a support team in each jail to identify and coordinate services for neurodivergent detainees

People who need personal care:

- A. Expedite coordination of reentry to home- and community-based services in an accessible setting, starting as early in the jail stay as possible

- B. Incentivize accessibility in new housing options, as well as home modifications in existing housing for returning persons
- C. Set aside funds to assist people with home modifications that may be needed in their home, if they are returning directly home

Conclusion

To effectively address the needs of people with disabilities in jails, it is crucial to shift systems change work beyond a compliance-based medical model. Instead, stakeholders should commit to a social model of disability that centers on identity, lived experience, and accessibility. By implementing disability-informed praxis and strategies such as peer support, individualized reentry planning, and cross-disability analysis, we can decarcerate jails and improve reentry outcomes for system-impacted people with disabilities. Ultimately, reorienting the philosophy behind jail disability strategies will not only contribute to reducing harm for people with disabilities, but it will also contribute to broader systemic reforms in our legal system.

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