

Beyond Coercion and Institutionalization: People with Intellectual and Developmental Disabilities and the Need for Improved Behavior Support Services

Executive Summary

Background

The goals of Home and Community Based Services (HCBS) are to provide supports that allow disabled people to live independently in the community. Behavior supports are one type of support provided under HCBS to do this. Specific services that fall under behavior supports can be very broad and are often defined inconsistently across states and services. Still, behavior supports can generally be defined — as one state disability services agency does — as “an array of services designed to support individuals who are experiencing or are likely to experience challenges accessing, and actively participating in the community as a result of behavioral, social, or emotional challenges.” The lack of consistency on specific services that fall within this definition creates challenges for evaluating best practices and quality of service across states.

In this paper, we will first review the history of community living and HCBS for people with intellectual and developmental disabilities in the US. We will then discuss definitions of behavior supports based on a review of existing community living and behavior support literature and our interviews with expert and service recipient stakeholders. We will then discuss existing challenges and barriers to effective behavior supports before making policy recommendations for service providers as well as federal and state policymakers that can improve the delivery of safer, more person-centered, equitable behavior supports.

History of Community Living Among People with IDD

Community living is when disabled people live in the same places as non-disabled people and get to make the same choices every day as non-disabled people. In general, people with IDD have reported that our definitions of community include a place where we have autonomy, self-determination, and can make choices and exercise control over our lives. HCBS serves as a critical resource for supporting the needs of disabled people while we live in the community.

Community living contrasts with living in an institution. An institution is a setting that restricts people from exercising control over their lives and which significantly segregates them from the community. Self-advocates often employ broader definitions of institutional settings and characteristics than those used in many other contexts, identifying institutional characteristics in settings that may not be considered “typical” or historic categories of institutions.

For most of the history of the United States, people with intellectual and developmental disabilities were excluded from community living. From the 1840s on, institutions entered widespread use in the United States. Early institutions were envisioned as therapeutic alternatives to other similarly institutional settings, such as poor houses and prisons, but rapidly became places that warehoused disabled people with no therapeutic benefit. Institutionalization peaked in 1967; exposure and public outcry about institutional conditions drove several waves of efforts — decades apart — to shift away from institutional approaches and towards community-based ones instead. However, deinstitutionalization efforts have not been accompanied by the resources to support people in the community. In many cases, new, smaller institutions that nevertheless retain these institutional characteristics have simply replaced these older institutions.



The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

Community Living and HCBS

The most recent wave of deinstitutionalization was precipitated by the Americans with Disabilities Act and subsequent litigation. In particular, the landmark case *Olmstead v L.C* played a crucial role. In this case, plaintiffs Lois Curtis and Elaine Wilson — two women with intellectual and mental health disabilities — sued the state of Georgia for failing to provide community-based support options, forcing them to be repeatedly institutionalized, even though their doctors and providers agreed that they could live in the community with supports. In 1999, the United States Supreme Court ruled in their favor, holding that Title II of the Americans with Disabilities Act did not permit states to require people to reside in institutions to receive disability services. Instead, people had a right to receive services in their community provided they were willing and able to do so. Following the *Olmstead* decision, additional litigation forced more states to offer home and community-based services (HCBS) to transition disabled people out of institutions. However, adequate funding levels for HCBS remains a significant barrier; while institution-based supports are a mandatory service under Medicaid, services under HCBS are not and are only provided via Medicaid waivers. States are afforded greater flexibility in covered populations and services but may also cap services and seldom provide full funding to the scope of population needs, leading to extensive wait lists and service gaps.

In addition, the shift away from formal institutions for service delivery has not eliminated the use of isolating and restrictive models that defined institutional models; instead, these elements of institutional service provision have often been replicated in community residential settings such as group homes. People with IDD residing in group homes frequently report that they continue not to be allowed basic choices such as what to eat, where to go during the day, or who to live with. These issues persist despite federal rulemaking establishing that people in community settings have these rights. Even beyond setting-specific issues, service provision often prioritizes service models that restrict control and self-determination in a variety of ways, leading to staff overriding or ignoring the preferences of the people they support, agencies and case managers developing plans and schedules without the input of people receiving services, or people being put under guardianship and having even less control of their support decisions.

Behavior support services.

Behavioral intervention for people with IDD is a history that parallels the history of institutionalization. Applied Behavioral Analysis is one of the most common and widely used intervention models, dating mainly from O. Ivar Lovaas's work at UCLA in the 1970s. Lovaas's work was based on operant conditioning, using external reinforcers to change behavior. Early ABA practice was frequently violent, involving yelling, striking, and shocking disabled children for noncompliance. While the use of violent aversives has fallen out of favor in recent years amid efforts to reform ABA practice, these have not been universally adopted. At the same time, the underlying goal of ABA — using behavioral compliance interventions to make people with IDD “indistinguishable from peers” — remains common. While ABA is most commonly associated with autistic children, autistic adults and other people with intellectual and developmental disabilities also experience ABA and related therapies.

Starting in the 1990s, many states and providers began to use services called Positive Behavior Supports. These services are typically described as employing some of the tools and techniques of behavioral analysis, such as functional assessments, but also incorporating additional frameworks around inclusion and person-centered approaches. However, PBS lacks a consistent set of definitions across professionals and states, meaning that many services described as PBS may not align with these principles. Further, many critics note that the behavior bases of PBS remain a significant component of PBS and that many interventions still focus on using reinforcers to change perceived problem behaviors. The fact that ABA and PBS remain the dominant models of behavior support means that other, more holistic behavior support approaches incorporating mental health and sensory approaches to behavior remain crowded out and have been slowly implemented.

Aims of this Paper

The current behavior support environment is characterized by a lack of agreement between providers, service systems, and government. Despite substantial agreement on these underlying aims, there is substantial variability in how behavior supports are best designed and implemented and how best to use behavior support to meet the needs of community-based care. The lack of consistent approaches creates disparities between states, waivers, providers, and approaches, with little research on the efficacy of individual service approaches to support best practices. In this paper, we review the state of behavior support service provision, identify areas for improved service delivery on federal, state, and provider levels, and provide policy recommendations to address these needs. A recurring theme in this review is that our service delivery models are not designed to support the present needs of people with IDD. Post-Olmstead developments have attempted to adapt a legacy service system to community support needs; however the underlying structure of service delivery systems that these developments built on remains a major obstacle to realizing these goals.

Methods

Literature Review

To identify policies and practices in behavior support provision, we examined existing literature on behavior support services. This included:

- Studies of positive behavior supports
- A review of available existing behavior support practice guidelines
- Research and practice guidelines concerning trauma and mental health in intellectually and developmentally disabled communities
- Existing survey data on service recipient experiences, state practices and expenditures regarding behavior support

In total, we reviewed 50 articles, documents, and guidelines. As we proceeded through our subsequent interviews, we solicited additional documents from our informants to guide our research further.

Stakeholder Interviews

Based on the above literature, ASAN identified and interviewed 20 stakeholders with policy expertise in HCBS or behavior supports and five stakeholders with experience receiving HCBS behavior supports as people with IDD. We developed an interview protocol for policy experts based on literature review findings and then translated this protocol into plain language, adapting the questions as needed to reflect the experiences and knowledge of service recipient stakeholders. Interviews followed a 90-minute, semi-structured format. Interviews were recorded and transcribed by ASAN staff.

Data Coding and Theme Creation

Throughout and following the interview data collection, the ASAN team reviewed interview notes and transcripts to identify themes related to HCBS behavior supports. The team developed codes for terms and phrases used by interviewees that reflected these themes and reviewed and revisited these codes as they continued to analyze transcripts. Based on these codes, the team identified major themes in the transcripts and formed descriptions of these themes. We summarized the major findings concerning these themes. We found the following themes:

- **Definitional Disputes:** Substantial disagreements from informants on definitions of positive behavioral supports, what they look like, and what they include.
- **Siloing:** IDD supports largely exist as a parallel system to mental health services and supports, impacting access to care that aligns with the recipient's needs.

- **Systems Change:** Legacy approaches and frameworks constrain many approaches to behavior supports. Informants aligned with a diverse range of services and approaches often emphasized the importance of systems change to successfully support implementation of services.
- **Lack of Resources:** Many informants noted that underfunding of HCBS, concurrent with a direct support provider workforce crisis and additional burdens imposed by COVID, poses major barriers to the implementation of supportive policies and ensuring that providers are equipped to provide more supportive approaches.
- **Limitations of Behavioral Approaches:** Many informants were highly critical of behavioral approaches. A frequent critique was that all approaches rooted in behavioral control and change are fundamentally coercive, even when ostensibly positive approaches are employed.
- **Person-Centered Planning:** Most informants agreed that there are significant concerns around the person-centered planning process and the extent to which it centers the individual service recipient. Many identified a need for greater safeguards to ensure fidelity to recipients' expressed needs and goals.
- **Concerning Trends:** One area of concern raised in interviews is a trend towards more significant provision of behavior support services in schools and similar settings that may carry a greater risk of defaulting to compliance-based approaches. Many informants also discussed the longer-term impacts of the COVID-19 public health emergency on the provider workforce and service access.
- **Approaches to Data and Assessment:** A point of disagreement among informants centered around data-based approaches to behavior intervention, an element of ABA that is retained in many positive behavior support approaches. Critics emphasized approaches that focus on building rapport and connection with service recipients over those focused on monitoring and categorizing discrete instances of behaviors.

Definitions

Challenges and Disparities in Definitions

Despite broad agreement that the goals of behavior support services are to support community access and participation of people with emotional and behavioral support needs that could otherwise limit access, this agreement on the generalized aims of services is where this consensus ends. There is a substantial disparity between states regarding the amounts and types of services covered and provided as behavior supports. These disparities reflect varying levels of system funding and priority placed on community living as a matter of policy preferences more broadly but are also a consequence of different values placed on models and delivery methods of behavior support, as well as different conceptions of the purpose of behavioral intervention, within this broad consensus of the overall aim.

The Dehumanizing “Behavior” Label

The challenges around behavior support terminology reflect disputes about the best approaches to provide support for people. The impacts of language extend beyond word choice itself— much of the language surrounding behavior supports reflects the history of behavioral intervention discussed previously, and this language offers a default framework through which many policymakers and providers view the objectives of behavior supports. As such, any language reform must include actual changes of service systems and frameworks to address the impacts of this history of behavior intervention.

A challenge posed by frameworks focused on behavior is that a wide range of actions that express or demonstrate individual preferences are often classified as “behavior” and considered an appropriate target for behavior change. Under behaviorist frameworks, this can lead to operationalizing wanted activities as a reward — or withholding them as a punishment — irrespective of service recipient consent or the value they get from those activities. Several interviewees noted that making desired activities contingent on a behavior goal is something that nondisabled people would rightfully see as coercive and disrespectful if applied to their own lives, despite their normalization for people with IDD.

Even absent this form of operationalization, behavior-focused approaches can be intrusive and coercive. Service recipients are often aware when their behaviors are monitored and assessed and may feel isolated by this monitoring or fear that openly expressing themselves will lead to punitive measures. Expert informants and service recipients both note that this form of monitoring can be a form of control and a source of trauma.

Clarifying “Challenging Behavior”

An additional challenge in the language of behavior support is the range of definitions of “challenging” behavior. Although a common target for intervention, there are a range of definitions of challenging behavior. The most common formal definitions focus on behaviors that pose physical safety risks or limit one’s access to the community. However, the same sources noting these definitions acknowledge that these terms are used to categorize broader ranges of behavior. Because challenging behavior is frequently used to justify interventions to change behavior — including the continued use of restrictive and coercive practices — this broadening carries with it a risk of inappropriate coercion and disregard of behavioral needs. Someone’s behavior can pose a challenge to different groups in different ways. Who it is that is impacted and the nature of that challenge is essential to establishing appropriate approaches to behavior supports. When the term “challenging” is applied equally to behaviors that pose serious safety concerns and those that create additional burdens on service providers, it conflates challenges caused by community access with the behaviors themselves, focusing intervention on changing behavior instead of underlying support needs.

In previous reports, ASAN discussed the risks associated with labeling harmless but unwanted behavior as “challenging.” Applying this label broadly to unwanted behaviors risks conflating actions — such as serious self-harm — which pose immediate safety concerns with behaviors that pose safety risks only when inadequate supports exist or which are harmless but inconvenience or annoy others. This definitional creep is concerning because a label of challenging can be used to justify the same type and intensity of intervention irrespective of the reason. Several expert interviewees recounted examples of providers targeting harmless behaviors and activities for intervention despite a lack of safety risk, simply for lack of understanding.

When a behavior is labeled challenging, service providers prioritize eliminating that behavior. This approach leads to prioritizing behavior change over addressing underlying needs or other sources of behavior. Behavior can have many sources, particularly for those lacking access to other forms of meaningful communication and relying on behavior to communicate these needs. A typical response to challenging behavior is using restrictive or punitive measures to get the person to stop the behavior. Several interviewees noted that many states retain provisions that allow restraint or other restrictive and coercive practices for challenging behaviors despite the imprecision of its usage for non-dangerous behavior.

Even when behavior is serious and dangerous enough to warrant intervention, focusing on stopping the behavior with restrictive practices can lead to neglect of underlying causes; addressing these sources can often ameliorate serious issues without restrictive approaches. Frequently overlooked causes of “challenging” behavior include a range of medical, mental health, and social sources that can impact people with IDD.

The language used to talk about people with IDD, and our behavior is important in large part because of the structure and biases of the underlying service system this language reflects. The term “challenging behavior” could be replaced with a different term that is less stigmatizing and imprecise, but without addressing the need for service system change, this would do little on its own. However, these language choices reflect priorities within the behavior support system that undermine many critical goals of community living, such as autonomy, dignity, and person-centered approaches. Priority needs to be placed on support service recipients’ needs through improved access to mental and physical health care, sensory and communication supports, support for acute needs that enable someone to remain in the community, and sufficient community support to allow people with IDD to meet our self-identified goals.

Existing Problems with Current Behavior Support Services

A False Division: Mental Health Services vs. Behavior Support Services

People with IDD are more likely to be diagnosed with mental health disabilities but experience barriers to gaining access to health care because of deep divides between mental health and IDD systems. People with co-occurring mental health disabilities and IDD are often siloed into one system and face reduced access to services through other systems. This siloing of services is largely a product of the historical misconception that people with IDD do not have mental health concerns or cannot benefit from mental health services. As discussed above, and as reflected by interviewed informants, early IDD services routinely neglected mental health concerns and viewed people with ID as not having mental health processes to benefit from traditional therapy. Instead, signs of mental health care needs were treated on a behavioral basis. This behavioral intervention can itself have traumatic impacts, compounding the additional risk of trauma experienced by people with IDD, while a lack of access to comprehensive mental health support due to siloing often leaves people with IDD unsupported for needs related to trauma. In addition, the lack of regard behaviorist interventions have for internal mental states leads to intervention approaches that further undermine internal motivation or exacerbate mental distress.

A long-term impact of the siloing of mental health and IDD services has been further reduced access to mental health services due to the structural consequences of this siloing. Few mental health systems have built the capacity or accommodation practices to be accessible to or to serve people with intellectual, developmental, or communication disabilities. At the same time, IDD systems frequently offer limited services beyond the narrow focus on behavior assessment and management frequently rooted in behaviorist approaches. When people with IDD have access to mental health services, it is much more likely to be in the form of psychopharmacology than therapy.

These issues are particularly pronounced for people with IDD without a reliable method of communication other than behavior. Functional labels reinforce the designation of people who rely on behavior to communicate as people with no insight into their needs and lives. In turn, this belief is used to justify behavioral interventions on the grounds that people relying on behavior to communicate do not have mental health support needs other than those supporting behavioral approaches. It even impacts the development of evidence, where the exclusion of non-speaking people and those with intellectual disabilities from non-behaviorist therapeutic research may further bias the evidence base for the efficacy of these approaches.

Even people with IDD who do have other reliable means of communication often face considerable barriers to accessing appropriate mental health care. Literature has consistently found that mental health professionals are often unprepared to work with autistic people with mental health disabilities. Similarly, people who use AAC to communicate experience significant additional barriers, including a lack of provider knowledge on how to work with AAC users, appointment length, barriers to scheduling and confirming appointments, and a lack of accessible telehealth platforms and resources.

Mental health service providers frequently lack training and competency with regard to working with people with co-occurring IDD and mental health disabilities. Studies have found that only half of mental health providers have received training on serving IDD populations during education, and few psychology programs provide training for working with IDD populations through the lifespan. Another consequence of the siloing between mental health services and IDD services is that few mental health providers are trained to work with IDD populations. These provider gaps limit the access that IDD people have to mental health services, which further feeds the perception that IDD service needs do not include comprehensive mental health, perpetuating a cycle of unmet service needs.

Limitations and Challenges of the “Behavior Support” Framework

Service systems' reliance on behavioral interventions creates a framework where people with IDD are foreclosed from accessing other services that can provide support for mental health needs, including psychotherapy, occupational and physical therapy, speech/language therapy, and peer support. Informants contrasted the ease of obtaining a behavior support plan with the difficulty of getting evaluated for these other services. A recurring note from informants was that many of these needed services fall outside of typical understandings of “behavior support” and are less available under Medicaid waivers for people with IDD. Informants noted that services like occupational therapy for sensory processing are underdelivered to adults with IDD and frequently unavailable through Medicaid waivers.

Changing and Modifying Behavior vs. Addressing Underlying Needs

The behavioral focus of behavior supports orients service goals towards controlling or changing behaviors rather than addressing underlying needs. In many cases, even when supports are identified as “person-centered” or “positive,” this underlying framework limits and dehumanizes those who experience it. Many things that are deemed problem behaviors are often normal, natural reactions to living within a controlling and dehumanizing service system, where people with IDD often lack control over our most basic life choices, are frequently disrespected, infantilized, surveilled, and even abused, and neglected with limited recourse.

While there has been wide recognition that large-scale institutions inhibit choice and control, are traumatizing and abusive, and adversely impact the disabled people who live in them, the disability service system has been slower to recognize that many of the same dynamics exist even in smaller, “home-like” congregate settings such as group homes, where people with IDD continue to be denied choice and control over their own lives. This restriction is one of many sources of trauma people with IDD experience; people with IDD are more likely to have experienced Adverse Childhood Events, more likely to be the victims of violence, including sexual violence, and face significant discrimination in criminal legal interactions, including police violence and having crimes against us ignored. All of these further contribute to trauma and mental health burden for many people with IDD.

Behaviorist interventions for challenging behavior often create a self-reinforcing cycle, where service systems neglect the underlying needs that cause behavior, leading to unwanted and traumatic interventions, and this leads to an increase in these behaviors due to either resistance to or negative mental impacts from these interventions, to which service systems respond by increasing the intervention intensity. Even when a person responds “positively” to these interventions and changes behavior to match expectations, this often leaves underlying needs unaddressed and the person with fewer means to communicate or express distress.

The Workforce Crisis and its Impacts

The HCBS workforce in the US is facing a severe shortage of workers, impacting the amount and quality of HCBS available to people receiving services through waivers. This crisis began before the COVID-19 pandemic, but the public health emergency has further exacerbated its scope and impact. HCBS support shortages have further burdened service recipients and providers in ways that have impacted the provision of behavior support.

Much of HCBS is provided by direct support professionals, who assist with a range of activities that includes activities of daily living, community activities such as shopping, attending appointments and social gatherings, routine health and hygiene tasks, and household maintenance. Despite the essential role DSPs play in ensuring that people with IDD are able to live in the community, they are paid extraordinarily poorly. DSPs frequently make minimum wage, and the average starting pay for DSPs was \$13.61 in 2020 (Bershadsky 2022). Because there is no national training standard for DSPs, they are typically classed as unskilled labor. Because there is no standard occupational classification for DSPs, there is also little concrete data on how many DSPs there are nationally. All of this contributes to essential support workers being underpaid, with extremely high turnover rates and worker shortages for a crucial role in support for disabled people.

With fewer DSPs, people with IDD receive fewer services, experience longer waits to receive services, and have fewer opportunities for individualized supports. Many are forced to receive services in congregate settings such as group homes due to a lack of access to individualized supports. As discussed above, this often leads to limits on control, choice, and dignity that people with IDD have over our lives. People who receive HCBS in congregate settings have the right to individualized services under the HCBS Settings Rule. Yet, lack of staffing means they have no opportunity to exercise their rights.

High staff turnover rates also mean that provider agencies are less willing to provide support staff with appropriate training to support service recipients. What limited behavior support training does exist is focused on responding to crises instead of preventing them, leading ill-equipped DSPs to default to coercive and restrictive practices to maintain control over clients.

Low wages and lack of training also create poor working conditions for DSPs. Large numbers of DSPs experience work-related stress and burnout, particularly those who work with people with behavioral support needs. DSPs can also experience secondary trauma from their work with clients with significant trauma burdens. All of these contribute to poorer service experiences for people with IDD, including fewer social interactions, less community integration, less respectful relationships between supporters and service recipients, and more frequent use of restraint and seclusion. In addition, high turnover limits the effectiveness of client-provider relationships, which are built on trust and understanding, including familiarity with routines, wishes, and communication methods. Without the time to build these relationships and little training or experience, the quality of support people with IDD receive suffers, and providers are more likely to employ restrictive coercive methods due to inexperience and expediency.

Restrictive and Coercive Practices

As discussed in our background, the use of restrictive, coercive, and aversive practices has a long history in behavior intervention. This is due to a history of lack of respect for disabled persons. The *Olmstead* decision and movement towards self-direction and HCBS have represented a policy shift towards respect and support for people. Still, many such practices remain in place despite law and policy.

Restraint and seclusion are some of the most notorious and dangerous forms of restriction and coercion, carrying immense potential for psychological and physical harm, including injury and death. Disability advocates have long advocated against their use, and the HCBS Settings Rule sets require providers to ensure that people are free of restraint and seclusion. Yet, despite these restrictions, these practices continue. The HCBS Settings Rule permits only narrow exceptions that require documentation of alternative efforts. Yet, many IDD waivers allow restraint and seclusion, leading to continued use despite these sharp limits.

Restraint and seclusion are not the only forms of coercion experienced by people with IDD. Even behavior plans that emphasize positive approaches can risk coercion in practice by relying on punitive or aversive methods to control behavior. Service recipients interviewed frequently described experiencing or witnessing restriction in activities or compliance-based coercion in behavior goals and identified support workers' lack of experience as a contributing factor. Service recipients recognized the use of restrictive measures as a sign of improper support approaches. They placed great value on the ability to live independently and seek desired activities without reward or punishment.

Under HCBS, the person-centered service plan is key to ensuring services meet HCBS recipients' needs. The person-centered plan is meant to ensure that recipients can designate their own goals and supports. However, the practice around the use of person-centered plans is inconsistent. A common concern raised by informants was the failure to center the person's own goals, often prioritizing providers or caregivers over disabled people themselves. When a disabled person is not able to set their own goals, even person-centered planning can be coercive. Plans made without the person's input can lead to calls for behavior change to meet undesired goals. They may lead to a lack of cooperation in these goals being interpreted as noncompliance or challenging behavior, justifying further restriction.

Lack of Individual Choice and Customization

Those who receive HCBS behavior supports frequently lack choice and control over services, even when "person-centered." Lack of available provider networks foreclose significant choices about the type and intensity of community services, forcing recipients into specific service models irrespective of their choice. This is further aggravated by the fact that some waiver systems, as described by one expert informant, offer pre-defined "menus" of support services based on IDD service recipient profiles instead of appropriately customizing services to people's individualized needs. In addition, service plans are often made with limited recipient input, despite requirements under federal rules, and frequently prioritize the decision-making role of guardians or other third parties over service recipients themselves. While most IDD waivers include the option of self-directing services, these options are not made adequately available to people with IDD, who utilize self-direction at far lower rates than other service recipients. These issues impact many of the services provided under HCBS in addition to behavior support, but also further limit the choice and control that people with IDD are able to exercise.

“Behavioral Crisis” Interventions

In the absence of adequate community-based mental health services, people with IDD and MHD face an increased risk of emergency room use for mental health crises. As a result, crisis services are frequently considered a frequent important component of behavior support services. However, when these interventions are designed poorly, they inhibit service recipients' ability to stay in the community rather than enhance it.

Mental health crisis services can benefit people with co-occurring IDD and MHD. Still, these services are frequently inaccessible to people with IDD and use response models that expose people with IDD to a greater risk of arrest or institutionalization. In an analysis of the IDD service systems in two states, the National Center for START services found that most survey respondents in each state said that crisis services were either unavailable or did not meet the needs of people with IDD. This lack of accessible crisis services increases reliance on police and emergency departments. This reliance is particularly concerning given the increased risk of police violence experienced by people with IDD, particularly people of color with IDD.

Mental health crisis responses are additionally essential but of limited use because they only enter use when someone is already experiencing a crisis. These crises typically occur within the context of unmet mental health needs that begin long before crisis events, meaning that more comprehensive and accessible mental health support can reduce the expensive and traumatic use of crisis and emergency services while reducing the risk of hospitalization and institutionalization following a crisis.

The Challenge of Data: Identifying and Clarifying Available Services

Throughout our research for this paper, we continually ran into a lack of consistent definitions and comprehensive data. This made it difficult for us to compare behavior support services across states, waivers, and providers, or, indeed, to tell which behavior support services were available in which states at all. Waiver applications or information available on state Medicaid websites rarely provide detailed information about services available, and national surveys of IDD service outcomes lack the detail needed to connect specific waived services to service recipient outcomes. Even when states do provide public information about what services their waivers will cover, this information is often so high-level and non-standardized that it is difficult to tell whether a given service is covered. People applying for waivers, or receiving waived services, also often struggle to comprehend the dense, complex documents that comprise the application and ongoing paperwork. This can further limit self-direction, if service recipients are not made aware of what services may be available to meet their needs or what limits may exist within a waiver.

Recommendations by Topic

Improving the current mental and behavioral support system for people with intellectual and developmental disabilities requires systems change at all levels. Providers, states, and the federal government must embrace systems change; however systems change without a change in the structures and attitudes that harm and restrict disabled people will not meaningfully improve conditions for people receiving behavior support services. It is incumbent on state and federal governments to provide the incentives, standards, funding, and oversight to ensure that practice aligns with aspiration.

Good “Behavior Support” Beyond Formal Services

“Behavior support services” may entail specific services, but these services are not all that is required to support people with IDD. People with IDD, like everyone else, deserve respect, dignity, and inclusion from others. We deserve to be treated our age and as the valued members of the community we are. Respect and personhood are the building blocks of self-determination and self-worth; without these things, no behavior support service will touch “challenging behavior.”

Additionally, services like occupational therapy or psychotherapy can people deal with “challenging behavior,” but these services are often excluded from the umbrella of “behavior support services. We call on state waiver programs and HCBS providers to cover these services as an integral part of HCBS, but also to recognize that not all services that help people with IDD live the lives we want will fit into a compliance-based, behaviorist framework. Rather than trying to fit more services into the “behavior support” umbrella, we want providers and states to recognize that people with IDD require holistic and varied supports to deal with all facets of life, not just services to deal with “challenging behavior.”

Addressing the False Division: Combining Mental Health and IDD Services

The decades-long siloing of mental health services off from IDD services results from, and perpetuates, the falsehood that people with IDD are not capable of the thought processes required to have mental ill-health. Such a siloed system cannot effectively serve people with IDD/mental health disability dual diagnosis because it excludes people with IDD from receiving mental health services. The federal and state governments must work to eliminate silos and improve services for people with dual diagnosis; similarly, IDD service providers must work with mental health service providers to ensure access to quality care for everyone.

Providers: improving provider practices

HCBS providers play a key role in ensuring service recipients can access mental health and IDD services. Providers should find ways to offer ongoing mental health services rather than only providing mental health supports during crises or to change behavior. As part of a holistic approach to mental well-being, providers must integrate mental health supports and trauma-informed practices into everyday interactions. Providers should also ensure their practices and culture support clients’ mental health rather than contribute to trauma.

Providers must closely examine all policies and practices to identify those which may cause trauma. This includes requiring staff training on dignity and respect, since staff dignity and respect for people with IDD correlates with improved outcomes and decreased “challenging behavior” among service recipients. Providers should also ensure that their practices promote self-determination for service recipients. A core part of this must be moving away from restrictive and congregate models of care and towards models that prioritize service recipients’ individual needs.

HCBS providers must also develop working relationships with mental health providers across a range of disciplines. This serves two purposes: helping mental health providers develop competency to care for people with IDD and helping HCBS providers develop best practices to support mental health among people with IDD.

States: rebuild IDD service systems to eliminate silos

States must take steps to ensure their policies do not needlessly silo mental health services and IDD services off from each other. States should complete comprehensive reviews of waiver and mental health services to identify barriers to and restrictions on services. When states find barriers or restrictions, they should rewrite policies to eliminate said barriers or restrictions.

Under the *Olmstead* ruling and the HCBS Settings Rule, states are obligated to ensure that disabled people are offered services in the least isolating setting. States must make sure they comply with the *Olmstead* mandate and that they and providers under their jurisdiction comply with the Settings Rule. States must remedy any violations of *Olmstead* or the Settings Rule swiftly. Further, states must ensure that there are clear, accessible grievance procedures for service recipients to report rights violations to both providers and the state directly.

States must ensure that people with IDD have equitable access to quality mental health services, rather than being stuck in behavior analysis and control. States must develop these services if they do not already exist and should work collaboratively with providers and other states to develop new service models. New services should be designed with people with IDD as members of the core development team and must be voluntarily and delivered in the least restrictive setting.

Federal: fund and incentivize states, enforce regulations that support integration

The federal government plays an essential role in reducing mental health siloing nationally. As such, it must ensure compliance with civil rights laws that give disabled people equal access to health programs (e.g., Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act). Federal authorities must ensure that disabled people do not face discrimination in mental health services. In particular, the federal government must ensure mental health services are accessible to and can competently care for people with IDD.

The federal government also must leverage funding to incentivize states to end siloing between mental health and IDD services. The Department of Health and Human Services (HHS) should spotlight successful models and provide pilot opportunities to develop system improvement; this includes the use of 1115 Medicaid waivers to promote integrated services. Special priority should be given to approaches developed by and with people with IDD or mental health disabilities ourselves.

However, the government must ensure that prioritized programs are voluntary for disabled people. People with IDD and/or mental health disabilities have the right to refuse care, even when others around us object. IDD services — including direct support — cannot be conditioned on receiving mental health care.

The federal government also must leverage its role in mental health provider education to ensure more providers receive training in intellectual and developmental disabilities. Federal authorities must ensure that Medicaid-funded residencies and training programs for psychiatric providers provide education on caring for people with IDD. The federal government must also designate people with IDD as a medically underserved population, which would open up significant funding and training opportunities for health care providers who want to care for people with IDD (Kornblau & Autistic Self Advocacy Network, 2014). The federal government should also use models such as Project ECHO (“The ECHO Model,” n.d.) and Agency for Healthcare Research and Quality (AHRQ) grants to expand provider education in serving people with IDD.

Strengthening and Improving the Workforce

The IDD service system is severely under-resourced. This has several consequences, all of which have significant negative impacts on people with IDD's quality of life. Direct support professionals (DSPs) receive low wages and minimal benefits and training from provider agencies for a job that is often stressful and sometimes traumatic. This has led to a workforce crisis with high levels of DSP turnover, high vacancy rates, and not enough DSPs for everyone who needs one. In turn, this makes it more difficult for provider agencies to offer meaningful and effective mental health supports, leading to heavy reliance on behaviorism and restrictive and coercive practices. Similarly, high staff turnover and lack of funding from Medicaid means provider agencies are less likely to offer robust training for DSPs. The federal government, state governments, and provider agencies must take steps to improve the HCBS workforce in order to provide comprehensive behavioral and mental health services to people with IDD.

Providers and agencies: improve workforce training and culture on supporting mental health needs.

HCBS providers must ensure that DSPs are trained in delivering high-quality behavior supports for people with IDD, including mental health supports. Behavior supports must be positive and person-centered, not compliance-based or punitive. Several of our interviewees emphasized the role of provider agency culture in ensuring behavior supports center people with IDD and do not merely rebrand control and restriction as "positive." Agencies should seek training curricula for their employees around mental health needs among people with IDD, respect and dignity, trauma-informed care, and compliance with federal regulations. These curricula should be developed through partnership with people with IDD, mental health providers, and experts in the field of IDD services.

Provider agencies should also support the mental health of staff as well as people with IDD. Secondary trauma is a major risk factor in staff burnout and attrition; experienced DSPs and other staff may be at the highest risk of these outcomes. Making sure DSPs and other frontline staff have access to trauma supports and mental health supports is essential to ensuring people with IDD receive the highest quality services possible.

States: Invest in the HCBS workforce

State governments, as the parties responsible for overseeing Medicaid waiver services, must do more to ensure funding and regulation for the HCBS workforce. States must devote more funding to HCBS and should ensure that provider agencies compensate staff appropriately. States must ensure that provider agencies report quality outcomes, as well as use of restrictive and coercive practices, and that the states in turn report these statistics to the federal government. States should also work to create and fund promising training practices for provider agencies. The focus of these trainings should be on improving quality of mental health supports and reducing or eliminating the use of restrictive and coercive practices.

Federal: Fully fund the HCBS workforce and ensure state compliance with federal regulations

The federal government must provide more funding for HCBS. The current system is desperately under-resourced and highly variable based on what state a person lives in. Rate-setting reforms must ensure that both DSPs and other frontline staff earn a fair, living wage and that wage reform does not affect provider agencies' capacity to provide services. The federal government must also raise Federal Medical Assistance Percentages (FMAP) for states to ensure that all people with IDD, regardless of what state they live in, receive high-quality and well-funded HCBS.

The federal government should also ensure states have adequate funding to implement comprehensive data monitoring and reporting systems. This will help the Centers for Medicare and Medicaid Services (CMS) within HHS conduct accountability monitoring, including enforcing quality reporting requirements within the Medicaid Access Rule. CMS should receive adequate funds to ensure HCBS quality reporting and remediation when states are not performing up to standard.

Improving Person-Centered Approaches

HCBS providers generally claim that all people they serve have person-centered plans that forefront the person's own stated wishes and goals. Yet these "person-centered" plans often amount to nothing more than a few perfunctory sentences about a person's likes, dislikes, and strengths followed by pages of the person's needs and goals someone else has set for the person. Despite requirements in the HCBS Settings Rule that services be person-centered, lack of accountability and monitoring means that HCBS are often provided in "block treatment" and involve restrictive and coercive practices like restraint and seclusion. States and the federal government should increase their oversight of providers to ensure that services are actually person-centered; providers should also work with service recipients to build person-centered plans that actually work for recipients.

Providers: Build robust support for true person-centered planning

Provider agencies must ensure that the person-centered planning process focuses on the goals and wishes of the person receiving services. Provider agencies cannot allow provider or family/caregiver goals for the person receiving services to take precedence over the person's own goals. Providers must regularly review plans to ensure the plans are being followed and continue to meet the person's needs.

Providers should explore a number of changes to the person-centered planning process to ensure that it is actually person-centered. Providers should review person-centered plans at least once a year as well as any time a service recipient requests a review. Case managers, DSPs, and other provider staff must ensure that service recipients know who should be part of the planning process and that the plan is followed.

Person-centered plans should be holistic rather than narrowly focused. They should include a range of goals and services, including those focused on mental health, sensory needs, and general health care. When behavior support services are included in plans, the focus should be on building connection and understanding over behavior monitoring and restriction. Providers must work to eliminate the use of behaviorist practices (including contingent reinforcement and operationalizing activities as rewards or punishments); this goes beyond merely eliminating restrictive or coercive practices. Providers must also address secondary effects of behaviorist interventions on service recipients, including trauma, loss of control, isolation from the community, and learned helplessness.

People with IDD need robust communication supports that meet our needs in order to fully participate in the person-centered planning process. Providers must ensure that service recipients who cannot communicate effectively through speech have access to effective alternative communication and should collaborate with speech-language pathologists and assistive technology centers to do this.

Finally, HCBS provider agencies must end the use of restraint and seclusion in all forms, including chemical/medication restraint. Person-centered planning must include finding non-restrictive and non-coercive alternatives to restraint and seclusion. Providers should also assess the impact restraint and seclusion have on service recipients and work to mitigate and alleviate trauma service recipients have from restraint and seclusion.

States: Support HCBS settings regulations and person-centered support practices

States have tremendous influence over how HCBS providers conduct person-centered practices via control over waiver and other IDD services. Therefore, states must ensure that their own regulations and practices, as well as provider practices, comply with person-centered planning standards within the HCBS Settings Rule and other federal regulations.

States must ensure that all HCBS providers align with the HCBS Settings Rule, particularly provisions covering community integration and ending the use of restraint and seclusion. States must take swift, decisive action to ensure their own and providers' compliance with the Settings Rule, including creating an accessible, transparent grievance process and providing timely resolutions to issues via an HCBS ombuds office.

It is essential that states fully support the aims of home and community based services and of the Olmstead mandate through ensuring that all disabled people receive necessary services in the least isolating setting possible. If people with mental health disabilities, including people with co-occurring IDD and mental health disabilities, are *de facto* segregated into psychiatric hospitals and other institutions, states have failed to honor this commitment. The Olmstead mandate extends to people with mental health disabilities, too, even when they make choices others may disapprove of.

States should explore ways to allow for self-direction of services and support people with IDD, regardless of support needs or degree of disability, to self-direct our services. During the COVID-19 public health emergency, many states used waiver flexibilities to allow for family members or spouses of service recipients to act as personal care assistants or DSPs. These flexibilities had significant benefits for service recipients and their families during an uncertain time and states should continue and codify these flexibilities even after the end of the emergency. However, states should still ensure that service recipients receive person-centered support (including a person-centered plan) and have help from a case manager.

Finally, states should address unmet communication needs among people with IDD by funding communication supports and speech-language services through both general Medicaid and Medicaid waivers. States should also ensure that people with IDD have access to communication supports during the person-centered planning process.

Federal: Hold states accountable for implementing and adhering to HCBS regulations

The federal government must ensure that states comply with laws and regulations surrounding HCBS (such as the HCBS Settings Rule), including ensuring states are appropriately sanctioning providers who break said regulations. If states are out of compliance, including when states are under corrective action plans, the federal government must ensure that states are moving towards compliance. The federal government should pay particular attention to state activities to end the use of restraint and seclusion, to ensure community integration, and to create accessible and timely grievance processes.

The federal government should also support state efforts to promote self-direction of services among people with IDD. This may look like increased funding to states, waiver amendments, and technical assistance. Part of this effort must be to make sure states are providing service recipients with proper supports, including communication supports, to take part in the person-centered planning process.

Better Strategies to Prevent and Respond to Crisis

Crisis response is integral to behavior support services, but the current crisis response system requires significant improvement. The current system is traumatizing, puts people at high risk of (re)institutionalization, and does not address needs that cause the crisis. The current crisis response system must shift to be part of a holistic system that can appropriately address the needs that underlie mental health crises.

Providers: Improve services and build relationships to address health needs

Service providers must focus on crisis prevention, not just crisis response, which includes focusing on the needs underlying a crisis. Essential to this process is treating people with IDD with respect and dignity; ableism and poor treatment has a negative impact on people with IDD's mental health (Branco et al., 2019; Jóhannsdóttir et al., 2022; Kattari, 2020).

We have previously discussed several ways providers can improve HCBS delivery for people with IDD. All of these recommendations play a role in improving mental health and avoiding crises. Ensuring that service recipients have community access, control their own supports and services, receive robust mental health care, have appropriate trauma care, and have strategies to self-regulate when they are upset all contribute to improved mental well-being among people with IDD.

IDD service providers should develop relationships with health care providers to ensure that service recipients' health concerns are addressed in a timely manner, including receiving preventive mental and physical health care. Improving access to routine care increases the likelihood that issues will be spotted before they rise to a crisis level.

States: Improve access to health care and invest in beneficial crisis supports

Improving access to primary physical and mental health care is an important part of crisis prevention. People who have a primary care provider are less likely to go to the emergency room for routine care (Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health & Human Services, 2021) and greater investment in outpatient mental health care reduces psychiatric hospitalization (Lanoye et al., 2017). States should prioritize investing in outpatient primary health care, including mental health care, for people with IDD and mental health disabilities.

States should also support the needs of disabled people by ensuring robust HCBS systems that provide needed support. HCBS, especially direct support, play an important role in making sure disabled people have access to health care. Furthermore, the HCBS Settings Rule mandates that HCBS recipients are able to live with respect and dignity, control their own services and supports, and participate in the community in a desired manner — all of which promote mental health and resiliency.

States also have a great deal of influence over crisis stabilization services available in the community. States should prioritize and fund community-based models that reduce institutionalization and hospitalization. These services provide mental health crisis services in less restrictive settings than hospitals or other institutions and can empower people to manage crises without removing them from their communities.

States must also support non-police responses to mental health crises, including services provided through the 988 Lifeline framework. States should work with local governments to create community-specific approaches to crisis response. States should encourage the development of non-police, non-coercive response systems staffed by mental health professionals who are trained to work with disabled people and who have extensive knowledge of local services and supports.

Federal: Enforce health care civil rights protections and support health needs of disabled people

The federal government plays a key role in ensuring appropriate responses to mental health crises. Core to this is ensuring greater access to preventive health care (including mental health care) for disabled people. The federal government must enforce and strengthen civil rights protections for disabled people in health care contexts.

The federal government must also ensure that people with IDD are not excluded from mental health services on the basis of our disabilities. Our interviewees noted that many mental health services categorically exclude people with IDD. One strategy for helping people with IDD gain equitable access to mental health care is to designate people with IDD, or disabled people as a whole, as a medically underserved population. Such a designation would allow the government to provide additional funding for mental health providers working with people with IDD and fund better and more training for mental health providers about IDD.

The federal government should incentivize, fund, and assist states to implement community-based crisis interventions instead of institutional crisis interventions. Models such as “living rooms” and peer respites have proven extremely effective and should be replicated in different contexts.

Finally, the federal government should continue to evaluate successes and challenges of the 988 Lifeline and to push for non-police, non-coercive responses to 988 calls whenever possible. The federal government should highlight and publicize successful state and local models of non-police, community-based crisis response.

Standardizing Definitions and Improving Behavior Supports Data

Variation in what are actually considered behavior support services and how various services (behavior-specific or not) should be implemented causes service quality and recipients' experiences to vary wildly. These variations stem from a lack of central data collection and standardization of definitions within the state and federal governments. Similarly, lack of centralized data collection and reporting from service providers makes it difficult to tell how any given provider defines any given service and what provision of that service looks like in practice.

Providers: Collect and report detailed data on services provided.

Providers must collect more detailed data on the HCBS they offer and report this data to state Medicaid agencies. Variations in service provision and quality mean that two people with the same disability and similar support needs can receive ostensibly the same service and have very different experiences. Provider reporting of data to states can help ensure that services are more standardized between providers and that states can intervene if a given provider is misrepresenting their services.

States: Create consistent definitions for behavior support services and collect utilization data from providers.

States must take active roles to ensure that behavior support services available under their HCBS waivers employ clear and consistent definitions and that service utilization data is made publicly available. Consistent definitions must be detailed enough to fully explain the scope of a service but should also be written in clear, plain language that people with IDD can understand. States should ensure that their state IDD waivers address the range of mental health supports and habilitative services covered above and that definitions of behavior support employed by the state are consistent with the range of mental and behavioral health needs that individuals with IDD have.

Additionally, states should go above and beyond addressing the needs articulated through federal mandates. State governments, researchers, policymakers, and CMS and other federal regulators must work together to collect and publish robust data on service utilization. States must also make efforts to clear waiting lists and make sure that all people who need HCBS can access these services in a timely manner.

Federal: Improve data collection and encourage greater detail in waiver applications

CMS and other federal authorities must ensure that information on Medicaid waivers across all states is available in a central location that uses clear, plain language in order to improve transparency in how services are provided and reimbursed for. Currently, CMS provides a searchable list of Medicaid waivers; however, this list provides only a very high level and often vague summary of each waiver (*State Waivers List*, n.d.). CMS must mandata additional data reporting from states (e.g., population served by each waiver, services provided by waiver) and ensure that its summaries of waivers are detailed and frequently updated.

CMS can also ensure improved reporting of waiver service utilization via rulemaking and requirements on states to report data. Current proposed rules as of the time of this writing would ensure better monitoring and oversight of HCBS as well as tracking delays and gaps in service provision. CMS should build on this rulemaking to ensure monitoring of gaps across a range of services, particularly behavior support services. While building this reporting approach, CMS should additionally encourage states to expand their current data collection and public reporting of service needs and utilization of services to foster continued innovation and improvement within state service delivery systems.

Conclusions

Despite significant variance in behavior support services between different states, waivers, and providers, there are clear commonalities. The behavior support service system is built on behaviorist, coercive, and often restrictive interventions that seek to control people with IDD rather than understand us. The result is a fundamental misalignment between the interests of service providers and recipients.

What service providers often identify as “challenging behavior” is better understood as reasonable responses to unreasonable circumstances. Most people do not enjoy having next to no choice, privacy, and control over their lives, but this is far too often a reality for people with IDD. Similarly, most people do not enjoy having comforting objects or experiences operationalized as rewards, but this is also a common experience for people with IDD. When people with IDD react to this irrational system with rational anger, annoyance, frustration, and sadness, our expressions of these emotions are too often labeled “challenging behavior” and targeted for extinction, too.

The source of this misalignment in interests is a failure on the part of providers to recognize that all behavior has a cause. What behavior analysts call “challenging behavior” is often an effort to communicate needs, distress, or resistance to intolerable conditions. “Challenging behavior” is too often the result of long-term unaddressed trauma. The main approach, far too often, is to force the person to stop the behavior, rather than looking at what underlies the behavior.

Behavior support services have largely evolved past “screams, slaps, and shocks”-style behaviorism. But the legacy of control-based approaches casts a long shadow. The inaccessibility of mental health services for people with IDD — reinforced by a siloed system based in behaviorist approaches — and the inability of providers to treat people with IDD as fully human has led to a continued “behavior support” crisis of the system’s own making. Until behavior support services fully divest from behaviorism and recognize people with IDD as autonomous human beings, the system will not meaningfully improve.

Effective behavior supports, then, address people’s underlying needs, remove barriers to supports and the community, and treat people with IDD as whole people with rich inner lives of our own. Policies that support these services are policies that support dignity, respect, inclusion, self-determination, and self-direction for people with IDD. The most critical policy approaches — including state compliance with *Olmstead* obligations and individual access to quality, self-directed HCBS — are already the subject of advocacy from disabled people. These approaches are not new, nor are they radical. Provider and government failures to adopt them do not make them so. Nor is this summation of the challenges around behavior support, including the way in which “challenging” behavior can constitute disabled people’s resistance to the indignities providers impose on them.

In 1992, more than 30 years before the publication of this paper, Michael Smull and Susan Burke Harrison published *Supporting People With Severe Reputations in the Community*, describing many of the same issues we describe in this paper. None of those issues, nor the authors’ proposed solutions, were novel or radical then. Neither are they now.

Thirty years later, we are still struggling to transform this system into one that supports the needs of people with IDD, and centers what people with IDD communicate about ourselves, rather than trying to suppress and change us. We hope that this paper, and the approaches to system change that we have recommended, can be a first step on this journey.

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This project was supported by Arnold Ventures, ICDL, and the WITH Foundation.