

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

## Introduction

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### Background

One of the primary aims of home and community-based supports and services is to provide what disabled people need to live as independently as possible in the community, including behavioral supports. Behavioral supports are often defined broadly and inclusive of a range of supports and service aims. The breadth of these definitions can often present challenges in identifying best practices or comparing services across different communities, states, and providers. Behavioral supports can be described — as one state disability services agency writes — 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” (Division of Disability and Rehabilitative Services, 2020). These definitions allow for great variability in services. This means the availability of services varies considerably across waivers and states. There has been limited study examining the approaches and aims that best support community living.

In this white paper, we first provide an overview of the history of community living services and policy for people with intellectual and developmental disabilities (IDD) in the United States. We then consider the issue of defining behavior supports. We address it both in terms of how people providing or receiving behavior supports define the concept and how ASAN defines behavior supports. We focus on the goals of behavior supports and what they should be, particularly as related to behavior deemed “challenging” or “dangerous.” We next address the problems with behavior supports as they are currently provided in many states, including the siloing of behavior supports for people with IDD from mental health services, the tendency of behavior supports to focus on modifying and changing behavior rather than addressing underlying causes, shortages in the direct support professional workforce that exacerbate problems within provision of behavior supports, and reliance on restrictive and coercive practices such as restraint and seclusion within the provision of behavior supports. Finally, we propose changes to federal, state, local, and service provider policies to create a safer, more equitable, more person-centered behavior support system.

### History of Community Living Among People with IDD

To identify the role of behavior supports in the current service provision environment, it is necessary to review the history of community living and home and community-based services. ASAN defines community living as “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” (Autistic Self Advocacy Network, 2021b). While the definition of “community” varies from person to person, ASAN found, in our report “Keeping the Promise: Self Advocates Defining the Meaning of Community Living” (Barrows et al., 2012) that community to people with IDD means a place where you have autonomy, self-determination, and can make choices and exercise control over your life. Many people with IDD receive home and community-based services HCBS in order to live in our communities. HCBS are long-term supports and services disabled people, including people with IDD, receive that allow us to live in the community. This includes direct support or personal care assistance, transportation services such as paratransit, and employment support services such as job coaches. We discuss HCBS in more detail in the section “Community Living and HCBS.”



*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 is different from life in an institution. While the Centers for Medicare and Medicaid Services (CMS) define “institution” or “institutional” in a variety of ways depending on the context, self-advocates have constructed institutions more broadly (Centers for Medicare and Medicaid Services, 2019; National Association for Children’s Behavioral Health, 2022). Self-advocate definitions characterize settings that segregate disabled people and disallow choice and control as institutions regardless of whether they fall into a “typical” or historical category of institution. For instance, ASAN defines institutions as “places that keep disabled people separate from our communities. [Institutions] don’t let disabled people make our own choices” (Autistic Self Advocacy Network, 2021b). Similarly, Self Advocates Becoming Empowered, the national self-advocacy organization for people with IDD, defines institutions as “An institution is any facility or program where people do not have control over their lives. A facility or program can mean a private or public institution, nursing home, group home, foster care home, day treatment program, or sheltered workshop” (Self Advocates Becoming Empowered, n.d.).

For much of the history of the United States, people with intellectual and developmental disabilities (IDD) were denied access to community living. Starting in the 1840s, institutions for people with IDD — specifically, state hospitals and state schools — became more widespread. These large-scale institutions were originally intended as a more therapeutic alternative to poor houses and prisons (Conrad, 2020; Trent, 2021). However, state hospitals, state schools, and similar institutions such as asylums and psychiatric hospitals quickly became hellish places that warehoused people with IDD and disabled people more generally with no therapeutic benefit. By 1967, the height of disability institutions’ popularity, 194,650 people lived in state institutions for people with IDD (Larson et al., 2023). Many people in institutions were placed there as children and would spend their lives in these environments. The names of institutions for people with IDD have changed, from state hospitals and state schools to training centers, to intermediate care facilities (ICFs) and development centers, to nursing homes and “intentional communities.” What has remained is the restrictive, controlling nature of institutions and the warehousing of people with IDD. For more information on the history and changing nature of institutions, please read ASAN’s toolkits on the history of institutions (Autistic Self Advocacy Network, 2020).

The shift from institutional approaches to community-based care has largely been driven by exposure of institutional conditions and resulting public outcry. It has occurred in several waves decades apart. However, efforts to reform institutions or move people out of them have seldom been accompanied by the resources to support people living in the community. Deinstitutionalization efforts without supports sufficient to help people successfully live in their communities have shifted people with IDD from one institution to another, often to settings that are smaller but retain limiting and coercive qualities.

## Community Living and HCBS

The advent of the Americans with Disabilities Act and subsequent litigation have caused a renewed shift from institutional approaches to disability and towards supported community living. *Olmstead v L.C.* has been pivotal in this transition. Lois Curtis and Elaine Wilson, two women with intellectual and mental health disabilities, sued the State of Georgia. The plaintiffs were institutionalized in the state mental health system despite doctor and provider agreement that they could live in the community with support. The state of Georgia failed to provide supports in their communities, forcing them to be institutionalized repeatedly. In 1999, the United States Supreme Court ruled in their favor, holding that Title II of the Americans with Disabilities did not permit states to require people to reside in institutions to receive disability services. Instead, disabled 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). HCBS are long-term supportive services that disabled people, including people with IDD, can receive in our homes and communities, such as direct support, paratransit, and employment support services. One challenge that remained was funding. Medicaid remains the primary payer for most long-term supportive services. These services are only mandatory for states to provide under Medicaid in institutional settings. Consequently, the main vehicle for providing community-based services is through waivers that allow states to use Medicaid funds to provide them. Waivers allow states to “waive” the requirement that they provide long-term supportive services in an institution and allow them to instead spend some Medicaid money giving people HCBS. These services are, by definition, optional for states to provide. This means that Medicaid does not require states to make these services available to every person who uses Medicaid. Waiver services afford states greater flexibility in covered populations and services, but these services seldom

receive the full funding necessary to meet the need for HCBS. This sometimes leads to decades-long waiting lists and gaps in services for people with IDD who manage to qualify for HCBS.

At the nexus between the lack of funding for HCBS and the slow deinstitutionalization process lies a trap for many people with IDD who attempt to access HCBS. Community residential settings, such as group homes, qualify to receive HCBS funding. They do not meet many legal definitions of an institution. However, these settings are often controlling and institutional in nature. People with IDD who have lived in group homes and other community residential settings often report that they are not allowed the most basic choices, such as what to eat for breakfast or where to go during the day. This can mean that a person with IDD waits years on a waiting list for HCBS only to be placed in a group home that is effectively a mini-institution.

Institutional thinking pervades long-term supportive services even when someone nominally receives HCBS in their community. The late autistic self-advocate Mel Baggs wrote “An institution is not created by the shape of the building. It’s created by who holds the power, and what kind of power they hold” (Baggs, 2018). Baggs’ perspective can be seen in how people with IDD who receive HCBS are systematically denied control and self-determination over their lives. Paternalistic attitudes, especially directed at people with intellectual disabilities, result in people who receive HCBS having little to no control over their own lives even if they live in their own homes. Direct support staff may impose their own preferences and beliefs on the people they support. Agencies and case managers may develop daily schedules for people who receive services without consulting those people. If a person is under guardianship, agency staff generally default to what that person’s guardian wants even if the person clearly expresses other choices. Institutional thinking can trap a person living in their own home in an “institution of one.”

### **Behavior support services.**

The use of behavioral interventions for people with IDD is a history that runs parallel to this history of institutionalization. One of the most common and prevalent interventions, Applied Behavioral Analysis (ABA), largely dates to O. Ivar Lovaas’s work at UCLA in the 1970s. Lovaas’s work was based on the behaviorist theories of B. F. Skinner and relied on operant conditioning, using external motivations to alter behavior. Much of the reinforcement used to change subject’s behavior was aversive and violent (Silberman, 2015). Lovaas described hitting, yelling at, and giving electric shocks to children who would not comply, stating, “you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense — they have hair, a nose and a mouth — but they are not people in the psychological sense” (Chance, 1974). A 1965 article in *Life Magazine* titled “Screams, Slaps and Love: A Surprising, Shocking Treatment Helps Far-Gone Mental Cripples” detailed Lovaas’s methods; its own title a testament to how little respect Lovaas and society at large had for people with intellectual and developmental disabilities.

Violent retaliation against people with IDD for non-compliance was commonplace in ABA and related interventions for years and, in some practices, remains to this day. While there have been attempts to reform ABA and remove some of the worst aversives, these efforts have not been adopted across the board. Similarly, removing aversives from ABA has not resulted in changes to the underlying theories and aims of ABA; that is, to make people with IDD “indistinguishable from peers.” Practitioners focus on behavioral compliance-based interventions using reward and punishment to change behavior and expression considered disordered. This mindset has had an outside impact on methods of behavioral support for people with IDD, influencing approaches beyond the ABA framework.<sup>1</sup>

While ABA is most associated with autistic children, it is also used with autistic adults and other people with intellectual and developmental disabilities of all ages.<sup>2</sup> ASAN, in our previous white paper “For Whose Benefit?: Evidence, Ethics,

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<sup>1</sup> See, for example, ASAN’s report “For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions” (2021a), specifically the section “‘New ABA’ is Still ABA.”

<sup>2</sup> See, for example, language in pro-ABA reports and studies such as “Research tends to feature child participants more frequently, however there are many [ABA-based] interventions that may be considered empirically established for both adults and children with IDD” (The Ontario Scientific Expert Task Force for the Treatment of Challenging Behaviour, 2019, p. 7), “Applied behavior analysis (ABA) principles and techniques provide a means of addressing the challenging behaviors of individuals with developmental disabilities” (Fallon & Desrochers, 2014), and “Common uses of ABA among adults is extensive and can be individualized across virtually any behavior of interest” (Hunyadi, 2021, p. 5), as well as studies that specifically apply ABA techniques to autistic adults or people of all ages with other intellectual and developmental disabilities (Corti et al., 2019; K. S. Davis et al., 2019; DeBiase et al., 2022; Gerhardt et al., 2022; Grey & Hastings, 2005; Hassiotis et al., 2009, 2011; Krentz et al., 2016; Lang et al., 2019; Matson et al., 2012; D. H. Reid, 2019; Rodriguez et al., 2022). Roscigno (2023) has also detailed how ABA and its derivatives are used in students labeled with emotional and behavioral disabilities and in children from low-income families, which in both cases disproportionately affects children of color.

and Effectiveness of Autism Interventions” (2021a), documented the decades of resistance to ABA by autistic people and our allies as well as emerging research undermining the common claim that ABA is the “gold standard” of autism intervention. While a full review of ethical concerns with ABA and similar interventions is beyond the scope of this paper, our concerns in “For Whose Benefit?” generally fell into three categories: consent violations and removal of autonomy, pathologizing unremarkable behavior, and interventions where the risks are greater than the benefits.

Beginning in the 1990s, many states and treatment programs have increasingly used services called Positive Behavior Supports (PBS). These services tend to be described as derived from the tools and techniques of ABA, often with particular emphasis on the functional assessment and analysis approach employed by ABA but also incorporating the frameworks around inclusion and person-centered approaches (Dunlap et al., 2009; Johnston et al., 2006). The full impact of this shift in approaches is contested. Many critics note that the behavioral bases of PBS remain a component of this approach and express concern that many interventions described as “positive” still rely on operationalizing reward and punishment to change behavior (Autistic Mutual Aid Society Edinburgh, 2022; Kohn, 2020; Memmott, 2017; Murray, 2020; Therapist Neurodiversity Collective, 2023; Van Gemert, 2018). These concerns are enhanced by the fact that — while some professional organizations have worked to define and provide standards for PBS — the lack of a consistent definition and set of practices means that some services described as positive behavior supports may not align with these self-ascribed principles. The Association for Positive Behavior Support (APBS) recently defined PBS as “a set of research-based strategies used to increase quality of life and decrease problem behavior by teaching new skills and making changes in a person’s environment” (The Association for Positive Behavior Support, n.d.); however, Johnston et al. (2006) noted that there are numerous definitions of PBS and not all of them agree with each other.

ABA and PBS are not the only frameworks for providing behavioral support services to people with IDD but represent a substantial market share of the services available and are two of the most accepted frameworks for behavior support (Broderick & Roscigno, 2021; Minnesota Positive Behavior Support Network, 2023). The overrepresentation of behaviorist interventions within IDD services leaves little room for other, more holistic behavior support services. While more conventional mental health approaches to behavior (e.g., cognitive behavioral therapy, assertive community treatment, trauma therapies) have been adapted for people with IDD, disability services have been slow to implement these approaches for many people with IDD who receive HCBS (The National Association of State Directors of Developmental Disabilities Services, n.d.). Access to mental health care is particularly limited for HCBS recipients who do not have reliable methods of communication other than behavior. The end result is people with IDD being locked in a system that views our actions through a behaviorist lens and does not afford us comprehensive mental health treatment.

## **Aims of this Paper**

The current behavior support environment is one characterized by a lack of agreement between providers, service systems, and governments. There is significant variability in how behavior supports are best designed and implemented, how to best promote community integration through behavior support services, and how the current service system can adjust to the emerging demands of community-based care. While there is agreement on these common aims, the lack of consistent definitions and approaches creates a service environment of tremendous disparity between states, waivers, providers, and approaches. Little research has focused on the efficacy of individual service approaches. Consequently, the available information about best practices for states and providers is limited.

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 that will address these needs. A recurring theme in our review is that existing service delivery models were not built to support the needs people with IDD have today. Post-*Olmstead* approaches to service delivery, including the use of Medicaid waivers to provide HCBS, attempt to adapt the delivery of these services to fit the needs of people seeking to live in more integrated environments than people with IDD in generations past. However, service systems themselves are an obstacle to adequate service provision where they are not structured to support the current experienced and desired lifestyles of people with IDD. They will continue to fall short of serving the disabled community without substantial reform.



## Methods

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### 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 people with intellectual and developmental disabilities.
- 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.

## Defining Behavior Support Services

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### Challenges and Disparities in Definitions

A major challenge is that of definitions. There is broad agreement that the purpose of behavior support services is to support the community access and participation of people with emotional and behavioral support needs that could otherwise limit access. “People with emotional and behavioral support needs” are typically defined as including people with “challenging,” “dangerous,” or “disruptive” behavior. However, this agreement on the generalized aims of behavior support services is where consensus ends. Substantial disparities exist between states and even between waivers within states in terms of amounts and types of services covered and provided as behavior supports (Rotholz et al., 2013).

This reflects differences in service systems and varying levels of system funding and priority placed on community living between states. An additional factor that complicates service delivery is a lack of professional consensus on the core elements of behavior supports, particularly concerning the core definition of essential concepts relating to behavior supports. For example, while the term “positive behavior supports” has seen increased usage for some classes of behavior supports, it lacks a universal definition across providers, agencies, and states using this terminology. Likewise, some purposes of behavioral intervention are not uniformly shared across providers or agencies, leading to behavioral intervention approaches that may undermine other aspects of community living by focusing on priorities that justify more restrictive practices.

### The Dehumanizing “Behavior” Label

The core challenges for defining behavior supports terminology reflect underlying disputes on the best approaches to supporting people with mental, social, or behavioral health needs. As such, it is important to address the varying approaches, language, and definitions providers and policymakers use with regard to the people who receive these services. As discussed previously, many of these linguistic choices reflect the history of behavior supports and the role of frameworks such as ABA in shaping supports, including how “behavior” is assessed, monitored, and targeted for intervention. It is not enough to change language to kinder terminology; we must also change practices, and move away from the approaches to support that produced this language, and which continue to deny agency to people with IDD.

One fundamental challenge in approaches to behavior supports is that actions expressing or demonstrating individual preferences are classified as “behavior” and, thus, appropriate targets for monitoring, intervention, or operationalizing as a behavioral reinforcer. Under behaviorist frameworks drawn from ABA, including many identified as PBS, this can lead to service providers withholding activities that people with IDD find pleasurable, rewarding, or comforting as punishment or a conditional reward. One expert interviewed noted that the distinction between these two can be thin: “That’s called response cost. And that’s a negative procedure, which is also used a lot and veiled as all positives. But what it translates into in a group home setting is, ‘you didn’t earn it.’” This approach is generally reserved for those disabled people who use behavior supports, particularly people with IDD. It would be unthinkable for an aide, assistant, or housing provider to make nondisabled adults’ engagement in private, lawful, comforting or pleasurable activities contingent on behavioral compliance. As an informant without IDD observed, “I don’t have good behavior every day. But I still get to have a glass of Chardonnay at the end of the night. Even if I goofed off at my job all day... I don’t have somebody standing there saying ‘no Chardonnay for you.’” However, many behavior supports recipients experience this kind of coercion on a daily basis.

Even without preferred items or activities being operationalized into rewards or withheld as punishment, support approaches oriented around “behaviors” can have traumatic and dehumanizing effects on those who receive services. Service recipients are frequently aware that their activities are monitored and assessed by behavioral specialists. Several interviews with both service recipients and experts noted that this monitoring process could isolate people or cause them to fear that they may be punished for their actions or for expressing their preferences openly. One expert informant recalled a case where a service recipient’s behavior supports became a source of stress because of this sort of monitoring, leading to further traumatic developments:

I think a lot about this one case where this gentleman had a one-to-one behavioral support [aide], and [the aide] followed him arm’s length, followed him around all day long. And he just was so upset that this aide was following him around everywhere. And it caused him to jump out of a window, because he wanted to try to escape from this behavioral support.

Similarly, service recipients described the knowledge of monitoring and excess regimentation characteristic of behavioral approaches as a source of stress. Once stakeholder described,

There was someone that I know that made a chart of everything that somebody had to do. And this was just their way of organizing. But that to me is a means of control. So that you can tell somebody, ‘you have to do this, this, and this before you do anything else,’ that would be one of the subtlest means of control that I would know.

## Clarifying “Challenging Behavior”

Beyond the issues that a behavioral lens carries for people with IDD, many of us additionally end up with the label of “challenging behavior.” There are many definitions of “challenging behavior,” however, Gur writes that the following definition by Emerson as the “most common definition of challenging behavior cited in the literature” (Gur, 2016, p. 46):

Culturally abnormal behavior(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit or deny access to and use of ordinary community facilities. (Emerson, 1995, p. 4)

While Emerson’s definition of “challenging behavior” is limited in scope, targeting only behavior that poses physical safety risks or would seriously limit one’s access to the community, the term has since become so broad as to be meaningless.<sup>3</sup> The challenge with the “challenging behavior” label is threefold: the label does not specify who the behavior presents a challenge to, the label is applied so broadly as to conflate harmless annoyances and actual danger, and labeling behavior as “challenging” often results in a focus on stopping the behavior over supporting the person engaged in it.

## “Challenging” to Who, Exactly?

A person’s behavior may present challenges to different groups of people. Behavior may be challenging to the person doing it (e.g., an autistic person who hits their head against the wall, resulting in a concussion). Behavior may be challenging to people immediately around the person (e.g., a person who plays loud music while doing their chores, annoying their roommate). Behavior may be challenging to the general good order of society (e.g., a politician who takes bribes). All three of these behaviors are clearly challenging to someone, but each represents a different concern. These distinctions have significant implications for the goals of behavior support, self-determination, and person-centered supports. When the word “challenging” is used interchangeably for each of them, it conflates challenges caused by barriers to community access (such as being required to have a roommate with competing access needs) with the behaviors themselves, identifying the problem in need of addressing as one of the person’s behavior, and not the support — or lack thereof — in their immediate context.

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<sup>3</sup> For instance, examples of “challenging behavior” in subsequent literature include: “avoiding tasks” or “refusing to work” (The IRIS Center, 2022), “knocking items off of shelves” (Rahn et al., 2017), “social withdrawal” (Bearss et al., 2015), “bouncing” or “rocking” (Rojahn et al., 2001), “obsessions, compulsions, and rituals” (*Autism and Challenging Behavior: Strategies and Support*, 2012), “crying” (Meadan et al., 2016), and “perseverating on topics” (Hieneman, 2015). It is important to note that in a later edition of *Challenging Behaviour*, Emerson and Einfeld write that “Since [1995], there has been a drift towards using the term ‘challenging behavior’] simply as a diagnostic label for people. This is both inappropriate and unhelpful” (Emerson & Einfeld, 2011, p. 5).

## **“Challenging” Does Not Mean Harmful**

As we have previously written in our report, “For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions” (Autistic Self Advocacy Network, 2021a) it is, at best, ethically dubious to apply “challenging behavior” and similar labels to unremarkable behaviors. Labeling all unwanted behaviors as “challenging” muddies the definition. Is “challenging behavior” behavior that truly poses harm to the person and those around them (e.g., a child hitting their head hard enough to cause a concussion)? Is it behavior — such as in many descriptions of “eloping” or wandering — where health safety risks exist but result from an inability to provide sufficient support and staffing? Or is “challenging behavior” behavior that poses no harm to the person and those around them but is annoying to people around the person (e.g., someone stimming by waving their fingers in front of their face)?

The problem with this definitional creep is that once behavior is labeled “challenging,” it is often met with the same types and level of intervention, no matter how “challenging” the behavior actually is. One of our expert interviewees recalled being asked to design a behavior intervention plan for a woman with IDD. After coming home from work in the evenings, the woman liked to sit quietly in her room and cut pictures out of magazines. “Sitting quietly and cutting up magazines” is not likely to harm the woman or others around her. It is hardly worth the label of “challenging behavior,” yet the woman’s support staff deemed it necessary to make a plan to change her behavior.

## **Eliminating Behavior but Not Taking Care of Needs**

Once a behavior has been labeled “challenging,” service providers often target the behavior for elimination. However, “targeting behaviors for elimination” ignores the person’s underlying needs. “Challenging behavior” can arise for many reasons. This is especially true in people who have no robust form of communication understood by others, for whom behavior is their only option to get a point across.

In many cases, once a behavior has been labeled “challenging,” the solution is to apply more and more restrictive and punitive interventions to try and make the person stop the behavior. A number of our interviewees noted that many states retain some provisions allowing the use of restraint and other restrictive and coercive practices for addressing “challenging” behaviors. This is frequently premised on interchangeable use of “challenging” to refer to both behavior that poses a serious safety risk and that which does not.

Even when behavior is “challenging” enough to warrant intervention, the solution is not just to target behavior for extinction with escalating restrictive and punitive interventions. All behavior has a cause. Addressing the cause will likely reduce incidence of the behavior without restrictive and punitive interventions. Dr. Clarissa Kripke’s talk on “Understanding Autism, Aggression and Self-Injury: Medical approaches and Best Support Practices” lists various health and non-health causes of so-called “challenging behavior” in people with IDD, including:

- Illness and medical conditions, such as broken bones, urinary tract infections, or acid reflux.
- Neurological conditions, such as migraines or epilepsy.
- Psychiatric conditions, such as depression or psychosis.
- Dental problems, like broken teeth or mouth pain.
- Abuse and neglect by caregivers, such as physical, emotional, or sexual abuse.
- Sensory overwhelm and the need to get away from sensory overwhelm, such as a person leaving a room whenever the lights are turned on.
- Sensory seeking, such as a person who rubs their face on blankets to feel the fabric.
- Communicating bodily needs and emotions, such as the need to use the bathroom or that the person is sexually aroused.
- Altered states from substance use, whether illicit or not, such as someone being drunk or someone experiencing reduced inhibition from a prescribed medication.
- Responding to a lack of social attention, respect, dignity, or fair treatment (Kripke, 2016).



Consider this example of a woman with IDD named Susan, from the excellent guide “Supporting People with Severe Reputations in the Community”:

Five years ago, Susan was living in an agency apartment in the community. However, Susan’s standards of cleanliness were not those of the agency. A control struggle began with a behavior program to increase Susan’s “compliance”. The struggle escalated when she stopped taking her medications. The agency countered with the need for live-in staff, Susan said, “If you move someone in here I will burn it down”, They did and she did. As a result Susan was institutionalized with one of the most disabling behavioral labels, arsonist (Smull & Harrison, 1992, p. 60).

Susan’s story illustrates the need to ask about and pay attention to underlying causes of “challenging behavior.” Susan burned her apartment down, most likely because she felt that agency staff did not respect her wishes of how clean to keep her apartment and to have privacy from live-in staff. To put it another way, Susan wanted to be treated with the same level of respect and dignity that adults without IDD get and have the same level of freedom to make her own choices, even if others did not agree with those choices. If the agency staff had stopped to consider Susan’s underlying wants and needs, and included her in the process, this situation would likely have ended with an intact apartment and an un-institutionalized Susan.

## **More Than Just Language Changes**

While the language others use to talk about people with IDD and our behavior is important, it is not the only or even main issue. The larger issue is the treatment of people with IDD and how people with IDD experience the disability services system. IDD services could, for instance, do away with the “challenging behavior” label in favor of more precise and less stigmatizing language. However, unless providers also change how the disability services system and its agents pathologize and label the behavior of people with IDD, we will end up in the same place but with different labels. Still, language is informative because it reflects priorities for behavioral intervention that undermine the principles of person-centered and positive approaches and default towards interventions oriented around controlling and changing behavior. Instead, the priority should be providing supports that focus on supporting service recipients’ access to the community. This could include adequate mental and physical health care, sensory and communication supports, supports for acute needs that enable someone to remain in the community instead of being tracked to inpatient hospitalization, institutionalization, or incarceration, and sufficient community supports to allow people to meet our self-identified goals. In our appendix, “Acceptable Goals of Behavior Supports” we review the range of acceptable goals of behavior supports and examples of how these goals can be met within treatment plans in detail.

## **Existing Problems with Current Behavior Support Services**

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

Studies have shown that people with IDD are more likely to be diagnosed with a mental health disability (MHD) than people without IDD (Lineberry et al., 2023). Despite this, there remains a deep divide between IDD services and mental health services. The two service systems rarely overlap (Pinals et al., 2022). This fragmentation results in people with co-occurring IDD and MHD being “siloe” into either the mental health services system or the IDD services system and receiving either mental health supports or IDD supports but not both. In this paper, we will primarily focus on people who are sorted into the IDD service system silo.

This siloeing comes from a fundamental misconception: that people with IDD, and especially people with intellectual disabilities, do not have the thought processes necessary to have mental health concerns. One of our professional informants illustrated this when describing her own history in the field:

“[When] I began in the field in 1971, the standard response is that people with intellectual disabilities could not have mental illness because they had no active thought process. And that bias is still with us to a great extent. ... I had a teenage girl [with an intellectual disability] who was clearly depressed. And I took her to a psychiatrist and the psychiatrist said, ‘No, she’s not.’ And eventually she succeeded in killing herself. So I know the dangers of this.”

What follows from this misconception is the siloing of services into two parallel systems that rarely, if ever, interface with each other. When people in the IDD service system have mental health symptoms, especially symptoms that involve “acting out” or “challenging behavior,” we are too often funneled into “behavioral interventions” that seek to change our behavior without addressing the underlying causes. This is particularly true if those causes are related to social — or emotional needs. These interventions do nothing to help with underlying mental health causes and often exacerbate mental health problems. Several informants noted that behavioral intervention can, itself, be a source of trauma and noted that this siloing creates a behavior support system ill-equipped to address trauma in people with IDD, leading to conflict between people receiving services and direct support professionals (DSPs):

The functional assessment creates a lot of problems: people are shamed about their behavior, we focus on what’s wrong with them. [...] What it translates into is people losing rewards, and everything having to be earned, and a power struggle on the ground level between the DSP and the person over their behavior. And this behavioral approach has created a lot of problems [...] we’re labeling people by their behaviors, we’re dehumanizing them by focusing on defining them by their one bad day, [...] and what’s lacking, what’s creating a hole is [...] we don’t have a trauma-informed approach. A trauma-informed approach would show that we need to be nurturing and supportive and focus on healing rather than “fixing” a person [by] focusing on changing their behavior.

This is also reflected in existing literature, which notes that people with IDD — particularly those with additional mental health needs — are more likely to have experienced trauma and less likely to receive support for processing trauma (Paceley & Tudor, 2015; Rich et al., 2021).

One major flaw of treating all mental health symptoms as “challenging behavior” is that behaviorist approaches do not consider the role of internal processes in behavior. Thyer, writing in the journal *The Behavior Analyst*, explicitly states, “Given that the ‘mind’ is completely eschewed as a potential causal mechanism by behavior analysis, it is clear that psychology is quite a different field” (Thyer, 2014, p. 139). A behaviorist framework sees people as bundles of behavior reacting to external stimuli. Such a framework would be intensely dehumanizing to anyone under its scrutiny but is especially harmful to people whose source of distress is internal.

The techniques employed by behaviorist interventions are at best callous and self-defeating and at worst outright abusive. Planned ignoring — where those around the person withhold attention or interaction until the person completes a task — teaches a person that their needs are not important and that others can choose to ignore them for seemingly no reason (Delahooke, 2015; Pretti-Frontczak, 2020). Token economies undermine internal motivation and lead to resentment by dangling rewards and punishments in front of a person for completing — or failing to complete — a task (Kohn, 2020). As discussed above by one of our informants, even when such a system is given a “positive” frame focused on offering rewards only, withholding rewards and privileges frequently becomes punishment in practice — a phenomenon employed in behavioral practices as an aversive known as “response cost” (Pritchard, 2013). Discarding a person’s subjective internal state as irrelevant to their behavior or motivations or referring to emotional states as “metaphysics” communicates that behaviorists do not care about the mental well-being of their clients, so long as those clients behave “properly” (*Behavior Analysis*, 2024; Montgomery, 2019) This makes behaviorist approaches inherently traumatic.

The present HCBS waiver systems were built on an already-siloed system of mental health and IDD services. IDD service systems and mental health support service systems are typically distinct entities serving different populations. The continued effects of this siloing have limited the availability of mental health services for waiver recipients. One informant observed that, because IDD service systems have frequently formed separately from mental health service systems, many mental health service systems have not built the capacity, competency, or accommodation practices to support the needs of people with developmental disabilities. Meanwhile, IDD systems have provided a narrow focus on behavior assessment and management which frequently default to the behaviorist approaches discussed above. The result is a mental health service system which is under-equipped to support the needs of patients with intellectual and developmental disabilities and a developmental disability service system that seldom addresses mental, social and emotional health needs except through behavior management approaches. This informant described this as follows:

With regard to separating out mental health and IDD, that’s because people didn’t believe people with IDD could have mental health issues. They thought they only had challenging behavior. And on the IDD side, they didn’t think that anybody on the mental health side had any issues with being neurotypical or atypical, which is complete

nonsense. So those dividing lines have undermined the capacity of the system to grow and develop and emerge in a better way. And what has resulted is a high use of crisis services, police, incarceration — a lot of people are in jail — and institutionalization.

So the last and least served, people who are considered to have behavioral challenges, are the ones who end up stuck in hospitals, institutions, and jails. And it's a breakdown of the system that has resulted in it. And because of the way the waivers are written, the right to refuse to serve people, even if it's discriminatory and in violation of the ADA, is prominent. So mental health providers will say "we don't serve people with IDD", which of course, is discriminatory, right? They couldn't say "we don't serve blind people," "well, we don't serve people in wheelchairs," "we don't serve the deaf community". Why [IDD]? Why can't you serve people with [IDD]? What's that about? But that's allowed in many states.

Even when people with IDD have access to services under the "mental health care" umbrella, these services are often limited to psychiatry, not psychology. People with co-occurring IDD and MHD may be prescribed psychiatric medication, usually under the auspices of "reducing challenging behavior." The use of antipsychotic medications is particularly concerning given their side effect profile and how often they are prescribed. Smith et al. (2022) found that between 21% and 74% of people with IDD are prescribed at least one antipsychotic medication despite the serious side effects of these medications. Additionally, prescription guidelines such as the National Institute for Health and Care Excellence in the United Kingdom state that "[antipsychotic] medication should be offered only in combination with psychological or other interventions" for "challenging behavior" and that these medications should only be used when other kinds of treatment, such as psychotherapy or treatment of medical conditions, have not helped (Deb et al., 2023). However, there is little, if any, evidence as to how often antipsychotic medication is used as a first-line intervention in people with IDD or how often antipsychotic medication is tried in tandem with behaviorist, rather than psychological, interventions.

This issue is particularly pronounced in people with IDD who do not have a reliable method of communication other than behavior. People with IDD who rely on behavior to communicate are often dismissed as "low-functioning," "non-communicative," or having "no insight" into their needs and lives. These labels, in turn, are used to justify the use of ABA and similar behaviorist approaches under the assumption that people who rely on behavior to communicate do not need mental health support so much as behavior modification. Despite the fact that several studies have hypothesized or established a link between mental health disabilities (particularly anxiety disorders) and "challenging behavior" in people with IDD, book chapters published as recently as April of 2023 and June of 2023 still posit that "challenging behavior" can be fit into one of four categories: gaining attention from others, sensory-seeking, escaping from an unwanted task or environment, or gaining access to tangible items (Bowring et al., 2019; Jessel & Saini, 2023; Oliver et al., 2022; Pruijssers et al., 2014; Rios et al., 2023). None of the "four functions of behavior" account for mental health status or psychiatric illness. Moreover, non-speaking autistic people and autistic people with intellectual disabilities are often excluded from participatory autism research but have been included in ABA research (Fletcher-Watson et al., 2019; Keating, 2021; Tager-Flusberg et al., 2017; Thurm et al., 2022). This may skew the evidence base, making it appear as if ABA and similar interventions are more effective for non-speaking autistic people and autistic people with intellectual disability than they really are.

Even for people with IDD who have reliable communication via oral speech, sign language, or AAC, the accessibility of mental health care remains a major concern. A systematic review of barriers and facilitators to autistic people accessing mental health treatment found that mental health professionals, such as therapists, are not prepared to work with autistic people with mental health disabilities (Adams & Young, 2021). Similarly, a study of the mental health care experiences of young adults with IDD found that "[mental] health providers may not consistently treat young adults with respect and may not believe young adults' mental health problems" (Kramer et al., 2019, p. 108). One of our expert interviewees described this service environment: "what I've seen around the country, that you're denied access to mental health waiver services, if you have a developmental issue, and you get relegated to one form of treatment, which is behavior modification."

While there is scant literature about barriers to accessible mental health care for AAC users, what exists points to significant barriers. This includes mental health professionals not knowing about AAC or how to interact with AAC users, appointment length not being long enough for AAC users to effectively communicate, and a lack of vocabulary around mental health within AAC systems (Noyes & Wilkinson, 2022; Watson et al., 2021). AAC users and people with IDD

who use a signed language as their primary language may also face barriers to simply making an appointment. While the comparison is not perfect, it is useful to look at the experiences of Deaf and hard-of-hearing people in accessing health care, as these groups often face similar barriers to care as hearing people who do not use oral speech. Studies of Deaf and hard-of-hearing people's access to health care have identified barriers such as appointment scheduling only being available by telephone, health care professionals not being familiar with TTY or video relay calls, policies that prohibit email communication with health care professionals, lack of sign language interpreters, inaccessible telehealth platforms, and resources only available in complex written English (Hinchcliff & Harrison, 2022; Recio-Barbero et al., 2020; Steinberg et al., 2006). While there is little research on the barriers faced by hearing people with IDD who do not use oral speech, there is no reason to believe that this group does not face similar barriers to Deaf and hard-of-hearing people. Additionally, just as Deaf and hard-of-hearing people may not understand complex written English due to language barriers and ableism and audism in education, people with IDD often need written communication and resources in simpler language.

One barrier to providing quality mental health services for people with IDD is that mental health providers are often untrained or undertrained in working with people with co-occurring IDD and MHD (Hemmings & Bouras, 2021). Williams and Haranin (2016) found that just half their sample of therapists had received education on IDD in school, while Huff (2021) noted that few graduate psychology programs in the United States provide training in working with people with IDD through the lifespan. While a variety of psychotherapies have been adapted for or shown promise in people with IDD and MHD, mental health providers are still often reluctant to work with people with IDD.<sup>4</sup> The siloing of mental health and IDD services is a self-reinforcing cycle. People with IDD are assumed not to need mental health services, so few mental health providers are trained in working with people with IDD. Since there are few competent providers available, people with IDD are not able to access mental health services. This leads to the perception that people with IDD do not need or want mental health services, and the cycle begins again. One informant described the bind this puts recipients in as follows:

Everywhere I go people say to me, well, we can't find therapists. And the therapists tell us they're not trained in working with autism or intellectual disabilities. And so they're not going to do it. They can't. But then we all know — we in the clinical world that — there is no training, maybe two trainings in two colleges in the entire country. I mean, there's very little to none. So that just puts us in a terrible conundrum.

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<sup>4</sup> Therapies adapted for people with IDD include: cognitive behavioral therapy (CBT) (National Institute for Health and Care Excellence, 2016; Willner & Lindsay, 2016), dialectical behavioral therapy (DBT) (Kraft, 2020; Miyamoto, 2021), psychodynamic psychotherapy (Beail, 2016; Beail & Jackson, 2013), mindfulness (Hwang & Singh, 2016; N. N. Singh et al., 2013), interactive behavioral therapy (IBT) (Burke, 2013), and eye-movement desensitization and reprocessing (EMDR) (Didden & Mevissen, 2022; Keesler, 2020). EMDR has been noted as particularly useful in working with people with IDD because it does not require significant oral speech from patients (A. Miller, 2021)



## Limitations and Challenges of the “Behavior Support” Framework

Service systems’ reliance on behavioral interventions creates a framework where people with IDD are foreclosed from access to mental health services. These may include, but are not limited to, individual or group psychotherapy, occupational therapy, physical therapy, speech/language therapy, support or affinity groups, peer support, and social activities such as community education classes. As one of our expert interviewees put it “Why can [people with IDD] all get a behavior plan, but they can’t get an [occupational therapy evaluation]?” Another informant drew a distinction between behavior supports provided under HCBS waivers as primarily focused on assessment and planning, and mental health supports:

I would say behavioral supports look like assessment, support planning, ongoing training, and working with the team to support the person. And then [...] there’s behavioral health supports. Behavioral health supports, to me, take more of a spin on the mental health treatments, things like therapy, things like counseling, again, all working together. But behavioral health supports typically are provided under the mental health umbrella in states.

A common observation from a number of our informants who provide support services outside of what is commonly considered “behavior support” is that these services are often unavailable under Medicaid waivers for IDD. One notable effect of siloing of behavior supports from other services is that many tools to support the mental, social, emotional and sensory needs of people with developmental disabilities are not well supported through IDD waivers. One informant, an occupational therapist serving children and adults, described the value of occupational therapy for sensory processing for autistic clients and noted that OT services were under-delivered to adults with IDD. This informant noted that only her child clients were covered through Medicaid, and typically through school-based services. By contrast, all of her adult clients were self-paying and typically did not have the option of seeking OT services through Medicaid waivers. Another informant discussed the ways in which therapy and other approaches to addressing mental health needs are often neglected under a behavior support framework:

The prejudice and the bias against people with intellectual disabilities has meant they’ve not benefited from developments that have occurred in the mental health field. So, for instance, as people in the 70s and 80s began to understand depression, began to understand what anxiety is, began to name bipolar disorder, our folks were still considered to have behavior problems. [...] And that continues. The way our system responded to behavior was behavior management.

## Changing and Modifying Behavior vs. Addressing Underlying Needs

The narrow focus of behavior supports causes many to be exclusively oriented towards controlling behaviors rather than addressing underlying needs. This occurs even when supports are labeled “person-centered” or “positive.” This framework of managing behavior is deeply dehumanizing to those targeted by it.

It is important to recognize that the actions termed “behaviors” in a derogatory sense, including “challenging behavior” or “dangerous behavior,” in people with IDD are often natural reactions to living within a dehumanizing and controlling service system. People who receive IDD services are routinely infantilized, disrespected, disallowed the most basic choices about our lives, monitored and tracked, abused or neglected, and disbelieved or written off as “non-credible” when we report any of this mistreatment. Very few people — whether disabled or nondisabled — would respond well to not being able to choose what they eat for dinner, to having their every action recorded on a behavior chart, to being denied opportunities to see friends because they hadn’t “earned the privilege” that week, or to being injected with powerful sedatives to make them more “easier to get along with.” Yet all these things are routine injustices that people with IDD who receive services face in our everyday lives.

It is unrealistic to expect anyone to react well to having their life controlled by an impersonal system that views them less as a person than a bundle of problems to be fixed or managed. It is even less realistic to expect people with IDD and mental health disabilities, which often impact one’s ability to regulate emotions, to react well. The disability services system understands this insofar as it knows this is part of why large-scale institutionalization is wrong. However, services systems have not fully internalized this fact when people with IDD are still being trapped in group homes

and other “home-like” settings that deny us virtually all control or choice. “Home-like” settings are not the same thing as actual homes. The people living in them know this. As one of our expert interviewees put it, “nobody in the [group homes], in my asking that question [‘Whose home is this?’], has ever said, ‘it’s my place,’ because it’s not their place, and they know it.” While the implementation of the HCBS Settings Rule may improve conditions in group homes and other congregate living situations somewhat, it will not fix the underlying problem — that people in group homes yield control over their lives to paid staff.

Beyond these indignities, people with IDD are more likely than those without to experience significant trauma. People with IDD are more likely to have adverse childhood experiences (ACEs), including abuse or neglect or having an absent or incarcerated parent (Reichman et al., 2018). Children, adolescents, and adults with IDD are also more likely than peers without IDD to experience bullying (Fisher et al., 2016; Griffin et al., 2019). People with IDD are also more likely to experience violent crimes, including sexual assault, at a rate higher than both people without disabilities and people with disabilities other than IDD (Harrell, 2021). In some cases, these crimes are classed as hate/bias crimes, although the number of disability-related hate/bias crimes on record is probably an undercount because of the way these crimes are reported (Landman, 2014; McKinney, 2018; Sherry, 2010, p. 74). Additionally, people with IDD face significant discrimination from police and the criminal legal system. This includes police violence and refusal by the criminal legal system to take crimes against people with IDD seriously (Autistic Self Advocacy Network, 2017a; Copenhaver & Tewksbury, 2019; The Arc’s National Center on Criminal Justice and Disability (NCCJD), 2015). All of these things contribute to mental ill-health and “challenging behavior” among people with IDD, especially when they go unrecognized and unchallenged.

“Challenging behavior” and behaviorist interventions are often a self-reinforcing, self-justifying cycle that traps people. A person has “challenging behavior” because their underlying needs are not being met. Service systems respond with interventions that do not consider why the person engages in the behavior or address the underlying needs causing the behavior. The person is often then subjected to humiliating, traumatic, and unwanted behavior modification interventions. In many cases, the “challenging” behavior increases because of resistance to or negative feelings about the intervention. When this happens, the intervention typically increases in intensity. At no point does anyone ask the person how they feel or consider the effect the interventions might be having on the person’s emotional state. Even if the person manages to control their behavior to the extent others expect of them, this frequently leaves them with the same unaddressed needs but fewer available means to communicate their needs or express distress. This only contributes to further mental and physical distress, in addition to any traumatic impact of the interventions themselves.

Labeling behavior coercion and control as “person-centered” or “positive” does not change the dehumanizing nature of the underlying framework. As ASAN previously noted in our report “For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions,” “new” or “gentle” ABA is still ABA — “[it] is still harmful to try and modify autistic traits or the appearance of autistic behavior, even if it is couched in toys and the appearance of fun” (Autistic Self Advocacy Network, 2021a, p. 18). The same principle is generalizable to all interventions that seek to control behavior and to all people with IDD. We have already discussed how language changes, while important, are not enough. The fundamental nature of the disability services and waiver system must change, and must truly center people’s goals and ways to support people positively.

## **The Workforce Crisis and its Impacts**

The home and community-based services (HCBS) workforce in the United States is facing a severe shortage of workers. This shortage seriously impacts the amount and quality of HCBS people on waivers received. Although this crisis began before the COVID-19 pandemic, the pandemic has only exacerbated its scope and impact. In this section, we will explore the extent of the HCBS workforce crisis, its effects on service recipients and providers, and its implications for the provision of behavior support services.

Many home and community-based services are provided by direct support professionals. DSPs assist disabled people and older adults with a variety of tasks, including activities of daily living (e.g., eating, toileting, bathing), community activities such as shopping and attending appointments, health and hygiene tasks (e.g., taking medication), chores and activities around the home (e.g., cooking, doing laundry), working for pay, and in social activities such as attending community events (President’s Committee for People with Intellectual Disabilities, 2017). The direct support workforce

is disproportionately made up of women, people of color, and immigrants, and DSPs are often the primary earners for their households (Bershadsky et al., 2022, pp. 2–3). In 2019, there were 4.6 million DSPs in the United States and the direct support workforce is slated to add up to an additional 1.3 million jobs by 2028 (Campbell et al., 2021, p. 6).

Despite the vital jobs that DSPs do and the growing need for direct support and care, direct support workers are paid extraordinarily poorly, including when compared to other direct care professionals or other frontline service workers. In many places, DSPs make minimum wage, and the average starting pay for DSPs across the United States was \$13.61/hour in 2020 (Bershadsky, 2022). For DSPs who are primary breadwinners, these wages are unsustainably low. This disparity in wages is partly because there is no federal training requirement for DSPs, nor is there a Bureau of Labor Statistics occupational classification for DSPs (Bershadsky et al., 2022, p. 2). Lack of training requirements leads to DSP work being seen as “unskilled” labor that does not need to be fairly compensated. Similarly, a lack of a standard occupational classification makes it difficult to track how many DSPs there are nationwide. It is also important to recognize the role that sexism, racism, ableism, and ageism play in devaluing care work that is overwhelmingly performed by women and people of color and overwhelmingly received by disabled people and older adults. And, unlike their counterparts who work in large, state-run institutions, DSPs are overwhelmingly not unionized, despite the fact that unionization often leads to higher wages, better benefits, and decreased turnover (Howes, 2014; Trombley, 2022).

All of this leads to a direct support workforce crisis, the impacts of which on people with IDD who receive HCBS cannot be overstated. The President’s Committee for People with Intellectual Disabilities (PCPID) found that “Nationally, the average annual turnover for DSP positions is an estimated 45 percent, with a range of 18–76 percent ... About 35 percent of DSPs leave their positions in less than six months, and approximately 22 percent leave within 6–12 months,” compared with a national turnover rate of 3.5% across all industries (President’s Committee for People with Intellectual Disabilities, 2017, p. 20). The COVID-19 pandemic only exacerbated this issue, with over half of DSP agencies reporting decreases in the number of DSPs they employed during 2020 and the turnover rate ranging from 27% to 80%, with an average turnover rate of 44%. The vacancy rate averaged 12% and 16%, for full-time and part-time positions, respectively (Bershadsky et al., 2022, p. 8).

People with IDD who receive HCBS feel the impacts of the direct support workforce crisis most acutely. When there are fewer DSPs, fewer people can receive services. Those who do often receive less individualized support and attention. In practice, this may look like people who were previously living in their own homes being forced into congregate settings such as group homes or nursing homes because there is not the staffing available for them to remain safely in their own homes. Given that people living in congregate settings make up a significant proportion of COVID-19 cases and deaths, it is imperative that people receiving HCBS remain in non-congregate settings (e.g., our own homes or family homes) whenever possible (Chidambaram, 2022; Musumeci & Chidambaram, 2021; Ochieng et al., 2021). But the impacts of being forced to move into a congregate setting go beyond health risks. As we have previously discussed, people living in congregate settings have significantly less choice and control over their lives than their peers in the community. Someone living in a group home may not have any real choice in who they live with, what they do during the day, or when they can attend community events. This is especially true when group homes and other congregate settings are understaffed because insufficient staffing may mean there are no staff members available to transport or support someone who wants to break off from the group and engage in activities of their choice. People who receive HCBS in congregate settings have the right to individualized services under the HCBS Settings Rule, but lack of staffing means they have no opportunity to exercise their rights.

High staff turnover rates also mean provider agencies may be less willing to train their workers due to concern about investing time and money in staff who will leave after only a few months. One of our expert interviewees spoke to this, saying, “I’ve heard executive directors say, ‘You know what, we can’t afford [to train people] right now,’ or, ‘[Why] train people that are going to be just leaving for three months?’” Because there are no federal standards for DSP training, and because state standards for DSP training vary, provider agencies have little incentive to offer or require more than the bare minimum. When training does happen, it rarely covers preventing crises and meeting people’s needs and instead tends to focus more on reacting to crises. Often, this training focuses on restrictive and coercive practices, such as restraint and seclusion. This, all too often, leads to a situation where DSPs are not trained or equipped to prevent and de-escalate crises. Therefore, they rely on restrictive and coercive practices. This leads to staff restraining or secluding service recipients, placing service recipients on controlling behavior plans, and overmedicating recipients keep them docile. None of these are appropriate outcomes.

Lack of appropriate staff coverage places significant stress on DSPs and other direct care workers. Metzger (2018) estimated that between “25% to 32% of DSPs experience work-related stress and burnout” and that DSPs who work with people with challenging behavior are more likely to experience stress and burnout. Kaminishi et al. define caregiver burnout as “the degree to which a caregiver’s emotional or physical health, social life, or financial status has suffered as a result of caring for a relative with major or mild neurocognitive disorder (NCD), other neuropsychiatric conditions, or functional impairment” (2018, p. 692). DSPs can also experience secondary traumatic stress (STS). STS is defined as “a parallel process in reaction to [professionals] empathically experiencing the psychobiological impact on clients of both their traumatic event(s) and their subsequent symptoms of PTSD” and shares structure with structure and symptoms with post-traumatic stress disorder (PTSD) (Sprang et al., 2019, p. 76).

Stress, burnout, and STS all impact DSP performance in caring for people with IDD. This, in turn, leads to poorer treatment for people with IDD, including fewer social interactions and less community integration for people with IDD and staff treating people with IDD with disrespect (Bigby et al., 2012; Qian et al., 2015; Stancliffe et al., 2022). While there is little data available on how staffing shortages in group homes and other HCBS settings affect the use of restraint and seclusion, there are studies linking staffing shortages in psychiatric facilities to increased use of restraint and seclusion (Galbert et al., 2023; McKeown et al., 2019). Additionally, there are studies linking reduction of staff stress in long-term care with decreased use of restraint and seclusion (N. N. Singh, Lancioni, Karazsia, & Myers, 2016; N. N. Singh, Lancioni, Karazsia, Chan, et al., 2016).

DSP turnover directly negatively affects the experiences of people with IDD who receive HCBS. Direct support is a personal, intimate profession. DSPs are involved in all aspects of a person’s life, from basic hygiene to full integration in the community. It is to be expected that people who receive HCBS would want and need DSPs who can commit to long-term work. When DSPs leave after only a few months, the person receiving services faces the prospect of working with a new DSP who may or may not be trained in providing the care they require and knows very little about their needs. Expecting people with IDD who receive HCBS to put our private lives on display for a revolving door of staff shows the disability service system’s lack of concern for service recipients’ privacy and safety. DSP turnover is not evenly distributed among people with IDD who receive HCBS, either. A study by the Council on Quality and Leadership found that people with IDD who have “behavior challenges,” Latinx people with IDD, people with IDD who lived in congregate settings, and people with IDD who received 6 or more hours of support per day all had increased likelihood of having a DSP change in the last two years (Friedman, 2018).

The lack of quality, trained DSPs means that a person with IDD who receives HCBS have little choice in service provider or who their DSP will be when they can access services at all. This results in little true ability to self-direct care. If a service recipient is unable to work with a particular provider, or a particular agency’s approach to support is incompatible with their needs, they may find themselves without access to a more appropriate alternative. People with IDD often find that we must stay with an unsuitable provider or go without services. Combined with the burdens of a high-turnover, direct support workers often lack the experience and training to provide the best care for the people they support. This leads to workers defaulting to restrictive practices out of expediency and inexperience and harming those they are supposed to support. As a result, the harms created by an overburdened workforce are transferred directly to those receiving services.

## **Restrictive and Coercive Practices**

One particular area of concern for HCBS behavior supports is the continued use of restrictive and coercive practices within behavior plans. As discussed in our introduction, restrictive, coercive, and aversive behavioral interventions have a long, sordid history because of past disrespect for the rights of disabled people. While *Olmstead* and movement towards self-direction and home and community-based services have represented a shift from “managing” disabled people to one of supporting us, many of these practices remain in use, often despite discouragement under the law.

Some of the most notorious forms of restrictive and coercive practices are restraint and seclusion. Restraints are interventions that restrict a person’s movements. These can be mechanical restraints intended to immobilize. They can also be chemical restraints — medications used to restrict someone’s movements through sedation. Seclusion is when someone is isolated without direct supervision, typically in an enclosed room. Both of these forms of restrictive practices are known to carry tremendous potential for physical and psychological harm, including injury or death. Disability advocates and civil rights groups have long advocated against their use. The HCBS Settings Rule requires providers to



ensure that service recipients are free of restraint and seclusion, with narrow exceptions that must be time-limited, and include documentation of less restrictive approaches to address needs that have been tried and failed. Yet, many IDD waivers permit the use of restraint or seclusion, leading to their continued use despite sharp limits under federal law. In interviews, expert informants expressed grave concerns about these practices, including the potential for physical and psychological harms from their use.

Restraint and seclusion are some of the most notorious and hazardous forms of restriction and coercion, but they are by no means the only coercion people with IDD experience. Even where behavior plans are “positive” in approach, behavioral tools carry inherent risks of coercion. Even when oriented towards rewards, these approaches are often effectively punitive as described above. These still amount to a form of control that can carry additional psychological harms by depriving people with IDD of control over our day to day lives, subjecting our activities to intrusion, imposition, and dehumanization.

Service recipient informants frequently described either experiencing restriction in activities or compliance-based coercion around behavioral goals — either for themselves or service recipients they knew. A common remark from service recipient informants was that the experience level of support workers were key to preventing coercion:

If you're out of the field for two or three years, they're going to require that you take the [training] courses again. I think that there should be some understanding of behaviors that different people can have, before somebody gets thrown into a situation that could be detrimental to everybody.

In general, service recipients recognized that use of restrictive measures as a sign of improper support approaches and highly valued being able to live independently, to seek jobs that they preferred, and to find recreation and volunteer opportunities that appealed to them without these activities being operationalized into rewards or withheld as punishments.

Under HCBS, the person-centered service plan is meant to be an integral part of tailoring services to an HCBS service recipient's needs. The person-centered plan is supposed to ensure that recipients can seek and direct supports and set goals that they designate and remain free of the kinds of restrictive and coercive approaches discussed here. The practice around person-centered planning, however, remains inconsistent with these aims. A majority of our professional informants agreed that person-centered plans frequently fall short in practice. Informants claimed that person-centered plans often prioritize the interests of providers or caregivers over those of disabled people themselves. Several informants described the practical impact of plans as being “provider-centered” or “parent-centered” plans when reflecting on this. When the disabled person is not the one setting the plan's goals, ostensible “person-centered” goals become a form of coercive practice, one which may feed additional restriction and coercion. Service plans formed without adequate input from the person may call for behavior changes to meet undesired goals. The lack of interest or cooperation with these imposed goals is then interpreted as noncompliance and “challenging” behavior. As one service recipient put it,

I will say that [...] the goal they wanted me to work on? That didn't help me because I didn't want to do it. And I didn't like to go and watch a video at the library. I said, “I'm sorry, I'm not doing that. I'm not doing that every day.” And guess what, did I do it? No, I didn't.

## **Lack of Individual Choice and Customization**

A significant problem for people with IDD who receive HCBS behavior supports is the lack of individual choice and control over services, even when services are required to be “person-centered.” People with IDD are often shunted into services that do not meet our needs because those services are “what's available” or what other people think will be best for us. While federal rules now require HCBS to be based on a person-centered plan — that is, a plan written by the service recipient and their team that focuses on the recipient's needs, wants, and goals and how services will meet them — in practice, services for people with IDD often do not include the service recipient in the planning process. The majority of waivers for people with IDD allow for self-direction of services; however, people with IDD rarely take advantage of this option. When we do, the person directing the services is often not the service recipient. These problems are not restricted to behavior support services, but they do contribute to the overall lack of control people with IDD have over behavior support services that are ostensibly for our benefit.

Person-centered approaches in disability services have existed for decades now (O'Brien & O'Brien, 2000). The goal of person-centered approaches is, according to the disability services divisions of several state governments, to support a person's control and self-direction over their services and life by learning about what that person considers important to them in different life domains (Department on Disability Services, n.d.; Developmental Disabilities Services Division, n.d.; Office for People With Developmental Disabilities, n.d.; Services for People with Disabilities, n.d.). Core to the idea of person-centered thinking and planning is that services should be matched to a person's needs, wants, and goals, rather than people being matched to available services. Yet, despite the promises of person-centered planning, many people with intellectual and developmental disabilities are still limited by what services are available to them (I. Brown & Brown, 2009; Frounfelker & Bartone, 2021). For example, Gould (2023) writes about his son, David, who has an intellectual disability, lives in a group home, and works in a sheltered workshop because those are the only options available in the county. One stakeholder informant, a parent of two autistic young adults receiving services, echoed this experience, describing:

All throughout the summer, I'm checking with the case manager, like, "Have you found somebody yet for the school year? Because school teachers go back to work." And they didn't have a one-on-one who was going to be able to be with my older son [...] for the beginning of the school year after he would come home from school. [...] There was no one. I talked to three separate agencies, and they all said, "We have waitlists, if you're willing to drive him 45 minutes, or if you're willing to pick him up 45 minutes from his home." And then after Christmas, the agency was able to find piecemeal for separate people who could make it work week by week. So then my husband ended up actually changing his work schedule so that he could be home when [my son] would get off the bus. So it has been a bit of a disaster.

While the HCBS Settings Rule "requires a person-centered process for planning HCBS, which means that the individuals receiving services direct the planning process and the plan reflects their own preferences and goals they have set for themselves" (Administration for Community Living, 2023), the quality of person-centered plans for people with IDD is often dubious. One of our expert interviewees described the options people with IDD have as a predetermined "menu" based on their "behavioral profile[s]" or medical needs. Another expert interviewee, who has worked extensively with people under guardianship, explained "I've seen a lot of Person Centered plans be really about some kind of third party, be it a guardian or other kind of decision maker than the person themselves. And it's really more driven by the wishes of that other person, as opposed to the person themselves." A third expert informant talked about person-centered plans that imposed goals on the person receiving services, saying a goal "gets justified as, 'well, it's best for the person if they're not aggressive to someone else. So we're going to train them not to be aggressive.'"

While many HCBS waivers for people with IDD offer the option for self-directed services, the majority of people with IDD who receive services do not choose this option. Self-directed services allow "participants, or their representatives if applicable, [to] have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process" (Centers for Medicare and Medicaid Services, n.d.). In other words, self-directed services allow HCBS recipients more choice and control over their services, including being able to hire and fire support staff, having more control over the services they receive, and being able to choose how they spend their services budget. Approximately 74% of state waivers for people with IDD allow self-directed services (Watts et al., 2022). Yet, according to National Core Indicators surveys, only 19% of people with IDD self-direct their services, as opposed to 39% of older adults and adults with physical disabilities (National Core Indicators- Aging and Disabilities, 2023, p. 130; National Core Indicators- Intellectual & Developmental Disabilities, 2023, p. 6). This number is further complicated by the fact that self-directed services do not require the service recipient to have sole control over their services. Rather, a representative of the service recipient (such as a parent or legal guardian) can be the one directing the services. The National Core Indicators survey of people with IDD found that, of those that have self-directed services, only 13% make most of the decisions about their services (National Core Indicators- Intellectual & Developmental Disabilities, 2023, p. 7). Other studies have found that, of people with IDD, autistic people and younger people are the most likely to use self-directed services (Bogenschutz et al., 2019).

Moreover, people with IDD who receive HCBS in residential, quasi-institutional settings (e.g., group homes, adult foster or host homes, assisted living facilities, or supported living settings) are often not eligible to self-direct their own services

under many state waivers (Bogenschutz et al., 2019). The SPARK Initiative report “Promoting self-direction in state and local I/DD programs” (2019) identifies a host of barriers to people with IDD self-directing our services, including administrative burdens such as paperwork, lack of knowledge about self-directed services, service provider reluctance to promote self-directed services, support worker shortages, and training and credentialing requirements. These barriers may most impact people with IDD who have the least power and who are in greatest need of self-directed services: those under guardianship, those who live in institutions and group homes, and those who need the highest level of support.

All of these issues contribute to the dissatisfaction and poor outcomes of people with IDD who receive HCBS. While little is known about how these issues impact behavior support services specifically, there is no reason to believe that these issues do not contribute to dissatisfaction and poor outcomes among people with IDD who receive behavior supports. Behavior support services, historically and currently, often exercise a great deal more control over recipients’ lives than other types of HCBS. It is unsurprising that this contributes to frustration, stress, and feelings of lack of control that can adversely impact disabled peoples’ mental health and quality of life.

## “Behavioral Crisis” Interventions

Without adequate community-based mental health services, people with IDD and MHD are more likely than people with MHD alone to go to the emergency room for a mental health crisis (Tint & Lunsy, 2015). As a consequence, mental health crisis services are considered an essential purpose for behavior supports. Yet, these interventions, when designed incautiously, can hamper service recipients’ ability to remain in the community, rather than enhancing it.

While mental health crisis services can be helpful to people with co-occurring IDD and MHD, these services also are frequently inaccessible to people with IDD and rely on police response and/or institutionalization or threats of the same. For instance, in their analyses of the service systems for people with IDD and MHD in Wisconsin and Rhode Island, the National Center for START services found that 60% and 55% of survey respondents, respectively, said that acute crisis services were either not available or did not meet the needs of people with IDD (Beasley et al., 2022; Klein et al., 2020). In both analyses, survey respondents reported that lack of accessible crisis response services led to over-reliance on police departments and hospital emergency departments. Such over-reliance is deeply concerning given poor and often violent treatment of disabled people by police or hospital staff (Iacono et al., 2014; Iacono & Davis, 2003; Perry & Carter-Long, 2016). It poses particular dangers for people with IDD who are people of color as well; according to public data collected by the Washington Post, unarmed Black men showing signs of mental health disabilities face substantially greater risk of being fatally shot by police than white men presenting similarly (Thomas et al., 2021).

Mental health crisis services, by their nature, are also reactive rather than proactive because they are only available to people who are already in crisis. Typically, crises occur within a context of unaddressed mental health needs beginning long before an acute crisis event. This means that more comprehensive and accessible mental health support can reduce reliance on expensive — and traumatic — use of crisis and emergency services while reducing the risk of hospitalization or institutionalization. One informant described the reactive nature of crisis intervention as follows:

Most of what I see in states, it’s the reactive stuff that’s taught to direct support professionals. There’s a few states that do it a little bit differently. But ultimately, they’re pretty much all the same vein. Some states create their own — like New York State, for instance, it’s called SCIP: “Strategies for Crisis Intervention and Prevention.” But the bulk of what you’re taught [...] it’s mostly reactive stuff. It’s not the proactive stuff that really and truly takes time to learn. Which scares me to be honest with you, because the reality is, if you give somebody a hammer, everything’s going to look like a nail. And crisis intervention, as important as that might be, you really need to understand human psychology and human communication and communication techniques, and that’s not going to come from a six hour training from any state.

Engaging with mental health crisis services is frequently traumatic for people with IDD and MHD. As we have already explored, mental health crisis services for people with IDD and MHD often involve interfacing with emergency departments and police officers, which carry their own risks of violence and trauma. People with IDD and MHD experiencing a mental health crisis also face heightened risk of being admitted or committed to a psychiatric ward or hospital. There is a great deal of writing, both by mental health professionals and by people with MHD, on the

iatrogenic trauma of psychiatric institutionalization (Black & Calhoun, 2022; Gilmer, 2019; Jina-Pettersen, 2022; Ward-Ciesielski & Rizvi, 2021), although we could not locate any literature specifically on iatrogenic trauma from psychiatric institutionalization among people with both IDD and MHD. Even if people with IDD and MHD experiencing a mental health crisis avoid psychiatric institutionalization, they may be institutionalized in other restrictive settings, such as group homes, ICFs, or general hospitals. At the same time, fear of losing access to the community through institutionalization can further heighten anxiety and intensify crisis situations, or discourage people from seeking support when experiencing emergencies.

A final limitation and challenge concerning crisis interventions is that the purpose of mental health crisis services is to stabilize people in the short-term, which may or may not involve addressing factors that led to the crisis in the first place. Without supports that address these underlying issues, mental health crises frequently reoccur, and lead to greater risk of institutionalization. Therefore, short-term stabilization cannot be the sole or even primary model of behavior support services available. Rather, mental health services to address the causes of mental health crises *before* they occur need to be an essential part of both behavior services and HCBS more broadly.

### **The Challenge of Data: Identifying and Clarifying Available Services**

One consistent challenge identified throughout our work was a lack of consistent definitions and comprehensive data. Behavior supports comprise a broad category with intense variability between states, waivers, and services for the types of supports provided to meet the needs of behavior supports. At the same time, the availability of a given service within a waiver is extremely difficult to assess. Waiver applications seldom list services with a degree of detail and specificity necessary to identify the nature of services covered, and limited information exists connecting listed categories of services to the actual experiences of service recipients in accessing and receiving these services. Where national surveys assessing state IDD services or community living and behavioral health outcomes exist, these surveys often lack the level of detail to connect services covered by waivers to outcome and service recipient experience as well (NCI-IDD, 2022; Rotholz et al., 2013).

The challenge of connecting service descriptions in Medicaid waivers to the experience of accessing these services in practice is further hindered by a lack of specificity about services provided within Medicaid waivers. While waivers often describe categories of service needs provided, they often employ different definitions from state to state and service to service, and often may often provide broader service categories than may be provided in practice. This also complicates efforts by consumers to understand what services can be covered under waivers and to understand whether the needs reflected by these waiver services are met in practice. Waiver applications which contain this information are also complex, dense documents which are difficult to interpret and understand by consumers, and this information is seldom presented in a manner which is comprehensive, yet accessible to consumers, particularly service recipients themselves. 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.



## Building an Improved Support System

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Improving the current mental and behavioral support system for people with intellectual and developmental disabilities requires systems change at all levels, from the individual provider level to state and federal policy intervention. Throughout our interview process, a constant theme, from policy experts to practitioners to service recipients, is that our system needs to change; embracing systems change is crucial to successful service delivery. However, just as changes to the language around behavior will not address the structural issues that harm and restrict disabled people, neither will an embrace of systems change that is limited to a change in provider attitude and culture. Throughout each of the recommendations below, we will call attention to the role of state and federal governments — to provide true, enduring systems change, it is incumbent on both 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

Although “behavior supports” may entail specific services, these services are not all that is required to support people with IDD. The fundamental floor of supporting people with IDD to lead valued, meaningful lives is treating us as people and with basic respect and dignity. Too often, health care professionals and service providers treat people with IDD in patronizing, infantilizing, and disrespectful ways. This disrespect results in people with IDD feeling unvalued, uncared for, burnt out, and like people around us do not feel like we are really people (Autistic Self Advocacy Network, 2021c; Downes, 2023). Friedman found that when provider agencies treated people with IDD with respect and dignity, the people they worked with both tended to have a better quality of life, and were found to experience less of what was considered “challenging behavior” (Friedman, 2021, 2022).

Additionally, many services, such as occupational therapy and sensory processing supports also support the social, emotional, and behavioral needs of people with IDD but are not traditionally understood as “behavior supports. As discussed above, this often leads to these services being excluded from behavior support services as part of waivers. An effective, successful behavior support system would promote access to these approaches. At the same time, it is equally important to recognize that many of these services are not behavior supports and that expanding the definition of behavior support to include these services would likely narrow or distort them. Service systems should accommodate approaches that do not necessarily fit compliance-based, behaviorist frameworks. As a professional informant who provides occupational therapy described broadening definitions of behavior and the impacts it could have on practice,

Within [ABA] practice they were trying to define everything as behavior [so that] they can address every single thing. They even had activities of daily living in there, [such as] showering and bathing. And so, if you're providing visual support, or, you know, elements of predictability in a person's life, is that a behavior support? I do see those as really helpful for some clients. But if it's rooted in compliance and invalidation of a person's experience in the world, then I see that as the opposite of helpful, and in fact, it's very damaging.

### 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

Providers play a critical role in reducing the impact of siloing on the mental wellbeing of service recipients. Providers and agencies should explore ways to bring mental health supports to their clients on an ongoing basis instead of relying on support plans which may only offer supports in crises or as interventions to monitor or change behaviors. As part of this more holistic approach to mental health support, providers should seek opportunities to integrate mental health support into their daily interactions with service recipients. This means that providers and agencies should seek opportunities to

integrate trauma-informed practices into service provision, whether or not those services are part of behavior supports. As part of this focus, providers and agencies should review practices and culture to ensure they support client mental health rather than contribute to trauma.

Providers should undertake a full review of policies and practices to identify those that may contribute to trauma. One means of doing this is for providers to require staff training on dignity and respect. As discussed above, practices that support dignity and respect are associated with improved wellbeing and quality of life, improved health outcomes, and also reported fewer incidents of “challenging behavior”. As part of this, providers also need to ensure that their service delivery practices align with these goals and that they are delivering services in a manner that supports self-determination. This means providers need to move away from restrictive and congregate models of service to delivery, towards models that prioritize supporting service recipients’ individual needs.

In addition, it is important for HCBS providers to develop working relationships with local mental health practitioners and services. These relationships serve a variety of purposes. First, they allow mental health clinicians and service providers to develop familiarity with the needs of IDD patients and develop capacity for serving these communities more effectively. Second, it affords opportunities for HCBS providers to develop approaches that are consistent with and supportive of best practices with regards to supporting the social and emotional health of service recipients *without* defaulting to approaches that aim to restrict or control behavior.

### **States: rebuild IDD service systems to eliminate silos**

Because state governments are responsible for developing and administering their states’ Medicaid waivers and IDD systems, state-level policy plays an essential role in addressing the siloing of mental health and IDD services. States should conduct comprehensive reviews of waivers to identify barriers to access to mental health services for people with intellectual and developmental disabilities, including but not limited to restrictions on mental health services available under IDD waivers relative to mental health waivers and limitations on non-behavioral services such as occupational therapy. Where states find these barriers, they should rewrite IDD waivers to eliminate them.

States have an obligation to ensure that disabled people are able to receive services in the least isolating setting. As we have discussed above, ensuring that people are receiving services appropriately and have their rights respected is a critical element of this. This means that one significant job states have is to ensure that services are actually being delivered in accordance with federal law. States should ensure that they are complying with their *Olmstead* obligations. Where states are not complying with the HCBS Settings Rule, they should move swiftly to bring themselves into compliance. An essential part of ensuring that the Settings Rule is followed and being complied with is to provide avenues for reporting and oversight, including providing an accessible, transparent grievance processes that recipients can use to report rights violations. A common perspective shared by informants was that *Olmstead* litigation and settlements have been an essential driver of service systems change nationally.

People with IDD must have equitable access to quality mental health services instead of being relegated to behavior analysis and control. States have an important responsibility to develop these services where there is unmet need and should collaborate across states to replicate promising approaches. When states develop new service models intended to reduce siloing and improve access to mental health, these services should be designed with the input of people with IDD ourselves. These services must be voluntary and delivered in the least restrictive setting possible, and should enhance states’ other obligations to ensure community integration and least restrictive settings, rather than undermining them.

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

The federal government can play several essential roles in reducing mental health siloing nationally. One of the most important things the federal government can do is ensure compliance with existing civil rights laws that ensure equal access to health programs for disabled people. In particular, the Department of Health and Human services should ensure that states and health care entities comply with Section 1557 of the Affordable Care Act and section 504 of the Rehabilitation Act, and ensure that disabled people are not being denied access to mental health services in a discriminatory manner. Throughout our research and stakeholder interviews, it has become clear that our mental health

care systems are frequently structured not to accommodate people with intellectual and developmental disabilities, and that very few mental health providers are motivated to develop competence in serving people with IDD.

The federal government also has a role in incentivizing, funding, and supporting promising state approaches to eliminating silos and improving access to mental health services. HHS should spotlight successful models and provide pilot opportunities to develop system improvement, including through funding opportunities and the use of 1115 Medicaid waivers to promote system innovation. When supporting innovation, the federal government should prioritize programs that meet disabled people's needs. Mental health services for people with co-occurring IDD and MHD must be voluntary. People with IDD and MHD have the right to refuse care or services, even if others around them object. Other services, such as direct support, cannot be conditioned on receiving mental health care. The federal government should also prioritize innovative approaches that employ input and feedback from people with IDD ourselves.

Finally, the federal government has an essential — but often overlooked — role in provider education which can be leveraged to ensure that more mental health providers receive training to competently serve the people with IDD. Through Medicaid-funded residencies, the federal government has the ability to encourage providers to develop expertise and competence in providing psychiatric care to people with IDD. As part of this, it is essential that the federal government recognize people with IDD as a medically underserved community, allowing programs such as HRSA's Teaching Health Center Graduate Medical Education program to prioritize building psychiatric capacity for these communities (*Teaching Health Center Graduate Medical Education (THCGME) Program, 2023*). The government can additionally use models such as Project ECHO ("The ECHO Model," n.d.), through funding opportunities such as AHRQ grants, to expand provider education and support in serving people with IDD well beyond the limited pool of specialists that exists at present. By expanding medical provider education on the mental health and access needs of people with IDD, the federal government has the opportunity to address a major form of structural disability discrimination caused by the historic siloing of mental health and IDD services.

## **Strengthening and Improving the Workforce**

A perspective shared by nearly every stakeholder interviewed for this project is that services for people with IDD are severely under-resourced. This lack of resourcing for providers negatively impacts the ID system's capacity for system change from the provider and agency levels on up. Direct support workers are burdened by low pay and benefits and limited support and training from provider agencies. As a result, the workforce of direct support workers is far too small to meet the needs of every disabled person who needs direct support, and experiences high levels of provider turnover, high levels of provider economic insecurity, and high levels of secondary trauma. Many informants linked these impacts of the provider crisis directly to challenges faced in providing meaningful, effective positive mental health supports. Informants noted that lack of experience and education often meant providers defaulted to behaviorism and more restrictive or coercive practices due to lack of experience, mental health training, or familiarity with clients. High staff turnover and lack of provider resources often rendered more robust training on best practices uneconomical for provider agencies.

Service recipient informants were also aware of these impacts, sharing professional perspectives that more restrictive approaches followed from lack of knowledge or experience, and additionally reporting high levels of service instability due to staffing shortages or providers aging out of the workforce. For all these reasons, workforce improvement is a critical part of ensuring that we can provide comprehensive behavioral and mental health supports to people with IDD.

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

As we have discussed above, DSP training and expectations around mental health support are critical to ensuring that behavior supports promote the social and emotional needs of service recipients rather than becoming a source of restriction and control. Provider agencies have a responsibility to ensure that support workers are effectively trained to provide supports that are positive and supportive, rather than compliance-based and punitive. Several informants familiar with Positive Behavior Supports emphasized the importance of agency culture in determining the success of Positive Behavior Supports, particularly in terms of ensuring that these frameworks center disabled people rather than

rebranding control — and restriction — based forms of behavioral intervention. Once again, supportive data suggest that clients of agencies that trained staff on dignity and respect reported greater wellbeing and improved health outcomes, greater satisfaction with services, and fewer emergency visits and instances of “challenging behavior.” Agencies should seek provider curricula around IDD mental health needs, respect and dignity of clients, trauma-informed care, and compliance with federal regulations such as the HCBS Settings Rule and civil rights protections. These curricula should be developed in partnership with people with IDD, disability advocates, and mental health experts.

Agencies should also support the mental health and wellbeing of staff as well as those of clients. Several informants noted that secondary trauma among workers is a major contributor to staff burnout and attrition, reducing quality and availability of supportive services. Experienced providers may be at greatest risk, further reducing service quality as the most experienced staff leave the workforce. Providing trauma supports and promoting resiliency in staff involved in providing direct support and behavioral supports is essential to providing high-quality, consistent support for people with IDD in return.

### **States: Invest in the HCBS workforce**

As the parties responsible for administering and implementing Medicaid and waiver services, state governments need to do more to ensure adequate investment in the HCBS workforce. States need to take steps to make the workforce better funded and resourced so it can provide recipients robust supports. As part of this process, states also need to invest in improvements in data infrastructure and quality reporting.

As federal Medicaid regulations make quality reporting an increasing priority, it is incumbent on states to ensure their agencies develop the data reporting infrastructure to support this. Many of these reporting requirements are reflected in present or forthcoming federal regulations, but states should build the necessary infrastructure to meet these reporting standards before compliance deadlines wherever possible because this oversight and reporting plays an equally critical role in state-level consumer protection and accountability.

States should also take steps to develop and invest in promising training approaches among providers. They should do this with a focus on developing provider competency regarding mental health support and non-coercive practices.

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

Home and community-based services need more funding. A broad consensus across the literature we reviewed and the professionals and service recipients we interviewed is that our current system is under-resourced. One of the most important things the federal government can do to support service improvements in HCBS behavior supports is to provide more robust funding for HCBS, including the HCBS workforce. Fully funding the HCBS workforce requires attention to both providers and agencies; as we have discussed above, we believe that agencies have a critical role to play in improving training and support for service providers, and as such it is equally important to overall funding levels, beyond simply ensuring that a greater share of HCBS funding goes to direct support workers themselves. Any rate setting reform should account for both the need for direct support workers to earn a fair, competitive wage and the need to ensure that DSP wage reform does not impair agency funding and capacity for wider provider-level reforms.

States also need to have adequate funding (in the form of Medicaid FMAP boosts) to ensure they are able to build and integrate the necessary quality and data reporting systems required under federal regulations. It is in HHS’s interest to ensure that states are able to implement robust and comprehensive monitoring and reporting systems. This will enable more effective accountability monitoring on CMS’s part. It is also essential that CMS enforce applicable quality reporting requirements, including those present in the Medicaid Access rule. CMS should be adequately resourced to ensure enforcement of federal HCBS quality reporting, and additionally needs to plan to step in with regulatory enforcement if states fail to develop adequate reporting systems.



## 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

Many informants raised concerns about the fidelity of person-centered planning. Multiple informants described person-centered plans as supporting goals set by providers or familial caregivers rather than recipients. It is essential that providers develop systems to ensure person-centered plans are being developed with recipient input and guidance at the core of the process, and that these plans are faithfully followed and reviewed to ensure they continue to support service recipients' needs.

To this end, providers should explore a number of structural and practice reforms to ensure that the support they provide is person-centered. It is critical that providers adhere to person-centered planning processes and best practices. This means ensuring that the person being served is the one identifying goals and supports to meet them, that plans are evaluated on a continual basis to ensure that goals are still appropriate and supports present in plans are actually being provided. Providers and recipients should do this at least annually and additionally at any time at the request of service recipients. Service recipients must be able to identify who should be part of the planning process and have a case manager responsible for ensuring that DSPs adhere to the person-centered plan. These case managers must be familiar with and in communication with the service recipient about their plan and services.

Person-centered plans should be holistic and comprehensive rather than focusing on a narrow set of services to meet a restrictive set of prescribed goals. They should include things like mental health counseling, occupational therapy, and other supports that fall outside of behavioral models depending on the recipient's needs. In general, behavior support services and assessment laid out in plans should prioritize connection and understanding between provider and recipient over behavior monitoring and restriction. Providers should avoid use of contingent reinforcement or other behaviorist interventions to control, restrict, or modify behavior, and should particularly avoid operationalizing activities and experiences important to the recipient as rewards or withholding them as punishments. Refraining from restrictive, coercive, or punitive behaviorist approaches is not enough, however. Providers must proactively consider and address the negative secondary effects of behaviorist approaches as they arise for service recipients, including trauma, loss of control, isolation from compliance based approaches, and the psychological impacts of over-monitoring.

It is important that people with IDD receive appropriate communication supports to interface with services, communicate needs, and build relationships. Providers should ensure that service recipients have access to robust forms of communication assistance that meet their needs. Communication supports are an integral part of ensuring that service recipients can meaningfully participate in the person-centered planning process and set goals that align with their priorities and self-identified needs. Providers should cultivate relationships with speech and language pathologists and assistive technology centers to ensure that they are following best practices to support communication needs and that clients can participate fully in services.

Finally, providers and agencies must end the use of restraint. When restraints are present in a person-centered plan, the provider team must work together with the aim of ending their use. Alternatives to use of restraint must be sought and should be revisited and reviewed whenever person-centered plans are. Providers should also consider the medical and psychological impacts of the use of restraint and incorporate appropriate supports to mitigate these harms into behavioral support planning. The use of restraints is frequently traumatizing, and consideration to the lasting impact of trauma should be made within this evaluation process.

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

States have tremendous influence over the nature of person-centered support practices. State governments have direct control over waiver services and IDD services and have oversight responsibility for compliance with federal regulations. It is critical that states ensure that support services are aligned with regulations such as the HCBS Settings Rule and ensure that HCBS is person-centered.

States need to ensure that all HCBS providers align with the HCBS Settings Rule. It is especially important to ensure that providers align with Settings Rule provisions ensuring community integration and access to the broader community as well as provisions restricting the use of restraint and seclusion. Where states are not compliant with the Settings Rule, they should work to comply as soon as possible. States should develop accessible and transparent grievance processes that provide timely resolutions to issues and designate an HCBS ombuds office to maintain ongoing oversight of providers and settings. States should ensure that all providers are reviewing person-centered plans on at least an annual basis, and at any time at the request of the service recipient. Most of all, it is essential that states fully support the aims and goals of Home and Community-Based Services and of *Olmstead* mandates, and ensure that all disabled people are able to receive services in the least isolating setting that meets their needs. This should be true for all disabled people, including people with IDD and people with mental health disabilities. If people with mental health conditions are tracked into psychiatric hospitals or other restrictive settings, whether through judicial processes or prioritizing expanded inpatient mental health capacity over improving access to community mental health, states have failed to honor this commitment.

States should explore opportunities to encourage self-direction of services and to support people seeking to self-direct services. During the COVID-19 public health emergency, some states used flexibilities in waivers to fund family members and spouses to support recipients as personal care assistants or direct support professionals. These flexibilities were crucial for service recipients to navigate the provider shortage which was further intensified amid the public health emergency. They also afforded recipients greater flexibility in receiving support from those familiar with their service needs and communication methods. Continuing these flexibilities and incorporating them into waivers is one way that states can promote more self-direction. However, states should also ensure that safeguards are in place and that service recipients are still receiving person-centered support and able to develop and modify a person-centered service plan with support from a case manager.

Finally, states should address unmet communication needs among IDD adults by funding communication supports and access to speech and language pathologists in their Medicaid waivers, ensure that these services are appropriately accessible and available to service recipients and that people with IDD have access to communication supports as part of the person-centered planning process.

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

The most important role the federal government has with regards to supporting person-centered planning lies in enforcing federal regulations and ensuring that states comply with the law. CMS should ensure that states are in compliance with the HCBS Settings Rule. Where states are under corrective action plans, CMS must ensure that states are moving towards compliance and that out-of-compliance providers no longer receive HCBS funding. CMS should pay particular attention to state activities around ending the use of restraint and seclusion in service plans and in state efforts to align with the rule's provisions on community integration and participation. CMS should ensure that states have an accessible, transparent, and timely grievance process.

The federal government should provide funding and technical assistance to ensure access to communication support and assistive technology among waiver recipients. The government should also support state efforts to improve communication access for recipients and ensure that effective communication support is integrated into person-centered planning processes for waiver recipients.

Finally, the federal government should also support and encourage state efforts to promote self-direction of services through waiver amendments and flexibilities, technical assistance, and additional funding opportunities.

## Better Strategies to Prevent and Respond to Crisis

Crisis response remains an important component of behavior support services, but it is one that requires substantial improvement. Our current behavioral crisis response system is traumatizing, puts people at heightened risk of institutionalization or reinstitutionalization, and often fails to address underlying mental, emotional, and social needs. Acute care is ill-equipped to address these long-term needs that, if left unremedied, frequently cause recurring crises. It will take quality, ongoing, holistic supports to prevent these incidents.

### Providers: Improve services and build relationships to address health needs

There must be a focus on crisis prevention alongside any attempts to reform crisis response services. Crisis response services *can* be helpful for people with IDD. However, reducing the number of crises a person with IDD has in the first place is key to the person's well-being. Essential to reducing crises is treating people with IDD with respect and dignity. Ableist treatment of disabled people, including disrespect and paternalism, has a negative impact on mental health (Branco et al., 2019; Jóhannsdóttir et al., 2022; Kattari, 2020).

Providers can improve on preventative mental health services by improving on HCBS delivery in many of the ways previously discussed. Ensuring that service recipients are able to engage with their communities, control their own circumstances, and get the support they need without unnecessary coercion or control are part of supporting the mental health needs of people with IDD. Trauma-informed approaches and service systems that treat people with dignity and respect can all contribute to improved mental health. Ensuring comprehensive mental health care and regulatory support through occupational therapy can all assist someone in avoiding crises as well.

Providers should develop relationships with health care providers, including mental health providers, in order to ensure that people's health needs are supported and that service recipients receive appropriate, accessible, routine mental and physical health care. Improved access to health systems can also prevent crises by identifying mental health concerns and medical issues early and providing supports before a crisis arises.

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

Many crises can be prevented through competent routine health care (including mental health care) for people with IDD and MHD. It is well-known that when people have access to a primary care provider or clinic, they are less likely to use the emergency room or other crisis services for routine care (Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health & Human Services, 2021; Petterson et al., 2009; Tsai et al., 2018). Similarly, investing in outpatient mental health care, including clinics that provide both primary physical and mental health care in an integrated setting, reduces psychiatric hospitalizations (American Academy of Child and Adolescent Psychiatry Committee on Health Care Access and Economics Task Force on Mental Health, 2009; Granholm et al., 2003; Hamilton et al., 2016; Lanoye et al., 2017). States should prioritize investment in health care access for people with IDD to address these access needs.

In addition, as outlined earlier, states can support the needs of disabled people by ensuring robust, faithful HCBS systems that provide the supports people need. Improved HCBS services not only ensure that disabled people are better able to meet their other health needs: compliance with the mandates of the Settings Rule also ensures people 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 the models of crisis stabilization available in the community. States should prioritize, incentivize, fund and scale up community-based models that reduce institutionalization and hospitalization, including short-term respite centers such as the “Living Room” model (Heyland et al., 2013), or in-home responses. These services can provide access to mental health supports in less restrictive — and less stressful — settings than hospitals or institutional settings. These tools can empower people to manage crises without removing them from the community. States should also consider the role of mental health crisis response services provided through 988. State and local governments have significant latitude to develop community-specific approaches to 988 crisis response. Where possible, states should encourage the development and use of non-police, non-coercive response systems with behavioral health practitioners who are extensively trained to work with patients with disabilities and who are knowledgeable about locally available supports and services.

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

The federal government plays several key roles in addressing behavioral health crises. The first is ensuring greater access to health services for people with IDD — including, but not limited to, behavioral health. To this end, it is essential that the government enforce and continue to seek to strengthen civil rights protections for disabled people within health care contexts. Access to appropriate, timely, health care is essential for identifying and addressing many sources of mental health crisis before a crisis occurs.

The federal government should also ensure that people with IDD are not being excluded from access to mental health services on the basis of our disabilities. Many informants noted that it was commonplace for mental health providers to refuse to provide services to people with IDD. One way the federal government can further assist people with IDD to gain equal access to health care is by designating people with IDD — or disabled people as a whole — as a medically underserved population. This designation would allow the government to provide additional funding opportunities to providers serving disabled people and could be used to ensure that sufficient numbers of mental health providers are trained and competent to provide health care to people with IDD. As mentioned above, this would be a critical component to providing additional opportunities to fund enhanced provider education.

Finally, the federal government should also incentivize, fund, and assist states to replicate crisis intervention approaches that aid in avoiding institutionalization. Several models that could provide assistance to people experiencing crises were described above. Where these models are successful, the federal government should encourage other states to adopt them. In addition, the federal government should continue to evaluate the successes and challenges of 988. Where local approaches to 988 response successfully divert people in crisis from institutionalization towards community-based mental health services — particularly when initial crisis responders employ non-police, non-coercive models, the federal government has an opportunity to highlight these approaches and encourage other states to adopt similar methods.

## **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 to people with IDD, particularly what behavior support services they offer. They must report this data to state Medicaid agencies. The goal of this data reporting should be to allow standardization of services between providers and to examine gaps in services. Variations in service provision and quality mean that people with the same disability, and even the same behavioral needs, can have vastly different experiences with behavior support services because they have different providers. Data collection and reporting can reveal gaps in service provision as well as expose opportunities for improvement among provider agencies.

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

States must take an active role in ensuring that behavior support services available under state HCBS waivers employ clear, consistent definitions that can be easily understood by service recipients, that service utilization data is made publicly available, and that additional steps are taken to address unmet need and delays in receiving services that interfere with a clear picture of how services are needed and used.

States should collaborate across states to develop consistent and detailed definitions of behavior support which prioritize the needs and goals of IDD individuals as detailed elsewhere in our paper. 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.



States should ensure that the services available under each of their Medicaid waiver programs are available to the public in plain language and accessible formatting to ensure that consumers know what services may be available to them and what needs they address.

Finally, states should go above and beyond in addressing the needs articulated through federal mandates. They should collaborate with national researchers and CMS to collect and publish robust data on service utilization, with an aim of identifying underutilized services and unmet needs within the service system. In addition, states must be certain to address unmet needs within their service systems and eliminate wait lists to ensure that all individuals with IDD are able to access service systems. In the interim they should monitor wait list populations, assess unmet mental health needs of individuals on waiting lists, and engage these individuals to ensure that they are able to access mental and behavioral health services, in addition to direct support services.

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

In order to ensure clarity and consistency in definition and sweep of behavior support within HCBS waivers, it is important to improve the information conveyed through Medicaid HCBS waivers. By improving the availability of detailed information made available through waivers, the federal government can facilitate both improved data collection about the services that states provide through HCBS and how these services are utilized, as well as greater transparency for service recipients in how services may be provided.

As an initial step, CMS should seek to improve its current presentation of approved waivers to make them more easily consumer-accessible. While CMS currently provides a searchable list of Medicaid waivers sortable by state, waiver authority, and approval status, each waiver is presented with only an extremely limited high-level summary which cannot be used meaningfully to identify service population or services provided, and a full waiver application that is frequently difficult for consumers to navigate and understand (*State Waivers List*, n.d.). CMS can provide additional information on the populations served by waivers, the services provided, and any service caps provided within a waiver as filterable terms, and ensure that its summaries of waivers are detailed in descriptions of services provided to ensure that the average consumer is able to retrieve information on waivers and the services. In addition, CMS should evaluate its waiver application procedures to ensure that they solicit information on services supported in sufficient detail to inform about the scope and applicability of services outlined within a waiver.

In addition, CMS can ensure improved reporting of service utilization related to waiver services. While many Medicaid waivers include a broad range of services provided, these services are not utilized equally, are often constrained by network adequacy and provider availability, and waivers themselves often include caps on service hours or other restrictions. As of the time of this writing, CMS has proposed new rulemaking which would improve oversight and monitoring of access to Medicaid services, including a range of HCBS. If this rulemaking is finalized as proposed, much of this new rulemaking will have an indirect benefit on data collection related to HCBS behavior supports. It will ensure that there is more robust reporting on critical incidents and service recipient grievances, which is instrumental in identifying adverse outcomes from support approaches. It will also require states to provide more data to CMS about unmet HCBS needs and inadequate provider networks, enabling policymakers to identify service gaps. In addition, these proposed rules propose to track delays service recipients experience in receiving direct support services. An additional step to build on this rulemaking that CMS should pursue is to expand the list of service gaps that it is monitoring, with a particular focus on behavior support services across a range of service modalities and clinical approaches. 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

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Despite the variance in behavior support services from state to state, waiver to waiver, and even provider to provider, there are clear commonalities, which we have reviewed above. Our behavior support system is built on behavioral interventions that have far too often defaulted to controlling or modifying the behavior of people with intellectual and developmental disabilities rather than seeking to understand us and facilitate our thriving. The result has frequently been a fundamental misalignment of disabled people's interests, and those of service providers.

Where providers have identified — and sought to alter — “challenging” behavior, much of that behavior is better understood as reasonable responses to intolerable circumstances. Like most people, adults with IDD do not enjoy having little control over our lives, limited privacy, and little choice in where we live, what we do, and who we share our lives with. However, this is an all-too-common experience among people with IDD. Still worse, things that people with IDD take comfort in — things we find rewarding, motivating, or gratifying — are often taken from us. Providers tell us to earn these things back. Such a system is a recipe for distrust, anxiety, and trauma, but, when people with IDD expressed distress or resistance under this system, those expressions are often labeled “challenging” behaviors as well.

The source of this misalignment is a failure to recognize that nothing that anyone does occurs without reason. What behavior analysts identify as “challenging behaviors” are often efforts to communicate needs or distress or acts of resistance. They reflect unmet communication needs or trauma that people were not given the tools to attempt to address. But, for far too long, the default approach to distressing or distressed behaviors has been to get the behavior to stop rather than to understand its underlying causes.

While the field of behavior support has evolved beyond its behaviorist past, the legacy of control-based approaches casts a long shadow. A lasting consequence of these approaches is the continued under-funding, under-support, and inaccessibility of a broad range of mental health services for people with IDD. This siloed system — itself a legacy of an approach to people with IDD that saw problem behaviors to correct rather than people experiencing normal emotions without the supports we needed — has erected barriers that prevent people with IDD from getting mental health care. The structure of the system has erected artificial barriers to accessing support and generated continued crises of its own making as a result. These crises are a product of a system built on the flawed foundation of behaviorism.

Effective behavior supports, then, are necessarily supports that address people's underlying needs, remove barriers to supports and the greater community, and treat people with IDD as whole people with goals and needs of our own. Effective policies that can support these behavior supports are those that foster dignity, respect, and community inclusion and afford people with IDD control over our own lives, goals, and choices. The most critical policy approaches are those already topics of advocacy in disability policy. These include state compliance with *Olmstead* obligations and individual access to quality, self-directed HCBS. While providers and governments struggle to implement these policies, they are not new or radical. 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 us. More than 30 years prior to this paper, in 1992, published *Supporting People With Severe Reputations in the Community*, describing many of these exact issues in detail.

Thirty years later, we are still struggling to transform this system into one that supports the needs of disabled people, and centers what disabled people 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.

## **Appendix A: Acceptable Goals for Behavior Support Services**

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This appendix addresses acceptable goals for behavior support services. Any goal for behavior support services must be rooted in an understanding that behavior follows from unmet needs. People “act out” or “behave badly” when their needs for safety, health, stability, connection, communication, respect, and control of their own lives are not being met. It is unrealistic and counterproductive to target behaviors for reduction and elimination without first ascertaining and addressing underlying unmet needs. Addressing behavior without addressing underlying needs is like pulling weeds in a garden without removing the roots: while the weeds may be gone temporarily, they will come back unless the roots are also removed.

Although we use the term “behavior support services,” many of the services used to meet people’s underlying needs are not behavior-specific or formally focused on addressing behavior. Definitions of “behavior support services” must be understood holistically, because all behavior exists in context. People with IDD who have “challenging behavior” may need a variety of services to address their needs, including, but not limited to, stable and supportive housing, direct support with basic and instrumental activities of daily living, general and specialized health care (including mental health care), employment supports, support to develop self-advocacy skills, and legal agreements, such as supportive decision-making agreements, that allow them to maintain control of their lives and services. Providing these services and supports is necessary not just to reduce or eliminate “challenging behavior,” but because all people, including people with IDD, should have the right to rich, fulfilling lives where they have the resources and support to make their own choices. Fundamentally, the ultimate goals of “behavior support services” and especially “positive behavior support” should not be eliminating negative or “challenging” behavior, but about empowering people to make choices and live their lives in ways that work for them.

In many cases, the goal of behavior support should be changing the person’s environment or how the people around them act towards them, rather than targeting a person’s behavior without changing what is happening around them. People with IDD who express “challenging behavior” are often acting perfectly reasonably in response to an unreasonable environment or treatment. An adult with an intellectual disability and minimal oral speech who gets angry and throws things when people talk to them like a child is reacting rationally in the ways they can to infantilizing, disrespectful treatment. Even when providers cannot ascertain the preferences of a person with IDD, an approach as simple as treating the person as you would like to be treated if you were in their position can help support that person’s needs and address concerning behavior.

We have divided our list of acceptable goals for behavior support services into five categories: seeing people as people first, addressing underlying needs, supporting mental health and well-being, supporting community integration, and addressing dangerous behavior. We chose these categories because they cover the vast majority of the underlying reasons why people with IDD are labeled with “challenging behavior” or placed in behavior support services. In this appendix, we do not dictate exact goals for behavior support services because what is an “appropriate” or “acceptable” goal will vary from person to person, within the limits we set in this appendix. We instead offer questions in each section for the person and their support staff to answer. We offer these questions with the hopes that the answers will help people with IDD and our support staff formulate reasonable and appropriate goals for behavior support services.

### **Seeing People as People First**

While many disability service providers claim to use strategies such as “person-centered thinking,” too many disability professionals treat people with IDD as if we lack internal experiences, insight into our needs and care, and even basic sentience. At best, said providers may allow that people with IDD have some limited capacity to communicate needs but without complex internality or insight. These are views commonly held about inanimate objects or pets, not people. People with IDD, and especially those with intellectual disabilities and/or significant support needs, are in the eyes of many staff subhuman. The causes of this problem are many and varied. However, two main causes most likely are a) training that teaches disability services professionals to see people with IDD as less than human and b) implicit and explicit bias against people with IDD that many disability services professionals hold (Friedman, 2019, 2023). This obviously has a substantial impact on how support staff treat people with IDD. It is also not without significant historical precedent — some of the first self-advocacy groups run by people with intellectual disabilities were called People First groups out of a need to be seen as people, not labels, first (The Minnesota Governor’s Council on Developmental Disabilities, 2023).

The basic idea underlying all behavior support services, and disability services writ large, must be that people with IDD are *people first*. There is no disability that renders someone subhuman, incapable of emotion or internal experience, or unworthy of basic courtesy. There is no disability that makes someone so entirely different from other people that they cannot be afforded the same human rights and social graces. Too often, disability services, and especially behavior support services, regard people with IDD as different from other humans to the point that basic knowledge of human development, neurology, behavior, and connection do not apply to us. This belief is unsupported by decades of research and is disrespectful and dehumanizing to people with IDD (Autistic Self Advocacy Network, 2021a).

It is true that people with IDD may engage in behavior that is difficult for us to control, which poses challenges or dangers to ourselves or others, or which prevents us from meeting our goals. It is true that people with IDD who engage in “challenging behavior” may need significant changes to our routines or environments to resolve the underlying causes of our behavior. It is true that supporting people with IDD who engage in “challenging behavior” can be difficult and have no clear solutions. But *none of this* means that people with IDD, even and especially those who engage in “challenging behavior,” are less than human. Disability services professionals must understand that people with IDD, no matter what, are people first and should be treated with grace and humanity.

While there is no single easy answer or training solution for educating disability services professionals on seeing people with IDD as people first, it is critical for ensuring behavior supports are provided with dignity and respect. Research points to interactions between people with and without IDD as a modulator of bias towards people with IDD (Capozza et al., 2016; Harrison et al., 2019; Keith et al., 2015). Interactions between people with and without IDD need to be conscientious of power dynamics and work to minimize power disparities. Interactions that recreate typical power dynamics — where people without IDD hold significant power and control over people with IDD — also reemphasize views of people with IDD as “lesser.” Interactions meant to reduce bias towards people with IDD must position people with IDD as *people*, not merely patients, clients, students, or other roles where the person without IDD has power over us.

## Addressing Underlying Needs

It is impossible to meaningfully address behavioral health needs without meeting essential human needs that impact behavior. Things like shelter, food and drink, appropriate clothing, hygiene, physical and mental safety, and connection with others are basic human needs. People with IDD have the same basic human needs, and the same rights to have these needs met, as everyone else. Attending to these needs should be the foundation of any services a person with IDD receives. If a person’s needs are met, many of their “challenging behaviors” will likely lessen naturally and may even cease. The blog post “A checklist for identifying sources of aggression” is of particular relevance here. Although the post was aimed at parents of autistic children, the information within it is relevant for anyone who works with people with IDD of any age (Chavisory, 2014).

These underlying needs fall into a number of domains: medical needs and pain, housing and food security, safety and freedom from abuse, communication, sensory needs, choice and control, respect and dignity, meaningful relationships, mental health support, and community integration. The last two domains are their own separate categories within this appendix.

### Medical Needs and Pain

As we have previously discussed in this white paper, “challenging behavior” may reflect unaddressed medical needs or pain. Adults with IDD are more likely than adults without disabilities to have chronic health conditions and are less likely than adults without disabilities to receive certain kinds of preventive care and screening, particularly as we age (Havercamp & Scott, 2015; Williamson et al., 2017). People with disabilities frequently experience diagnostic overshadowing — the tendency of health care professionals to attribute symptoms of an unidentified physical condition to a person’s disability — particularly when we have developmental disabilities that cause physical impairments (Lougheed, 2019; A. Singh et al., 2023). Health care professionals often delay investigating the root causes of pain and discomfort in people with IDD, especially if the person with IDD has no reliable means of communication other than behavior.



Too often, diagnostic overshadowing leads to people with IDD living with significant pain and discomfort without relief and no way to express it other than through behavior interpreted as “challenging.” The effects of this on long-term physical and mental health, quality of life, and risk of being placed in traumatic behavioral interventions can be devastating. As an example of this, the Supporting Access For Everyone, or SAFE, Project through the Developmental and Behavioral Pediatrics Network collected testimony on the state of health care for people with IDD from self-advocates, family members, health care professionals, and other stakeholders at a public forum. Much of the testimony speaks to how poor the health care people with IDD receive (aucdnetwork, 2022b, 2022a).

People with IDD must receive the support we need in order to effectively manage physical health needs related to both chronic and acute conditions. This support cannot be predicated on a person living in an institution or in a provider-owned residential setting, such as a group home for people with complex medical needs. It is essential to ensure that people with IDD have access to the medical care we need — including in-home health care, when appropriate — and receive preventive and primary care as well as specialist care. People with IDD may also need health information resources, such as patient education materials or after-visit summaries, in cognitively accessible formats or may need specialized transportation to and from medical appointments. Support staff should also assist with care coordination needs, such as meeting with a health care case manager, a medication management provider, or support staff trained in assisting with medical appointments. The overall goal is to empower people with IDD to be active participants in our own care and ensure that we have access to health care when and how we need it.

### ***Questions to Answer About Medical Needs and Pain When Writing Behavior Support Goals***

- Does this person have pre-existing physical health conditions or chronic illnesses?
  - ◊ If so, what are those physical health conditions or chronic illnesses?
  - ◊ If so, are those physical health conditions or chronic illnesses well-controlled?
- Does the person have access to routine health care?
  - ◊ Preventative/primary care?
  - ◊ Specialist care?
- Does this person have the tools they need to communicate about their health care needs?
- How does this person communicate when they are in pain or sick?
  - ◊ If they are in pain, can they let someone know?
  - ◊ Can they indicate a specific health care problem/area of pain?
  - ◊ What other ways does this person communicate when they are in distress?
- Does this person have providers they trust to communicate with about their health care needs? Are these providers knowledgeable about these needs?
  - ◊ Doctors?
  - ◊ Support staff?
  - ◊ Medication management?
  - ◊ Case management?
- Does this person have health care information they need available in formats they can understand?
- Does this person live in a setting where health care is provided at their residence? How does this impact care coordination?
- Does this person have a reliable way to get to medical appointments?
- Does this person have other unmet health care needs? What services or supports need to be put in place to meet these needs?

## Housing and Food Security

All people need somewhere to live and enough to eat and drink. Without meeting these basic needs, it is impossible for people to live the lives they want and to thrive. However, people with IDD are disproportionately likely to experience both homelessness and food insecurity. An estimated 30-40% of people experiencing homelessness have a cognitive disability, even though people with cognitive disabilities make up only 5.4% of the general U.S. population (M. J. Brown & McCann, 2021; W. Erickson et al., 2023).<sup>5</sup> Similarly, in the U.S., approximately 34-40% of households with an adult with a cognitive disability reported food insecurity, compared to 12% of households with no adults reporting a disability (Peng et al., 2020; N. Schwartz et al., 2019).

These statistics are further complicated by needs related to housing accessibility and dietarily appropriate food among people with IDD. A person with IDD who uses a wheelchair may technically be housed; however, if their housing has stairs and no ramp, they may effectively be housebound. An autistic person who cannot cook for themselves may have access to food via SNAP; however, if SNAP benefits do not cover prepared food, they may still experience food insecurity. Similarly, a person with IDD and gastroparesis who needs to supplement their food intake via feeding tube formula may be able to buy food at a grocery store, but if their insurance or benefits do not cover feeding tube formula, they are not food secure.

If a person with IDD does not have adequate, accessible housing and food they can prepare and eat, meeting these needs is of the utmost importance. *Everyone*, regardless of disability, should have access to housing and food, and a lack of these things exacerbates existing disabilities and may lead to new disabilities (Coleman-Jensen & Nord, 2013). Disability service agencies must work with other agencies, such as those that provide food and housing to individuals who are or may be at risk of homelessness and food insecurity, to identify and help individuals who might benefit from cross-agency services.

When disability services agencies provide residential living spaces, they must adopt a “housing first” model and provide housing to people on their caseloads experiencing or at risk of homelessness, regardless of whether those people are sober, receiving medical/psychiatric treatment, or have “challenging behavior.” Housing First is an umbrella term for service models for people experiencing or at risk for homelessness that, as the name suggests, focus on getting people into housing without first requiring them to be sober, in treatment for mental health disabilities, or meeting any other measure of “housing ready.” Housing First has been shown to reduce high-cost service use (e.g., psychiatric hospitalization, residential substance use treatment) among people involved in it, as well as being effective for people with multiple types of disabilities, including IDD (Downs & Sage Computing Staff, 2023b, 2023a; Peng et al., 2020; N. Reid et al., 2021). Behavioral health needs related to a disability must never be an excuse to deny someone a stable home.

Finding adequate, accessible housing for people with IDD, particularly those whose disabilities mean they cannot live in a typical house or apartment, must not mean warehousing people in an institution, group home, or assisted living facility. Even beyond congregate facilities, it also cannot mean modifying more independent housing to effectively trap a person with IDD in “an institution of one.” For example, a person with IDD who wanders out of their house at random may require additional support, but does not need to live in a place where the front door is always locked and only a staff member can open it. More appropriate supports for such a person might look like teaching them to alert someone before they leave, having them carry a cell phone or other method of contacting a support person at all times, and using visual supports to remind a person of what they need to leave the house.

Even if a person with IDD has adequate, accessible housing and food to eat, their “challenging behavior” may still have roots in housing or food issues. This ties into issues related to choice and control. Someone who lives in a group home where they can only leave the house on group outings with staff would understandably be frustrated about their housing situation, even if it is adequate, accessible housing. Someone who receives pre-made frozen meals as a waiver service would understandably be frustrated if the meals were poor-tasting, repetitive, and difficult to reheat, even if they technically have enough to eat. People with IDD have as much right to have a say in our housing and meals as anyone else, and to want to have options that are acceptable and even desirable. We do not have to accept the first accessible option to us just because we have a disability. Support staff must consider whether housing or food issues contribute to a person’s behavior, even if the person is housed and has enough food.

<sup>5</sup> It is difficult to find statistics on homelessness or food insecurity among people with IDD specifically. Therefore, we use the U.S. Census Bureau category of cognitive disability, defined as a person who, “because of a physical, mental, or emotional problem, [has] difficulty remembering, concentrating, or making decisions” (US Census Bureau, 2021).

## Questions to Answer About Housing and Food Security When Writing Behavior Support Goals

- Does this person have stable long-term housing?
  - ◊ Is this housing safe? Does this person feel comfortable using their home?
  - ◊ Is this housing accessible? Can this person use everything they need in their home?
- Does this person have stable food access?
  - ◊ Do they have access to food they enjoy eating?
  - ◊ Do they have access to food that meets their physical health needs? For example, feeding tube formula or special diets.
- Does this person have a history of trauma around food or housing? For example, loss of freedom to choose food in a group home.
- Does this person receive benefits to help with food or housing? If not, would they be eligible for benefits? What resources would be helpful?
- Does this person need support to stay safe in/around the home? For example, someone who wanders.
  - ◊ How can we do so in a way that respects the person?
- Does this person need support staying safe around food? For example, someone with Prader-Willi Syndrome.
  - ◊ How can we do so in a way that respects the person?

## Safety and Freedom from Abuse

People with IDD are more likely to experience abuse and neglect than people without disabilities, as well as adverse childhood experiences (ACEs), bullying, and other traumatic experiences (J. Collins & Murphy, 2022; Cook & Hole, 2021; Curtiss & Kammes, 2020; Didden & Mevissen, 2022; Fisher et al., 2016). This risk is even greater for people with IDD who live in congregate settings, such as institutions and group homes (B. Collins, 2015; Department of Health and Human Services, Office of Inspector General et al., 2018; Egusa, 2023; Hall, 2021; Serres & Howatt, 2019; Winkler, 2023). Abusers prey upon people with IDD for a host of reasons, including, but not limited to:

- People with IDD may depend on other people for personal care and may not have much, if any, control over our care.
- People with IDD are taught (implicitly or explicitly) to let others touch us and follow along with what others say, especially when the others are staff. Someone with an IDD may not believe they can say “no” to unwanted contact from staff members or others around them.<sup>6</sup>
- People with IDD often receive little or no education about abuse prevention, “appropriate touch,” and recognizing and reporting abuse.
- People with IDD, especially those who do not communicate with oral speech, may not have a reliable way to tell others when we are abused.
- People with IDD, particularly those under guardianship and those living in congregate settings, have little or no choice in our daily lives or living situations, making it harder for us to escape abuse.
- People with IDD are often socially isolated and may not have anyone outside our caregivers who we can report abuse to.

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<sup>6</sup> As ASAN and others have previously documented, ABA and other behaviorist interventions are often rife with consent and bodily autonomy violations towards people with IDD, including tactics such as hand-over-hand prompting or interventionists refusing to take “no” for an answer (Autistic Self Advocacy Network, 2017b, 2021a). While ABA and behaviorist interventions are some of the worst offenders for violations of bodily autonomy, these violations can occur in any service or intervention. Such violations stem from service providers’ mistaken belief that people with IDD do not have as much right to bodily privacy and safety as anyone else.

- People with IDD, especially those who live in congregate settings and/or work or go to school in segregated settings, are often isolated and “hidden” from the community. People with IDD who live, work, or go to school in these settings may also have much less access to community resources or authority figures to report abuse to.
- People with IDD may face additional accessibility barriers that make it difficult for us to report or escape abuse (e.g., domestic violence shelters may not be accessible to someone who uses a wheelchair or a ventilator).
- People with IDD who are multiply marginalized (e.g., women with IDD, people of color with IDD) who report abuse often face retaliation both because of their IDD and their other marginalized identities.
- Other people may misattribute signs of abuse (e.g., unexplained bruises, depressed mood, uncharacteristic sexual behavior) to behaviors or symptoms of a person with IDD’s disability.
- Other people may view people with IDD who report abuse as “unreliable” or exaggerating claims of abuse, particularly if the alleged abuse happened at the hands of a professional or authority figure.
- Other people do not see people with IDD as fully human and thus deserving of safety and freedom from abuse and maltreatment (*Abuse and Exploitation of People with Developmental Disabilities*, 2023; L. A. Davis, 2011a, 2011b; Hartmann & Sheldon, 2019).

Nobody should have to tolerate abuse, neglect, or maltreatment, and survivors of such experiences should have the support they need to express whatever feelings they have. Yet, insofar as any survivor is given needed support, survivors with IDD are afforded it less than those without IDD. Reactions to abuse in people with IDD are often labeled as “challenging behavior” and treated with behaviorist interventions without trying to ascertain the actual cause. This happens despite abuse being recognized as a cause of “challenging behavior” among adults with IDD (E. Bradley & Korossy, 2022; Fallon & Desrochers, 2014; Van Den Bogaard et al., 2019). Additionally, children (with or without IDD) exhibit “challenging behavior” as a reaction to being abused or witnessing abuse (Al Odhayani et al., 2013; *Children and Domestic Violence*, 2013). While there are adapted forms of various trauma therapies for people with IDD, these services are not available or accessible to many abuse survivors with IDD, who get funneled primarily or exclusively into behavioral management approaches.

People with IDD face additional safety hazards in our living arrangements and in the community. For example, in a report prepared for the federal Consumer Product Safety Commission, the Fors Marsh group noted that people with IDD are more likely to be injured or killed unintentionally by common household products, such as furniture, kitchen appliances, and household chemicals (Fors Marsh Group, 2021). Other studies have found that people with IDD are more likely to face risks in the community, such as injuries from traffic collisions and being abducted by strangers (Didden et al., 2021; Driscoll et al., 2023). These risks can be modified and lessened through education and environmental modification; however, people with IDD often do not receive support with modifying risks (Finlayson et al., 2015; Goh & Andrew, 2021; Hughes et al., 2020).

People with IDD, like everyone else, should be able to live safely and free from abuse, neglect, and maltreatment. We should receive any support we need to achieve this, including support from community organizations not focused on disability (e.g., resources for survivors of sexual violence, household lead abatement programs). Unfortunately, community organizations that promote household and community safety or advocate for people experiencing abuse or interpersonal violence often do not account for the specific needs of people with disabilities, including people with IDD. Moreover, students with IDD are often excluded from classes that talk about safety and abuse prevention. This is especially true of sexual education (Holmes, 2021). While school curricula and community organizations should provide appropriate education and support on a variety of personal safety and abuse prevention topics for people with IDD, the reality is that they do not. In these cases, HCBS providers must fill the gap when it comes to education and environmental modification.

Regardless of whether other education and support resources are available, disability support services must take active steps to prevent abuse, neglect, and maltreatment of people with IDD in their care. This can include training for support staff on recognizing, addressing, and preventing abuse; offering sexual/relationships education and home and community safety trainings for people with IDD; implementing procedures about how to properly label and store potentially dangerous household materials; facilitating connections between people with IDD and community



organizations dealing with abuse prevention and with home and community safety; and promptly addressing abuse and health and safety hazards when they do occur. HCBS providers should work with existing groups to develop trainings and educational materials, such as by working with an organization for survivors of sexual assault to develop abuse prevention lessons for people with IDD.

While efforts to reduce abuse and health and safety risks are important, these must not infringe on the rights of people with IDD, including those outlined by the HCBS Settings Rule. For example, a foster home for adults with IDD cannot mandate that a resident cannot have a lock on their bedroom door because they often have their partner over and “staff need to check in to make sure your partner isn’t hurting you.” There are ways to prevent, recognize, and address abuse without denying someone a basic right to privacy. Similarly, a group home cannot mandate that kitchen and butter knives be locked away and only staff be allowed the keys under the reasoning “someone might use a knife to hurt themselves.” There are ways to educate people on knife safety, and prevent people from using knives as weapons, without wholly restricting access to utensils used to prepare and eat food. Limiting access to knives may be an appropriate rights modification for a *single individual* who uses kitchen knives to self-harm or to threaten others, but only for that individual, and only after less restrictive options (e.g., knife safety education, supervision around knives, and services to address self-harm or aggression) have been tried and exhausted.

Finally, HCBS providers must recognize that services themselves can be a source of trauma or contribute to abuse. As we have previously discussed in this paper, ASAN and many others view ABA as inherently abusive and dehumanizing, regardless of whether obviously abuse (e.g., therapists shouting at or hitting clients) is present. Interventions that incorporate elements of ABA, or are similarly rooted in behavior modification, should be viewed with extreme skepticism. Even when a service or intervention is not rooted in behaviorism, it is important to recognize that no one approach benefits all people. A given psychotherapy may benefit one person with IDD but harm another. Services should be individualized; providers should not write a service as an option for someone with IDD because the service worked for another person with IDD, nor should providers assume a service will work for someone with IDD because it worked for another person with IDD.

### **Questions to Answer About Safety and Freedom from Abuse When Writing Behavior Support Goals**

- Has this person ever experienced abuse?
  - ◊ Was this abuse in relation to an intervention or service provider?
  - ◊ Does this person have other marginalized identities that make them more vulnerable to abuse?
  - ◊ How can we work with this person in ways that make them feel safe?
- Does this person have a reliable means of communication to report abuse?
- Does this person have a person they trust to report to if abuse happens to them?
- Has this person received accessible sexual education?
  - ◊ Does this include education about boundaries, consent, and abuse?
- Does this person have access to the community, who might recognize and report abuse?
  - ◊ Does this person have friends/peers in the community?
  - ◊ Does this person go to school or work in the community?
- Does this person have access to community resources to address abuse?
  - ◊ Are these resources accessible?
- How can we help someone stay safe at home while having freedom of choice?
  - ◊ Ex. Accessible education about household chemicals, assistive devices, etc.
- Have this person’s support staff been trained on recognizing, addressing, and preventing abuse?

## Communication

Access to the necessary tools to communicate and be understood by others is essential for having a fulfilled and meaningful life. However, there are few reliable estimates of the number of people with IDD who cannot rely on oral speech alone to communicate. Beukelman and Light estimate that approximately 5 million people in the U.S. could benefit from augmentative and alternative communication (AAC); however, this estimate does not include breakdowns by type of disability (Beukelman & Light, 2020). Augmentative and alternative communication refers to ways of communicating that either supplement or replace oral speech. AAC systems and methods may include gestures, body movements, and facial expressions; writing, typing, or drawing; pointing to pictures, words, symbols, or letters; and using high-tech text-to-speech software applications or dedicated devices (*Augmentative and Alternative Communication (AAC)*, n.d.). Similarly, the AAC Counts Project collected estimates of people who could benefit from AAC by disability but these data are far from complete (Szymanski et al., 2023). This lack of data makes it difficult to quantify the scope of unmet communication needs among people with IDD. Yet even based on this incomplete data, it is clear that a significant portion of people with IDD have unmet communication needs. Many people with IDD currently have no effective means of communication other than behavior.

Meeting communication needs is essential to effectively supporting people with IDD. Without an effective, robust system of communication, a person cannot fully interact with the world around them and cannot express themselves fully. This, understandably, leads to communication breakdowns and misunderstandings, which can lead to “challenging behavior.” It is important to remember that behavior is a form of communication and that changes or escalations in behavior should be viewed similarly to changes in other forms of communication. Someone who has a radical, unexplained shift in their behavior is most likely to be trying to communicate some underlying change or discomfort.

The goal of communication interventions and communication supports should be to provide suitable communication methods so that people can communicate in other ways than behavior. There are various options for AAC systems, including no-tech AAC (gestures, body language, facial expressions), light-tech/low-tech AAC (paper and pencil for writing or drawing, picture or word cards or boards), mid-tech AAC (electronic devices that can say a few set pre-programmed words or phrases), and high-tech AAC (software applications or electronic devices that convert text to speech, regardless of whether the text is already pre-programmed in the system) (*Types of AAC*, n.d.). Mid- and high-tech AAC systems often allow for alternative access methods (such as mouse or switch access, head tracking, and eye gaze) as well as other tools (for example, keyguards, styluses and pointers, and mounts) to make AAC more accessible to people with physical disabilities (“AAC and Physical Access,” 2022). For light-tech options, partner-assisted scanning, in which a partner scans through options on a communication board or book and the person moves their body to signal yes or no, may work for people with significant physical disabilities and limited mobility (Burkhart & Porter, 2006; Edwards, 2018). Additionally, some people with IDD use a signed language as their primary language, such as American Sign Language or ProTactile.<sup>7</sup>

While a full review of AAC systems is out of the scope of this appendix, we suggest some basic universal guidelines for implementing AAC with people who primarily use behavior to communicate. First, support staff should presume that a person is capable of learning to use some form of AAC beyond behavior as communication. This does not mean a person has to perfect their use of a high-tech AAC system; it can look like someone learning a few signs related to basic needs or someone learning to signal yes/no as a staff person scans through a list of choices. Second, staff should not assume that a form of AAC is useless because a person does not master it within a few weeks. AAC can take months, if not years, to learn, especially if someone has multiple or fluctuating conditions that affect their ability to learn and communicate (tuttleurtle42, 2021). Adults with IDD may take longer to learn an AAC system than children with AAC; however, nobody is too old for AAC (Zangari, 2014). Finally, even if a person is not interested in a certain AAC method or system, support staff should still keep the system around and model it with the person. Many, if not most, AAC users use multiple forms of AAC and people who are initially resistant to certain forms of AAC may take to them after a while.

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<sup>7</sup> Signed languages are full languages with complex grammar, vocabulary, and syntax. Languages are not forms of AAC and it is incorrect to refer to a signed language as a form of AAC, just like it would be incorrect to refer to a spoken language as a form of AAC. There are communication systems and forms of manually coded English that utilize signs (e.g., Makaton, Signed Exact English) which can be considered forms of AAC; however, these systems differ significantly from full signed languages such as American Sign Language or British Sign Language (*Augmentative and Alternative Communication*, 2022; *Frequently Asked Questions*, n.d.; Hoffman, 2008; Mansfield, n.d.). ProTactile is a tactile signed language used by some DeafBlind people (Leland, 2022).

Dave Hingsburger, in his book “First Contact: Charting Inner Space: Thoughts About Establishing Contact With People Who Have Significant Developmental Disabilities,” outlines five steps for making “first contact” and getting to know someone with an IDD that significantly impacts their communication. These are:

1. Be playful. Have an open mind and be willing to explore new things. Talk to the person you are supporting with interest and empathy, even if they can't respond in a way you can understand.
2. Watch the person. Look for how they react when you talk to them. Notice and acknowledge their reactions, even small ones.
3. Respect all kinds of communication. Nobody is “non-communicative,” even if their communication is hard to understand. Respect how the person communicates as a real language, not just a stand-in for “actual” language. Document how the person communicates. Keep a “dictionary” of how they communicate and what their various actions or behaviors mean. Make sure the “dictionary” is accessible to everyone who works with the person.
4. Use real empathy. Be open and sensitive to how the person feels. Even if you do not have the same experiences as the person, you probably have experiences with the same emotions they have. Relate to how the person feels and use that shared emotion to make change. Acknowledge the person's experiences and their emotions, even if those experiences are very different from yours.
5. Acknowledge contact when it happens. Tell and show the person that, even if you do not understand what they are saying, you know they are trying to say something. Comment on their reactions and clarify what they mean (Hingsburger, 2000a).

Hingsburger also discusses the question “What if contact does not happen?” in “First Contact.” Recognizing that contact may not happen, even when a support person is trying to make contact, he writes that not every support person is going to like every person with a disability and vice versa. Contact may not occur between a person with IDD and a particular support person but that does not mean the person with IDD is non-communicative or that they might not try to communicate with a different support person. Hingsburger draws a comparison to making a phone call and nobody picking up: “It certainly doesn't mean no one's home. It just means they are screening their calls. Let someone else try” (Hingsburger, 2000b).

### ***Questions to Answer About Communication When Writing Behavior Support Goals***

- Can this person communicate reliably with oral speech? What about a sign language?
- If not, does this person have access to AAC?
  - ◇ Does the type of AAC meet their needs?
  - ◇ Has this person been given time and training to learn AAC?
  - ◇ Are support staff trained to use and model AAC?
- How does this person use behavior to communicate?
- Does this person have a variety of communication partners to try and connect with?

### **Sensory Needs**

People with IDD have a range of needs regarding sensory processing and sensory input. Some people with IDD exhibit sensory seeking (i.e., specifically looking for and engaging in activities that provide significant sensory input) whereas others exhibit sensory avoidance (i.e., avoiding activities or environments that provide a lot of sensory input). Some people with IDD are hyperreactive to sensory input (e.g., a person who reacts in pain when someone gently touches them) while others are hyporeactive to sensory input (e.g., someone who does not react at all to a loud, harsh noise). Many people with IDD experience both sensory seeking and sensory avoidance in different environments and at different points in our lives (Bodison et al., 2022; Crane et al., 2009; Galiana-Simal et al., 2020).

Although most of the research on sensory processing and input in people with IDD has been on autistic children, other research suggests that sensory issues are present in a wide range of IDDs and other disabilities, as well as in both children and adults (Crane et al., 2009; Gawlas & Blaskowitz, 2020; L. J. Miller et al., 2021; NHS Lanarkshire, n.d.; Pfeiffer et al., 2014; van den Boogert et al., 2022). Notably, sensory processing and input may also be impaired or different in people with mental health disabilities such as anxiety and schizophrenia. Given this, it is imperative that HCBS providers and providers of other services for people with IDD offer sensory accommodations, regardless of their client's diagnosis or age. In provider-owned settings, such as group homes and assisted living facilities, it is also good practice to build or modify settings to be more sensory friendly before a resident requests accommodations (Bulatova, 2023; Casson et al., 2021; T. Fletcher et al., 2023; Gaines et al., 2016; Murtadhi, 2021; Washington et al., 2021; Yi, 2021).

Types of modifications and accommodations can include:

- Modifications for visual processing, including using a muted color palette, soft (non-fluorescent) lighting, and organization strategies that minimize clutter.
- Modifications for auditory processing, including soundproofing rooms or installing stereo systems that can play background music or white noise.
- Modifications for olfactory processing, including proper ventilation of locations with strong smells (such as the bathroom or kitchen), limiting use of fragrance or scented products, and using aromatherapy in private spaces.
- Modifications for tactile processing, including clear pathways between spaces, soft surfaces (e.g., using rugs or carpeting on the floor), comfortable furniture (including furniture that allows a person to move around, such as swings or rocking chairs).
- Modifications for vestibular and proprioception processing, including limiting stairs within and around the house, plenty of space to move around, indoor and outdoor sensory rooms or areas, and using knobs and handles that are easy to grasp (T. Fletcher et al., 2023; Gaines et al., 2016; Geilman, 2016; Healy, 2020; Lutz, 2023; Manfredi & Kelceoglu, 2018; Whetzel, 2016; Yi, 2021).

“Challenging behavior” in people with IDD may result from sensory over- or understimulation. A common example of this is meltdowns among autistic people, many of whom report that their meltdowns are caused by an inability to cope with sensory input from their environments (Lewis & Stevens, 2023; Nason, 2019). Modifying someone's environment, even in very simple ways, can have an outsized impact on their behavior. “Sensory-friendly” environments will look different for each person; however, simple and common modifications can help reduce sensory over- or understimulation for people with a wide range of needs. In settings where multiple people with IDD live, such as group homes or assisted living facilities, providers must be aware of conflicting sensory access needs. For example, one person may need to move around and make a lot of noise while another may need a quiet, calm environment. Residents must always have a space to go to if they need a different sensory environment and shared spaces (e.g., the living room or kitchen) should vary between having calmer times and busier times. Providers must properly staff congregate settings so that people are not trapped in sensory-unfriendly environments that they cannot escape due to a lack of staff.

Returning to the idea that behavior supports must be interdisciplinary, providers should help a person with IDD schedule an evaluation with an occupational therapist when they suspect sensory needs as an underlying cause of behavior. Occupational therapy can help people with IDD manage their sensory needs, sensory processing and regulation, and can also aid in gaining adaptive skills (*What Is Occupational Therapy?*, 2023). Medicaid in all states covers basic occupational therapy services and many state HCBS waivers cover additional occupational therapy services (Friedman & VanPuymbrouck, 2018). As with all behavior supports, the focus of occupational therapy needs to be on addressing underlying needs, changing environments, and helping the person learn coping and regulation skills, not compliance-based interventions to eliminate a behavior.



## Questions to Answer About Sensory Needs When Writing Behavior Support Goals

- How does this person respond to common sensory stimuli, like bright lights, loud noises, or pain?
  - ◊ Does this person seem to be hypersensitive to certain stimuli?
  - ◊ Does this person seem to be hyposensitive to certain stimuli?
  - ◊ Does this person seek out or actively avoid certain stimuli?
- What sensory accommodations or modifications might benefit this person?
  - ◊ At home?
  - ◊ In the community?
- Does this person have access to a sensory-friendly environment at all times?
- Does this person have other disabilities or conditions that could impact their sensory regulation?
- Does this person have access to occupational therapy?

## Choice and Control

People with IDD often do not have even the most basic control over our lives. This is most evident with guardianship, which effectively removes a person's ability to make decisions about parts or all of their lives (Shotwell, 2022). However, people with IDD not subjected to guardianship also experience reduced choice and control over our lives, especially if we live or work in provider-owned settings. Provider rules that restrict when and where people with IDD living in provider-owned settings, are allowed to go out, as well as “block treatment,” where all people living in a provider-owned setting are expected to go on an outing, regardless of their actual wishes, substantially limit the choice and control of people with IDD living in provider-owned settings (Stancliffe et al., 2022). While the HCBS Settings Rule is supposed to remedy many of these issues, enforcement of the Rule is spotty at best, with many states receiving exemptions from fully implementing the Rule right away (Administration for Community Living, 2023; Aguilar, 2023).

Petner-Arrey noted that, in a study of people with intellectual disabilities and their support workers, support workers' focus on the health, safety, and wellbeing of people with ID often led to reduced choice and control for people with ID, which then led to increased “challenging behavior” (Petner-Arrey, 2011). Although support workers and other disability professionals do not always knowingly exert influence over people with IDD's choice and control, the power differential between a support worker and a person with IDD creates a constant risk of undue influence. Training support workers on this power differential, and how to account for it in interactions with people they support, is crucial.

Support services should work to empower people with IDD to have greater choice and control over our daily lives. Whenever possible, people with IDD should be able to self-direct our services, including being able to hire and fire our own support workers, having control over when and where we receive services, and controlling which tasks we receive support with. Self-direction of services should be available to people regardless of the waiver they are on and regardless of where they live; people who live in provider-owned settings should not be categorically excluded from self-direction of services.

Beyond choice and control over services, people with IDD must have control over our everyday activities, both small and large. As the HCBS Settings Rule has made extremely clear, it is not enough for people to be able to choose what they eat for breakfast or which color shirt they wear. People with IDD should also be able to make larger choices, like where we live, where we work, who we live with, who provides us services, and what we want to do in the future. The presumption should be that people with IDD have both the right and ability to make choices about our lives, even if we need support. When people with IDD do need support to make decisions and direct our lives, we should have access to supported decision-making and other tools that let us keep legal control over our lives, rather than being forced into guardianship.

People with IDD may need significant time and help to make choices about our lives and develop self-advocacy skills, particularly if we have lived in institutions or other controlling environments for large parts of our lives. Support staff should offer a person with IDD choices about their day and life whenever possible, even if the person is not readily able to answer. Similarly, support staff should encourage people with IDD to get involved in local self-advocacy groups and

organizations for people with IDD. Many self-advocacy groups offer specific training on the rights of people with IDD and on developing self-advocacy skills. Being exposed to peer mentors with similar disabilities, needs, and life stories who successfully self-advocate may also help people with IDD gain confidence in our self-advocacy skills.

### **Questions to Answer About Choice and Control When Writing Behavior Support Goals**

- Is this person under guardianship or living in a setting that restricts their control?
  - ◊ Ex. Provider-owned settings that use “block treatment”
- Have this person’s support workers been trained on how to empower choice for the people they support?
- Does this person have self-direction over their services?
  - ◊ Do they choose their support workers?
  - ◊ Do they choose where and when they get services?
  - ◊ Do they get to choose what they receive support with?
- Does this person get to control their everyday life?
  - ◊ Does this include big and small choices?
  - ◊ Do they have the support they need to make choices?
- Has this person had the chance to develop self-advocacy skills?
  - ◊ Local self-advocacy groups?
  - ◊ Peer mentorship or training?

### **Respect and Dignity**

People with IDD deserve respect and dignity, just like everyone else. However, people with IDD who receive HCBS report that support staff and other HCBS workers often do not respect us (Autistic Self Advocacy Network, 2021c). Friedman concluded that, on two validated measures of bias around disability, the majority of disability professionals in the study showed both explicit and implicit bias towards people with disabilities (Friedman, 2023). Similarly, Jansen-van Vuuren and Aldersey (2020) noted that people with IDD face significant public stigma, including disrespect, in our daily lives. There is little research on how people with IDD experience disrespect from support staff and disability professionals in the community. However, given the historical and current realities of how incarcerated and institutionalized or hospitalized people with IDD and other disabilities experience disrespect and poor treatment from staff, there is little reason to believe similar attitudes do not exist in community settings, especially quasi-institutional settings such as group homes (Badcock & Sakellariou, 2022; Cabral et al., 2023; A. Fletcher et al., 2021; Hultman & Hultman, 2023; McCormick et al., 2021; Stangis, 2021; Toohey, 2020).

The effects of disrespect and lacking dignity on people with IDD cannot be overstated. Ableism — discrimination against people with disabilities — is based in lack of respect for people with disabilities and undergirds the poorer treatment of people with disabilities in every facet of life: education, medical treatment, housing, employment, access to the community and from childhood to old age (R. L. Brown & Ciciurkaite, 2022; Devandas-Aguilar, 2019; Hamraie, 2022; Hodge & Runswick-Cole, 2013; Jammaers & Zanoni, 2021; Jóhannsdóttir et al., 2022; Kattari, 2020; Kwon & Archer, 2022; Lett et al., 2020; Lindsay et al., 2023; Livingston, 2000; Marcum, 2017; Morgan, 2018; Nario-Redmond & Silverman, 2020; Olkin et al., 2019; Sanmiquel-Molinero & Pujol-Tarrés, 2020; Taccone, 2023; van der Horst & Vickerstaff, 2022). While there is little research on the effects of ableism on the health of people with disabilities, research on other forms of discrimination (e.g., racism, sexism) suggests that the stress and stigma of discrimination leads to worse mental and physical health outcomes in other marginalized populations (Carter et al., 2019; Paradies et al., 2015; Pascoe & Smart Richman, 2009; Schmitt et al., 2014). The social effects of ableism and discrimination on people with disabilities may also limit a person with IDD’s quality of life significantly. Ableism and discrimination in social situations may lead to a person feeling unwelcome in those situations. This, in turn, may lead to a person avoiding certain situations, which itself can

have disastrous effects. If a person refuses to go to doctor appointments because medical staff continuously treat them with disrespect, this can have severe consequences for their health.

Support staff have two duties: to treat people with IDD in their care with respect and dignity, and to help people with IDD in their care build plans for what happens when someone disrespects them. In a society where ableism shows disabled people that we should not expect respect, it is the responsibility of support staff to model respectful behavior. Some kinds of respectful behavior include calling someone by the name and pronouns they choose, listening to disabled people and taking their needs seriously, and treating adults with IDD like we are adults rather than children. The golden rule of “treat others as you wish to be treated” is a good standard for support staff to consider if they cannot figure out the wishes of the people in their care. Support staff should also strive to become more aware of their implicit and explicit bias, and recognize the effects of ableism on people with IDD.

Support staff should also help build the self-advocacy skills of people with IDD, so we have the tools to respond to disrespect on our own. Staff can remind people that we have the right to be treated with respect and dignity, and talk to people about what respect and dignity are. Staff can also point out when someone is being disrespectful, and model what responding to disrespect looks like. Taking this a step further, staff can create role-playing exercises with someone with IDD about what they would do in a situation where they were being disrespected. It is also important to connect people with IDD to self-advocacy groups, or other groups designed to help people with IDD build self-advocacy skills.

### ***Questions to Answer About Respect and Dignity When Writing Behavior Support Goals***

- Has this person been discriminated against in specific situations?
  - ◊ How can we help this person feel safe and respected if they need to be in these situations?
- Does this person have support staff that treat them with respect and dignity?
- Does support staff get training on implicit and explicit bias?
- Does this person have a way to communicate if someone disrespects them?
- Does this person have people they trust to report to if someone disrespects them?
- Does this person have access to ways to learn self-advocacy skills and/or how to respond to disrespect?

### **Meaningful Relationships**

All people deserve to form relationships that are meaningful to them. This can include friendships and acquaintanceships, romantic and intimate relationships, professional and employment relationships, family relationships, and relationships with helping professionals, such as doctors or support staff. Only a person themselves can define what “meaningful” relationships are for them, because each person will have a different view of what “meaningful” relationships are.

People with IDD should be supported in forming the relationships we find meaningful. This starts with making sure we have meaningful access to the community and to a wide variety of people we could potentially form relationships with, including people without disabilities. These relationships should form naturally, meaning that people are not paid or compensated for their relationships with a person with IDD. Too often, people with IDD grow up going to school in segregated special education classrooms, where our non-disabled peers are rewarded materially for interacting with us. We may participate in “Best Buddies”-style programs that often function as little more than résumé fodder for our non-disabled peers. Once we graduate, we may move into disability-specific housing, like group homes or special apartments, and work at sheltered workshops or enclaves where our coworkers are also people with IDD. Outside of work relationships with other people with IDD and family relationships, our only relationships may be with support staff and health professionals who are paid to work with us. Almost never do staff allow us to foster a romantic or intimate relationship with anyone, disabled or not. In other words, people with IDD may never have a meaningful relationship with someone we do not live or work with, receive care or support from, or who is not paid or rewarded to interact with us. If we try to form friendships or romantic/intimate relationships with people on our own terms, we are often punished and labeled as having “inappropriate social behavior.”

Many people with IDD also struggle to form lasting friendships or romantic/intimate relationships, due to differences in how we socialize and understand social norms. These differences are often pathologized and land people with IDD in “social skills training” that encourages us to mask our disabilities and act non-disabled. Such training is not accessible for people who cannot mask our disabilities and is often deeply traumatic to those who can. These trainings teach people with IDD that we cannot have access to meaningful relationships unless we learn to act non-disabled (Kraemer, 2021; *Social Skills Training*, n.d.). This is not only untrue but incredibly harmful to disabled people. Rather than relying on social skills training, support staff should encourage the people with IDD in their care to be their authentic selves, and form relationships based on mutual understanding and respect.

There are many ways that support staff can assist people with IDD in cultivating meaningful relationships. Support staff should enable people with IDD to engage with our communities in ways that make organic relationships more likely to form, such as going out to a bar or club, taking a community college course, or joining a local organization. People with IDD should be able to take part in the activities we choose, and have the opportunity to meet new friends or partners. These opportunities should exist regardless of what support staff think the person in their care is capable of, and should not be predicated on being able to appear non-disabled.

### **Questions to Answer About Meaningful Relationships When Writing Behavior Support Goals**

- Does this person get chances to form meaningful relationships?
  - ◊ Do they have access to the community to meet new people?
  - ◊ Do they have access to friendships outside of school or work?
  - ◊ Do they have the chance to make friends that are not paid support?
- Does this person have freedom to start a romantic or sexual relationship?
  - ◊ Has this person received comprehensive accessible sexual education?
  - ◊ What support does this person need to maintain these relationships?
- Does this person have access to organic social opportunities?

### **Supporting Mental Health and Well-Being**

People with IDD, like everyone else, experience a range of internal emotions, sensations, and reactions to the world around us. For many people with IDD, this includes co-occurring mental health disabilities (MHD) and/or trauma responses. Historically, many disability professionals believed that people with IDD did not have the cognition required to experience mental ill-health or trauma (Werges, 2007). Today, there is a much greater understanding of both the prevalence of mental health disabilities and trauma among people with IDD (Bouras & Holt, 2007; Keller, 2019; Matson, 2019; Smull & Harrison, 1992). However, IDD and mental health services have yet to apply this understanding fully in the creation and adoption of services for people with dual IDD/MHD diagnosis.<sup>8</sup> Many IDD and MHD services, even those that nominally serve people with dual diagnosis, are still rooted in behaviorist models of dealing with “challenging behavior,” which view human neuropsychology as wholly irrelevant to “treating” behavior. This leaves said services unable to properly address co-occurring MHD in people with IDD, because the assumption is that MHD are irrelevant. This, obviously, is unacceptable given the decades of knowledge we have about trauma and dual diagnosis in people with IDD.

HCBS providers, and other providers of IDD services, must partner with mental health providers and services to create and implement quality competent, humane, and client-directed mental health services for people with IDD. People with dual diagnosis must be involved at every level of service creation and implementation, not merely as patients or recipients of services. Service creation and implementation cannot be a one-and-done deal; mental health services for people with IDD must be continually self-evaluating and reflecting on whether they can service the needs of the community and how to improve.

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<sup>8</sup> In this appendix, we use “dual diagnosis” to refer to people with both an IDD diagnosis and a mental health disability (MHD) diagnosis.



We have divided this section into five main topics: ensuring baseline mental well-being, preventing and addressing trauma, addressing co-occurring conditions, linking people to mental health therapy, supporting the proper use of psychotropic medications, avoiding and de-escalating crisis, and active crisis support. Each section builds on the last, starting with universal mental well-being supports for all people with IDD and ending with advice on providing support to people with IDD who are in an active mental health crisis.<sup>9</sup>

Many of our recommendations in this section parallel those in the Minnesota Department of Human Services Psychotropic Medication Manual (2024), which provides excellent guidance on psychological medication, therapy, and assessment of “challenging behavior” in people with dual diagnosis. While we wrote this appendix prior to the publication of the manual, we would be remiss if we did not mention it as a stellar example of the guidance and centralization of resources we want to see from states.

## Baseline Mental Well-Being

People with IDD have the right to access support for everyday mental health and well-being. According to the Substance Abuse and Mental Health Services Administration (SAMHSA) and the World Health Organization, “mental health” is not just the absence of mental illness or emotional turmoil; it encompasses “emotional, psychological, and social well-being” and affects a wide range of everyday decisions, actions, and feelings. Mental health does not look the same for every person and different people may experience the same events as having very different effects on their mental health (*Mental Health*, 2022; *What Is Mental Health?*, 2023).

People with IDD can experience good or bad mental health, with the presence or absence of diagnosable mental health disabilities. Mental health is something that fluctuates on a regular basis; this is true regardless of disability status. People with IDD, just like those without disabilities, should have the tools and support we need to understand our baseline mental well-being. While these tools will vary from person to person, supporting mental health mirrors our general framework for providing “behavior supports” in many ways. Support staff and caregivers should work to meet the basic underlying needs of people with IDD, including physical health and safety needs, the need for respect and control over our lives, and the need for meaningful relationships and community integration. People with IDD should also be able to check-in with support staff and caregivers about how we are feeling and get support around difficult situations and emotions. Support staff do not need to be experts in mental health care but they should be trained in recognizing signs of possible poor mental health in people with IDD.

### *Questions to Answer About Baseline Mental Well-Being When Writing Behavior Support Goals*

- What does baseline mental well-being look like for this person?
  - ◊ What is a good day vs a bad day? Etc.
- Who is responsible for checking in about this person’s well-being?
- Does this person have access to mental health screening to ensure baseline well-being?

## Trauma

HCBS providers, support staff, caregivers, and other disability and mental health services professionals must be aware of trauma among the people with IDD they serve. Trauma is injuries, reactions, or stress resulting “from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that [have] lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being” (Substance Abuse and Mental Health Services Administration, 2014a, p. 7). While it is impossible to calculate the exact percentage of people with IDD who experience trauma at some point in our lives, such a percentage is likely to be high. There is thus an impetus for disability services providers to implement trauma-informed approaches in their practices and for providers, support staff, and caregivers to make referrals to trauma-specific mental health services when appropriate.

<sup>9</sup> Many of our recommendations in this section parallel those in the Minnesota Department of Human Services Psychotropic Medication Manual (2024), which provides excellent guidance on psychological medication, therapy, and assessment of “challenging behavior” in people with dual diagnosis. While we wrote this appendix prior to the publication of the manual, we would be remiss if we did not mention it as a stellar example of the guidance and centralization of resources we want to see from states.

People with IDD are vulnerable to a range of traumatic events or experiences throughout the lifespan. People with IDD experience both “big T” and “little t” traumas (Barnhill et al., 2023, p. 34; Harvey, 2019). “Big T” traumas are larger, easily identifiable traumatic events, such as being abused or neglected, having a serious illness, having a loved one die, or being institutionalized or incarcerated (Barnhill et al., 2023, p. 34; Straussner & Calnan, 2014). “Little t” traumas are smaller, often less discrete ongoing traumatic events, such as experiencing social isolation and exclusion, frequent moves to new care placements, bullying, and dehumanization (Harvey, 2019; Straussner & Calnan, 2014). People with IDD are also at greater risk of, and deal with the lifelong consequences of, adverse childhood experiences, or ACEs (Hoover, 2020; Morgart et al., 2021; Vervoort-Schel et al., 2021); these include abuse or neglect, violence in the household, parental separation or divorce, and incarceration of a family member during childhood (*About the CDC-Kaiser ACE Study*, 2022; Felitti et al., 1998).

Trauma has extensive negative effects on people’s health and well-being. SAMHSA has compiled a chart documenting the physical, emotional, cognitive behavioral, and existential effects trauma has on health in both the short- and long-term. These can include:

- Emotional effects, such as numbness, anger, shame, anxiety, and emotional detachment.
- Physical effects, such as gastrointestinal distress, faintness, sleep issues, increased startle responses, and chronic health conditions such as heart disease.<sup>10</sup>
- Cognitive effects, such as difficulty concentrating or remembering, intrusive thoughts and flashbacks, self-blame, and suicidal ideation.
- Behavioral effects, such as restlessness, irritability/short temper, avoidance of situations reminiscent of the trauma, increased use of drugs and alcohol, and increased high-risk behavior (such as unprotected sex).
- Existential effects, such as decreased self-efficacy, despair about the future, increased cynicism, and hopelessness (Substance Abuse and Mental Health Services Administration, 2014b, pp. 62–63).

SAMHSA’s chart, while extensive, is drawn from sources that focus on a general population, rather than people with IDD. While there is no reason to believe that people with IDD do not experience the same ill-effects of trauma as those without IDD, people with IDD who experience trauma may present differently than people without IDD who experience trauma. In particular, people with IDD who experience trauma may present with an increase in “challenging behavior,” including increases in aggression and self-injury (Rittmannsberger et al., 2020; Rowsell et al., 2013). Because neither IDD professionals nor mental health professionals are typically trained to recognize trauma and related conditions (e.g., post-traumatic stress disorder/PTSD) in people with IDD, “challenging behavior” secondary to trauma may not be immediately or at all attributed to the trauma itself.

It is therefore imperative that HCBS providers, support staff, and other caregivers for people with IDD familiarize themselves with signs of trauma among people with IDD and implement trauma-informed approaches. Trauma-informed approaches, also called trauma-informed care, are programs or systems that “[realize] the widespread impact of trauma and understands potential paths for recovery; [recognize] the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and [respond] by fully integrating knowledge about trauma into policies, procedures, and practices, and [seek] to actively resist re-traumatization” (Substance Abuse and Mental Health Services Administration, 2014a, p. 9). Trauma-informed approaches are not the same as specific trauma treatment or services for trauma survivors; they are ways of conducting programs, organizations, or services of any nature.

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<sup>10</sup> Perhaps the most well-known study exploring the relationship between traumatic experiences and long-term physical health effects is the original ACEs study, which found “a strong dose response relationship between the breadth of exposure to abuse or household dysfunction during childhood and multiple risk factors for several of the leading causes of death in adults. Disease conditions including ischemic heart disease, cancer, chronic lung disease, skeletal fractures, and liver disease ... also showed a graded relationship to the breadth of childhood exposures. The findings suggest that the impact of these adverse childhood experiences on adult health status is strong and cumulative” (Felitti et al., 1998, p. 251).

There is little literature on implementing trauma-informed approaches within HCBS or other IDD services. However, Keesler (2014) gives an overview of ways HCBS providers and other IDD service providers can make their services more trauma-informed. Using Fallot and Harris's (2011)<sup>11</sup> five principles of trauma-informed care — safety, trustworthiness, choice, collaboration, and empowerment — Keesler offers the following suggestions:

- **Safety:** IDD service providers must build and enhance safety among people they serve through modifying both the environment and interactions between staff and people with IDD. This can look like training staff in crisis prevention and de-escalation, making sure physical spaces are both accessible and welcoming, helping people with IDD build self-advocacy skills, and developing individualized support plans that recognize a person's trauma history, among other tactics.
- **Trust:** IDD service providers must build trust with the people they serve. Establishing clear expectations and boundaries is important, as is having consistency in interactions between staff and people with IDD. For example, if a person with IDD has a recurring appointment on a particular day and time, staff should help them with transportation to the appointment every time.
- **Choice:** IDD service providers must offer people with IDD extensive opportunities for real choices. Service providers also must offer people with IDD the opportunity to take risks and try new things. Support staff should not assume that a person's difficulty making decisions or lack of knowledge of different choices means that person cannot make decisions.
- **Collaboration:** IDD service providers, support staff, and people with IDD must work together to make decisions and solve problems. Service providers should encourage support staff to work together between themselves and with people with IDD. Service providers and support staff should also encourage clients with IDD, when appropriate, to problem-solve between themselves and rely on each other for help and advice.
- **Empowerment:** Service providers and support staff must empower people with IDD to make decisions and direct our own care. Support staff should work with people with IDD to identify strengths and abilities rather than focusing on deficits and inabilities (Keesler, 2014, pp. 37–38).

Exact strategies for implementing trauma-informed approaches will vary from one service provider to another and will depend heavily on the individual needs of the people they serve. For instance, a group home whose residents all have extensive histories of institutionalization and neglect may use different trauma-informed techniques than a job coaching agency that works mostly with people living in their own housing. However, basic strategies and underlying principles for trauma-informed approaches should remain the same between different organizations.

We stress here the importance that IDD services not retraumatize people with IDD as a basic component of trauma informed care. People with IDD are more likely to experience both more recognizable “Big T” traumas as well as smaller, recurring traumas related to loss of choice and control. Routine practices within IDD services, such as guardianship, institutionalization, restraint/seclusion, token economies and other behaviorist interventions, deficit-based language and interventions, and constant infantilization and patronization, are all traumatic. A group home that, for instance, calls themselves “trauma informed” after getting rid of physical restraints is not actually trauma informed if they still utilize token economies to make people earn seeing friends on the weekends. A speech therapist that calls their practice “trauma informed” because they do not use hand-over-hand prompting when teaching AAC is not actually trauma informed if they practice planned ignoring when their client does not use the AAC device. Eliminating within IDD services is not as simple as eliminating obvious abuse and neglect; it also involves getting rid of practices that deny people choice and control.

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<sup>11</sup> Fallot and Harris's 2011 report itself is also a useful tool for organizations looking to implement trauma-informed approaches. The majority of the content focuses on outpatient mental health care and social services for people with mental health disabilities but could easily be adapted for IDD services.

## Questions to Answer About Trauma When Writing Behavior Support Goals

- Has this person experienced trauma?
  - ◊ If so, what kind of trauma?
  - ◊ What setting?
- What sorts of trauma services has this person received in the past, if any?
- Does this person have support staff trained in trauma-informed care?
- How are this person's services trauma-informed? What could be done to prevent re-traumatization?

## Addressing Co-Occurring Conditions

Co-occurring conditions are other disabilities or chronic health issues that occur alongside an IDD. While estimates of how many people with IDD have a co-occurring mental health disability vary between 14% and 70%, more recent estimates put the number around 35% (V. Bradley et al., 2019; Lineberry et al., 2023; NADD, n.d.) This is significantly higher than the prevalence of mental health disability in the general United States adult population, which is approximately 23% (Substance Abuse and Mental Health Services Administration., 2022) While there is little data on the prevalence of serious mental illness among adults with IDD, data from the Netherlands shows that many people with serious mental illness also meet the criteria for intellectual disabilities, suggesting that the two conditions co-occur (Nieuwenhuis et al., 2017, 2019; Seelen-de Lang et al., 2019).<sup>12</sup>

However, mental health disabilities often go un- or misdiagnosed among people with IDD. There are several reasons for this: in particular, diagnostic overshadowing, communication challenges impacting a person's ability to report internal experiences, and lack of knowledge about IDD/MHD dual diagnosis. Diagnostic overshadowing refers to "the tendency for clinicians to attribute symptoms or behaviors to an IDD" and therefore underdiagnose co-occurring mental health disabilities (Kuehl, 2023, p. 348). Diagnostic overshadowing can lead to professionals refusing to assess a person with IDD for mental health disabilities, or insisting that a person with IDD cannot have mental health disabilities, even if the person is quite clearly displaying signs and symptoms of a mental health disability (Jopp & Keys, 2001).

Moreover, accurate diagnosis of mental illness generally requires the patient to discuss their subjective internal experiences. This may prove difficult, if not impossible, for people with IDD (Charlot et al., 2022). For instance, an autistic person with an intellectual disability may misunderstand the question "do you hear voices when nobody else is in the room?" as referring to telephone calls and answer "yes" despite not experiencing auditory hallucinations (Hurley, 1996). These issues only increase for people with higher support needs and fewer robust methods of communication (Carnaby, 2008; DiStefano et al., 2020; Oliver et al., 2022).

Another contributing factor is the dearth of professionals who are trained in assessment and care of people with dual diagnosis. Mental health services and IDD services are often siloed off from one another, leading to health care professionals being trained in one field or the other, but not both (Bellegarde et al., 2022; Pinals et al., 2017). This disparity persists in part because mental health professional education does not cover care of people with IDD in any substantial detail (Marrus et al., 2014; Vi et al., 2023). All of this means that when mental health professionals with experience treating people with IDD do exist, the wait times to see them may be months if not years long (Lamar, 2020).

Despite these issues, proper and timely diagnosis of co-occurring mental health disabilities for people with IDD remains a priority. Mental health diagnoses are often a "gateway" to mental health services; for a person to qualify for the services or treatment they need, they must first have an appropriate diagnosis. This is especially true if a person needs more intensive services (e.g., assertive community treatment or partial hospitalization programs) because these services often only accept people with certain diagnoses. Further, improper diagnosis may lead to a person receiving too much, too little, or inappropriate types of treatment, which can increase "challenging behavior" and aggravate the underlying

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<sup>12</sup> "Serious mental illness," abbreviated SMI, is a subset of mental health disability defined by SAMHSA as "a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities." While the term encompasses a range of mental health disabilities, the most common forms of SMI are bipolar disorder, major depressive disorder, and schizophrenia (*Living Well with Serious Mental Illness*, 2023; *Mental Illness: Definitions: Serious Mental Illness*, 2023)



mental health disability. If a clinician mistakes a person with co-occurring intellectual disability and bipolar disorder's manic episodes for "challenging behavior," the clinician might then prescribe inappropriate medications or refer the person to interventions that will not help.

Because of this, it is essential that support staff and caregivers help people with IDD seek out professionals who understand dual diagnosis. Support staff and caregivers should advocate for the needs of the people they support and help the people they support develop self-advocacy skills within mental health care settings. While support staff and caregivers should not presume to speak for the person, they work as intermediaries by clarifying or restating questions for the person they support and helping clarify the person's answers, if need be. (In our example of a person who answers "yes" to "Do you hear voices when nobody else is in the room?", support staff could help clarify for the person that the question is not referring to telephone calls or people yelling from other rooms.) Support staff and caregivers may also function as proxy respondents who can provide additional information on a person's health or symptoms, though they must be careful to not speak for the person (Costello & Bouras, 2006; Ricciardi, 2013).

### **Questions to Answer About Co-occurring Conditions When Writing Behavior Support Goals**

- Does this person have co-occurring mental health disabilities?
- Has this person been assessed for mental health disabilities?
  - ◊ Was this assessment done in a way that led to an accurate diagnosis?
    - Were the assessment tools/surveys accessible?
    - Were modifications made to make the tools more accessible?
    - Was the diagnostician trained in working with people with IDD?

### **Access to Psychological Counseling and Therapy**

Psychological counseling and therapy can be a powerful tool in working with people with IDD and co-occurring mental health disabilities as well as people with IDD with "challenging behavior." People with IDD may benefit from a number of different psychotherapy modalities and types of services. Therapy must be individualized — there is no one "best" therapy modality for all people with IDD. While support staff and caregivers can play a vital role in therapy for a person with IDD, therapy should not be used as a way to force a person with IDD to comply with the wishes of our caregivers.

Many existing psychotherapies have been adapted for people with IDD. The majority of research on adaptive psychotherapies focuses on cognitive behavioral therapy/CBT (Jahoda et al., 2017; Willner & Lindsay, 2016) and dialectical behavioral therapy (J. F. Brown, 2018; Lew et al., 2006; McNair et al., 2017). There is also some evidence for the effectiveness of adapted forms of acceptance and commitment therapy/ACT (Byrne & O'Mahony, 2020; Y. Garcia et al., 2022; Patterson et al., 2019; Patterson & Golightly, 2023), narrative therapy (Mayer et al., 2023; McKenzie-Smith, 2020), compassion-focused therapy/CFT (Cowles et al., 2020; Patterson et al., 2019; Willems et al., 2022), psychodynamic psychotherapy (Beail, 2016; Beail & Jackson, 2013; McInnis, 2016), and eye movement desensitization and reprocessing therapy/EMDR (Byrne, 2022; Penninx Quevedo et al., 2021; A. N. Smith et al., 2021). Other psychotherapies may work for people with IDD if the therapist makes accommodations to meet the needs of the person — for example, using simpler language or visual supports (Witwer et al., 2022).

Regardless of the exact psychotherapy approach(es) used, people with IDD benefit from psychological counseling and therapy just as people without IDD do: when counseling or therapy is individualized to a person's needs and situation. Witwer et al. write "Psychotherapy is effective for many individuals with [IDD] ... Mental health professional training programs rarely address the need to adapt psychotherapy for clients with disabilities" (2023, p. 5). People with IDD do not necessarily need to be in IDD-specific psychotherapy; many people with IDD can participate in standardized or general psychotherapy programs with the right accommodations. As we have previously discussed, there is no "one size fits all" therapy or treatment for people with IDD. A psychotherapy or counseling approach that works for one person with IDD may do nothing for another person with IDD, even if the two people have roughly the same needs.

Support staff and caregivers should work with the person with IDD to find a psychotherapy or counseling approach that works for the person. Support staff and caregivers can help with identifying needs and goals for therapy, what the person wants or does not want in a therapist, and what approaches have or have not previously worked for the person. Support staff and caregivers can also help a person with making appointments and “interviewing” potential therapists. If needed or desired, support staff and caregivers can help provide therapists background information on a person’s condition and strategies for engaging with the person.

While individual psychotherapy may be helpful to many people with IDD and mental health disabilities and/or “challenging behavior,” it is not the only option for psychological counseling. Group therapy, support and skill-building groups, and psychosocial rehabilitation services may also play a role in a person’s treatment. Peer support services, or services delivered by a person who also has lived experience of IDD/MHD diagnosis, also may play an integral role in someone’s care. There is extensive evidence for peer support services in mental health care (Repper & Carter, 2011; Shalaby & Agyapong, 2020) and emerging support for peer support services among people with IDD in various fields (Friedman, 2017; Marks et al., 2019; A. E. Schwartz et al., 2020). Because peer support services are provided by people who have lived experience with IDD/MHD diagnosis, they may be more accessible and acceptable to people with dual diagnosis than other forms of care or support.

Finally, therapy cannot be used as punishment or as a way to force people with dual diagnosis to comply with the wishes of their caregivers. While caregivers and support staff can certainly share their goals or wishes for the person as part of therapy, a focus on compliance only serves to destroy the therapeutic relationship and turn psychotherapy into another tool to undermine the person’s own goals. When psychotherapy is used to force compliance, the person receiving therapy learns that they cannot trust their therapist, that anything they say or do may be used against them, and that their needs are less important than others’ needs. Therapy must be person-centered and must focus on the goals, development, and overall well-being of the person at the center of it.

### ***Questions to Answer About Psychological Counseling and Therapy When Writing Behavior Support Goals***

- Does this person have access to psychotherapy?
- What kinds of psychotherapy have or have not worked well for this person in the past?
- Does this person have a choice over what method of therapy they receive?
  - ◊ Does this person get to choose whether they attend an adapted form of therapy for people with IDD or not?
- Does this person get to choose who their therapist is?
- Does this person have therapy that is responsive to their individual needs?
- Can this person choose to refuse therapy?
- Can this person access other kinds of support, like community groups?

### **Use of Psychotropic Medications**

This section will focus on the use and abuse of psychotropic medications to treat both mental health disabilities and “challenging behavior” among people with IDD.<sup>13</sup> Because this appendix is largely aimed at support staff, HCBS providers, and other non-medical professionals, the recommendations will focus largely on advocating for the responsible prescription and use of psychotropic medications for people with IDD. We will, however, include citations for guidelines for prescribing psychotropic medications to people with IDD that support staff and HCBS providers can share with mental health clinicians and medication prescribers.

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<sup>13</sup> Psychotropic medications is the formal term for mental health medications, or medications that “affect the mind, emotions, and behavior” by acting on the central nervous system. Broad categories of psychotropic medications include antidepressants, mood stabilizers, anti-anxiety medications, antipsychotics, stimulant medications, and medications to help manage substance use disorders (Ernstmeier & Christman, 2022).

People with IDD are routinely prescribed psychotropic medications for “challenging behavior,” despite most psychotropic medications lacking FDA approval for that use (Charlot et al., 2020). Many psychotropic medications have significant side effects and the use of multiple psychotropic medications at once (polypharmacy) runs an additional risk of drug interactions that range from unpleasant to fatal (Charlot et al., 2020; S. R. Erickson et al., 2022). While psychotropic medications can be an effective part of treatment when used as labeled for mental health disabilities, they are not a sole treatment on their own and should not be used alone to manage or reduce “challenging behavior.”

Too often, people with IDD receive psychotropic medication prescriptions despite not having a mental health disability that indicates use of those medications. This is particularly notable in people with IDD prescribed antipsychotic medications. For instance, Deb and Limbu (2023) estimate that of adults with IDD who receive antipsychotic medication prescriptions, 72% have no known mental health disability that would indicate the use of antipsychotics; similarly, Sheehan et al. (2015) found that about half of the people with IDD who had “challenging behavior” they surveyed had been prescribed antipsychotic medications despite only 12% had a record of severe mental illness.

While we could not locate statistics on how many psychotropic medication prescriptions to people with IDD are initiated by the person with IDD themselves rather than a family member, support person, or residential care staff, it is important to look at the use of “challenging behavior” as a reason for prescription. As Clarissa Kripke, a primary care physician with extensive experience working with people with IDD and “challenging behavior” points out, “[challenging] behavior is not a patient complaint. ... “Challenging behavior” is a caregiver complaint, a complaint for someone who’s supporting someone else” (Kripke, 2016). The widespread use of “challenging behavior” as a reason to initiate psychotropic medication points to psychotropic medication being used not to actually reduce psychiatric symptoms and internal distress a person with IDD feels but to placate and sedate the person, making them less of a “challenge” to the staff tasked with supporting them. This amounts to chemical restraint, a practice banned under the HCBS Settings Rule (42 CFR § 441.530 - *Home and Community-Based Setting*, 2014).

HCBS providers and support staff must address “challenging behavior” holistically, not simply by having a medical professional prescribe psychotropic medications for a person with IDD. Providers and staff should first consider whether a person’s basic needs, including the need for community integration and self-direction, are met, and, if not, what could change to meet these needs. Providers and staff must try a range of non-pharmaceutical interventions, including psychotherapy, before pursuing medication. Providers and staff should also consider whether environmental and interpersonal factors are causing the problem, for instance, whether a person is “acting out” around a staff member because of a disagreement between the person and staff member. Given that many psychotropic medications cause substantial side effects, including side effects that may continue to affect someone after the medication is discontinued, providers and staff must take extreme caution with using psychotropic medication for “challenging behavior.” Providers and staff should only consider behavior that poses a real danger to the person or others (e.g., self-harm or serious physical aggression) as a candidate for psychotropic medication once all other options have been exhausted; behavior that is merely annoying to others should not be targeted for medication.<sup>14</sup>

In cases where the person with IDD also has a diagnosed mental health disability, psychotropic medication may be warranted. However, prescribers should adhere to guidelines on prescribing psychotropic medications to people with IDD/MHD dual diagnosis. Several sets of guidelines and toolkits exist, two from the United States and others from Canada and the United Kingdom as well as an older guide from the World Psychiatric Association (Barnhill et al., 2023; Bhaumik et al., 2015; Deb et al., 2009; *Developmental Disabilities Primary Care Program*, 2021; *Health Care for Adults with Intellectual and Developmental Disabilities*, 2021; Faculty of Psychiatry of Intellectual Disability, 2016; Sullivan et al., 2018). While these guidelines all differ slightly in their recommendations, they all embrace the same core principles, including:

- A person with IDD should have comprehensive medical and psychiatric assessments performed before starting psychotropic medication in order to rule out physical or environmental causes of symptoms. These assessments should ideally be performed by professionals who specialize both in a relevant field (e.g., primary care, neurology, psychiatry) and care for people with IDD.

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<sup>14</sup> For a more in-depth discussion of what constitutes dangerous behavior, see the section on “Addressing Dangerous Behavior.”

- Psychotropic medications should be used in conjunction with psychotherapy and other psychosocial activities.
- Psychotropic medication prescribers should work with other members of the person's care team.
- Psychotropic medications should be limited to the lowest number of medications and lowest dosage of each medication that is still effective. Prescription of multiple medications in the same class or doses that exceed the usual maximum dose of a medication should only be considered when lower dosages have been ineffective.
- Psychotropic medication prescribers should regularly monitor for response to treatment and side effects among people with IDD taking psychotropic medications.
- Psychotropic medication prescribers should be aware that people with IDD/MHD dual diagnosis may have atypical symptoms or atypical reactions to medications.
- Psychotropic medication prescribers should consider reducing or discontinuing medications not indicated for the diagnoses or symptoms a person has (e.g., someone on an antipsychotic who does not have symptoms of psychosis should be a candidate for tapering off the antipsychotic).
- People with IDD prescribed psychotropic medications should, along with their caregivers or support staff, be given information on their medications in a format they can understand.
- If psychotropic medications are prescribed to a person with IDD in crisis, said medications should be discontinued as soon as possible once the crisis has resolved.

People with IDD/MHD dual diagnosis should, whenever possible, have the final say on whether they take psychotropic medications, what psychotropic medications they take, and what dose of psychotropic medications they take. HCBS providers, support staff, and psychotropic medication prescribers should inform the person of their options in a way the person can understand. This may include finding or creating plain language or Easy Read handouts about a particular medication, creating visual schedules for taking and managing medication, or talking a person through the pros and cons of different medications they could try.<sup>15</sup> Providers and staff should never use psychotropic medication as a punishment.

### **Questions to Answer About Psychotropic Medications When Writing Behavior Support Goals**

- Does this person take psychotropic medication? Are they at risk of being put on psychotropic medication?
  - ◊ Are they diagnosed with a mental health disability that warrants taking these medications?
- What external factors could be addressed in this person's life before trying medication to control behavior?
  - ◊ Are this person's basic needs being met?
  - ◊ Do they have freedom of choice?
  - ◊ Do they have a good reason to "act out"?
- Has this person received comprehensive medical and psychiatric assessments to rule out other conditions?
- Has this person's support team tried non-pharmaceutical interventions before medication?
- Is this person a threat to themselves or others?
- If medication is necessary, is this person educated about their medication?
  - ◊ Are support staff also trained about psychotropic medication?
- Does this person have access to medication management?
  - ◊ Do their medication types and dosages make sense?

<sup>15</sup> The SPECTROM Project in the U.K. has created Easy Read handouts of medication information for many common psychotropic medications (Deb & Limbu, n.d.). Similarly, the website [easyhealth.org.uk](http://easyhealth.org.uk) maintains a library of Easy Read resources on various health topics, including mental health and psychotropic medication (*Welcome to Easy Health*, n.d.). In the US, both the National Institutes of Health and the Food and Drug Administration maintain online libraries of information about psychotropic medications, although these are not usually in plain language or Easy Read (*Drugs, Herbs and Supplements*, n.d.; *Drugs@FDA*, n.d.). The book "Helping Parents and Teachers Understand Medications for Behavioral and Emotional Problems: A Resource Book of Medication Information Handouts" (Dulcan & Ballard, 2015), though aimed at parents and teachers of children taking psychotropic medications, may also be relevant to support staff and caregivers of adults with IDD taking psychotropic medication.



## Avoiding and De-Escalating Crisis

While meeting basic underlying needs, attending to co-occurring mental health issues, and providing proper psychosocial support through community integration all help reduce the chance of a person with IDD experiencing crisis, they do not eliminate the risk. Staff and caregivers must take steps to anticipate crises and document how to respond to and de-escalate crises in a crisis or safety plan. Whenever possible, the person with IDD should write their own crisis plan and/or help lead the process of writing the crisis plan. When a person seems to be on the verge of crisis, staff and caregivers should intervene in ways that are likely to de-escalate the crisis without putting additional demands on the person.

A core part of avoiding and de-escalating crises, when they do happen, is ensuring all people working with the person with IDD know what a crisis looks like, what the warning signs of a crisis look like, and how to effectively respond to crisis escalation with dignity and care. Crucial to this is making a crisis support plan to document what crisis escalation and warning signs look like as well as how to respond. There are various templates for crisis planning available online, including formal psychiatric advance directives as well as less formal options like WRAP plans and safety plans.<sup>16</sup> Crisis planning, whenever possible, should be completed by the person it is meant to help. If this is not possible, staff should conduct crisis planning in consultation with the person. Regardless of who completes the crisis plan and what type of plan they use, crisis planning should reflect the preferences and needs of the person.

Regardless of what planning tool or template is used, the person or people completing the crisis plan should document and describe a few key situations and ideas. These include:

- What a person does when they are calm and happy,
- What triggers may cause a crisis,
- Any situations that might resemble a crisis or escalation but are not (e.g., documenting that if the person is bored, they may try to disassemble furniture, but this is not a crisis and does not need a crisis response)
- How caregivers and others around a person can avoid triggers,
- What can help the person cope when being around a trigger is unavoidable,
- What a person does when they are agitated or upset but not yet in crisis,
- What helps the person calm down when they are agitated or upset but not yet in crisis,
- What the person looks like when they are in crisis,
- How to best keep the person and those around them safe during a crisis (e.g., by having non-essential people leave the area, by removing access to kitchen knives),
- When to call for external resources or help (e.g., calling in extra staff, contacting the person's family, calling for an ambulance),
- What the person looks like when they are recovering or de-escalating from a crisis, and
- How to best support the person when they are in recovery after a crisis.

Foundational to crisis planning is seeing crisis, agitation, and general “big emotions” as human responses to either internal or external causes, not just “behaviors” to be managed. Even if someone is not “acting rationally” or is responding to something nobody else can perceive, there is still a cause to their behavior and a need that needs to be met. Behavior is multicausal and multifaceted, not merely someone attempting to gain or escape attention, tangible objects, sensations, or situations. Even if someone is trying to gain attention or objects or avoid a situation or sensation, that is a legitimate need that should be considered and explored. Caregivers may not always be able to meet someone's needs, but acknowledging that someone has a need and is trying to express it the best they can.

Ideally, the person themselves should describe what is and is not a crisis for them. Not every behavior that challenges staff or caregivers constitutes a crisis and not every crisis a person might experience is outwardly visible to others. If the person and caregivers disagree on what constitutes a crisis, they should invite other people who know the person well

<sup>16</sup> For a more detailed list of resources for crisis support planning, see Appendix B: Selected List of Crisis Support Planning Resources.

into the conversation to hear other perspectives. If it is not possible for the person to describe how they define crises, caregivers should document what situations or triggers make the person very upset, dysregulated, agitated or in what situations caregivers are not able to de-escalate the person or ensure the person's general safety. Crucially, situations where the person's behavior is annoying or hard to understand but where the person is not dysregulated or posing an active safety risk to themselves or others should be counted as crises. Caregivers should consider documenting such behaviors in a crisis plan as "situations that resemble a crisis but are not."

In terms of avoiding crises, staff and caregivers should aim to reduce the person's exposure to triggering situations while not isolating the person from all risk or infringing on the person's rights. For example, a person who needs help bathing and dressing but also has significant trauma triggers related to sexual assault should ideally be allowed to choose which staff help bathe and dress them to reduce the risk of being triggered. Staff, along with mental health care providers, should also work with the person on coping skills and processing trauma so they are more able to calm themselves if a non-chosen staff member has to assist them with bathing and dressing. Similarly, a person with IDD who is in recovery from alcohol addiction should have support in their sobriety, including ensuring they can live in an alcohol-free space if they choose. But avoiding all mention or reminders of alcohol is not a realistic goal for anyone — for instance, the person may pass by a bar while running errands out of the house. Staff should therefore support the person in developing skills to cope with reminders of alcohol or urges to drink.

While crisis de-escalation techniques will depend heavily on the strengths and needs of the person and their caregivers, it is possible to provide some basic guidance. Deborah Lipsky and William Richards, in their book "Managing Meltdowns" (2009), outline the SCARED model of responding to autistic meltdowns and other crises among people with IDD. The components of SCARED are:

- **Safe:** Focus on making sure the person in crisis is physically safe. Remain with the person. If possible, remove other people or distracting objects from the space.
- **Calm:** Remain calm; do not let your emotions get away from you. Use a "strong, calm and reassuring voice." Do not add a lot of extra stimuli by talking at the person more than is necessary.
- **Affirmation:** Understand that the person is doing the best they can to manage the situation, their emotions, and their responses. Acknowledge that the person is doing their best. Use the person's name when you talk to them and acknowledge their stress. Do not try to challenge their responses or ask more questions than needed.<sup>17</sup>
- **Routine:** Let the person engage in routines or activities that help them calm down, even if the activities do not seem to have a purpose (e.g., someone walking in circles). If the person needs support to engage in a calming routine (e.g., needing fidget toys from another room), help them find the support. Do not try to rush the person through their routine or try to talk about what happened before they are calm.
- **Empathy:** Try to understand what is happening from the person's perspective. Understand that while the person's crisis may have effects on others, the person in crisis is the one most affected. Do not shame the person or make a big deal out of the effects their behavior or emotions have on others. Acknowledge that the person is experiencing stress and uncertainty.
- **Develop (or revise) a crisis plan:** Once the person is no longer in crisis, work with them to develop, revise, and implement strategies to reduce the frequency and severity of crises. Involve others, such as the person's family or other staff/caregivers, if needed. Do not rely on generic strategies or strategies developed without input from the person. Continue to work with the person to develop both coping skills for them to use and de-escalation skills for those around them to use (Lipsky & Richards, 2009, p. 19).

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<sup>17</sup> People in crisis may say things that do not match with others' reality; e.g., a person saying that someone else "wants to hurt me" even though nobody around them is trying to hurt them. This can be a sign of psychosis and/or a response to previous trauma (for instance, the person saying someone else wants to hurt them may have previously lived in a place where they were physically abused when they got upset). In either case, people responding should not try to directly challenge the person's beliefs ("nobody wants to hurt you!") or encourage the person's beliefs ("okay, let's find who wants to hurt you and set them straight"). Empathizing with the person's beliefs ("I would also be scared if someone wanted to hurt me") and giving the person options to help with their situation ("would you like to talk about how we could help you stay safe from the people who want to hurt you?") can help establish trust and de-escalate the situation (*How Can I Communicate with Someone Experiencing Psychosis?*, 2023).

The SCARED method, and other strategies for assisting people in crisis, are not foolproof and will not necessarily work “out of the box” for every person. Staff and caregivers should work with people with IDD to develop individualized strategies to support the person through and de-escalate crises. Any strategy used, however, must start by recognizing that people with IDD are human, with a range of emotions, and that while our emotions may present differently than in people without IDD, we still deserve the same care and grace as anyone else in crisis.

### ***Questions to Answer About Avoiding and De-Escalating Crisis When Writing Behavior Support Goals***

- What does this person look like when things are “normal”/not in crisis?
- What can trigger or cause a crisis for this person?
  - ◊ What can be done to avoid triggers?
  - ◊ How can others help this person cope when they have to be around triggers?
- What does this person do when they are pre-crisis? What does it look like when they are in crisis?
- What helps de-escalate crisis situations?
  - ◊ What are concrete things this person or their support staff can do?
- Does this person have a crisis support plan?
  - ◊ Did they get to lead or help make this plan?
- What supports or modifications can be made to this person's daily life to avoid crisis?
  - ◊ How do we make sure any modifications preserve this person's freedom?

### **Active Crisis Support**

Providing support for people with IDD who are in active mental health crises is often challenging and unpredictable. Crisis response needs to be even more individualized than most “behavior support” services because people, with or without IDD, often require different help than they do when not in crisis. Despite this need for individualization, we present some general guidelines here to help people with IDD and our support staff deal with active mental health crises. These guidelines are: creating crisis support plans ahead of time, locating IDD-competent resources, promoting push-in over pull-out services, non-involvement of police, and avoiding institutionalization whenever possible.

We detailed the process of developing crisis support plans in the previous section; therefore, we will not cover the topic in detail here. However, developing and using crisis support plans does mean that staff/caregivers should be trained on how to implement the plan during a crisis, and what steps to take during a crisis, before a crisis occurs. If, for example, a person's crisis support plan involves evacuating other people from common spaces during a meltdown, staff and caregivers should practice doing this before a crisis happens. Staff and caregivers should practice parts of the crisis support plan enough that they can easily perform the skills or tasks even when someone is in crisis.

Staff and caregivers should as part of crisis planning find mental health crisis services willing to work with people with IDD/MHD dual diagnosis. Although all mental health crisis services in the United States are supposed to be accessible to people with IDD, the reality is that many are not (Lamar, 2020; Pinals & Edwards, 2020; Substance Abuse and Mental Health Services Administration, 2020). This does not mean that every person with dual diagnosis will need specific IDD/MHD crisis services but rather that staff and caregivers should identify crisis services that will not categorically exclude or refuse to care for people with IDD.

Crisis support services should be push-in, not pull-out. People in crisis should be able to stay in their usual living situation unless there is an immediate danger to the person if they stay or if the person requests alternative placement. This should operate similarly to push-in services in schools for students in special education, where students remain in mainstream classrooms and specialists “push-in” to classrooms, rather than pulling students into segregated settings for services (Morin, 2019). Push-in crisis services may look like flexible or increased staffing, more frequent access to community-based mental health supports, and changes in routine to decrease stress (such as letting a person stay home from work for a few days until the crisis passes).

When pull-out services (such as out-of-home respite or peer-run crisis housing) are used, they should be no more restrictive than the person's usual housing. People with IDD's right to community integration does not go away when a person is in crisis. Pull-out crisis services also should be located within the general area a person usually lives in whenever possible. If this is not possible, pull-out crisis services should at least be located within a community with similar access to community resources as the person's usual residence. Pull-out crisis services must be considered HCBS under the HCBS Settings Rule; institutional or presumed institutional placements are not acceptable.<sup>18</sup>

HCBS providers must also seek out resources that either do not work with law enforcement or minimize the role of law enforcement to the greatest extent possible. Involving law enforcement in mental health or behavioral crises results, far too often, in violence towards the person in crisis. Perry and Carter-Long estimate that “a third to a half of all [law enforcement] use-of-force incidents involve a disabled civilian” (Perry & Carter-Long, 2016, p. 7). Law enforcement treatment of people with IDD and/or mental health disabilities, especially people of color with IDD and/or MHD, is often callous, mocking, and violent. The cases of Ethan Saylor, Neli Latson, Kajieme Powell, or Arnoldo Rios Soto and Charles Kinsey illustrate this in great detail.<sup>19</sup> Even though many law enforcement departments use “crisis intervention teams” (CIT) to respond to people having mental health and behavioral crises, the evidence that CIT training actually leads to fewer arrests, prosecutions, injuries, and deaths among people with mental health disabilities during law enforcement encounters is mixed at best (Haigh et al., 2020; Peterson & Densley, 2018; Rogers et al., 2019; Westervelt, 2020).

Even when law enforcement responses to people in mental health or behavioral crises work “well,” the response is traumatizing to the person in crisis and those around them. For this reason, HCBS providers must actively research crisis response options within their communities that do not involve law enforcement. The Bazelon Center for Mental Health Law and the group Interrupting Criminalization have both written extensively on alternatives to police response for mental health crisis (Alternatives to the Police: Responding to People with Mental Illness, 2021; Diversion to What? Evidence-Based Mental Health Services That Prevent Needless Incarceration, 2019; Kim et al., 2021). The website “One Million Experiments,” a joint project of Interrupting Criminalization and Project NIA, also documents community projects that seek to offer alternatives to policing, many of which involve mental health resources (*About One Million Experiments*, 2022).

Beyond avoiding police encounters, responses for people with IDD engaged in mental health crises must also avoid institutionalization as much as possible. This includes institutionalization aimed at both people with IDD or dual diagnosis but also aimed at people with mental health disabilities. Crisis response must realize that being institutionalized in a psychiatric ward or hospital, no matter how brief or how “nice” the ward is, is still institutionalization and still traumatic. Survivors of psychiatric hospitalization have spoken out about poor treatment, including routine violence and dehumanization (Black & Calhoun, 2022; From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves, 2000; Gilmer, 2019; Jina-Pettersen, 2022; Ward-Ciesielski & Rizvi, 2021). Moreover, case-control studies have shown that people who are hospitalized in a psychiatric inpatient setting for suicidal thoughts or actions are more likely to kill themselves after discharge as compared to people who received community-based treatment for the same concerns (Jollant et al., 2022; Musgrove et al., 2022; Qin & Nordentoft, 2005; Walter et al., 2019).

Furthermore, inpatient psychiatric settings, insofar as they meet the needs of *anyone* seeking crisis services, do not and cannot meet the needs of people with IDD/MHD dual diagnosis. General inpatient psychiatric settings are loud, busy places that often rely on forms of talk or group therapy that require oral speech from patients. Patients who cannot

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<sup>18</sup> Unfortunately, many short-term residential crisis services for people in mental health crisis require clients to be independent in activities of daily living (ADLs). People with IDD who need support with ADLs may be placed unnecessarily in hospitals or other institutions, such as nursing homes, during mental health crises because of this. HCBS providers and staff should proactively identify residential crisis services that serve people with IDD/MHD dual diagnosis before a crisis happens.

<sup>19</sup> Saylor was a white man with Down Syndrome who law enforcement restrained and killed after he would not leave a movie theater (Perry & Carter-Long, 2016, pp. 13–14). Latson is a Black autistic man with an intellectual disability who was incarcerated for a decade, much of it in solitary confinement, for assaulting a law enforcement officer who manhandled and restrained him while arresting him for a crime he did not commit (“Advocates Applaud Full Pardon of Neli Latson, a Young Black Man with Disabilities, After Decade of Injustice - Autistic Self Advocacy Network,” 2021; Perry & Carter-Long, 2016, pp. 14–15). Powell was a Black man with a mental health disability who law enforcement killed after responding to reports of him “acting erratically” (Perry & Carter-Long, 2016, pp. 20–21). Law enforcement shot at Rios Soto and Kinsey because Rios Soto was carrying a toy car the officers thought was a gun. Rios Soto is Latino and autistic and Kinsey is Black and was Rios Soto's DSP. Law enforcement shot Kinsey multiple times in the leg (Çevik, 2019; E. Garcia, 2018).



speakers or who most effectively communicate through other methods do not benefit from these therapies and are often subjected to more intense restraint and seclusion than their speaking peers (Corbin, 2019; Kuriakose et al., 2018). There are specialized psychiatric units that claim to more effectively serve people with IDD/MHD dual diagnosis. However, these units almost universally use behaviorist methods, such as ABA, to promote “routine,” thus further contributing to the traumatization people with dual diagnosis face within inpatient psychiatric settings (Charlot, 2016; Kuriakose et al., 2018; McGuire et al., 2015; Siegel et al., 2014; Vinqvist et al., 2022).

Because of all these factors, staff and caregivers must make every effort to avoid involving inpatient psychiatric services as part of a crisis response. This may include not involving crisis services known to use involuntary commitment/“active rescue” in their responses (such as 988), finding alternative peer-run crisis respite sites, and avoiding hospitals or emergency departments known to rely heavily on psychiatric commitment (Bossing et al., n.d.; Wipond, 2023). In no case should staff or caregivers use the threat of involuntary commitment to force someone to comply or to “behave well” (e.g., “you better start behaving correctly or I’ll take you to the hospital and have them lock you up.”).

### **Questions to Answer About Active Crisis Support When Writing Behavior Support Goals**

- Does this person have a crisis support plan?
- Does this person have access to services that serve people with IDD/MHD dual diagnosis?
- Does this person have access to services that will support them in a crisis in their own homes (push-in services)?
- If pull-out services are necessary, do these services preserve this person’s freedoms?
  - ◊ Can they still access the community?
  - ◊ Are these services close to their home or community?
- Do support staff have training in crisis intervention that does not involve institutionalization or law enforcement?
  - ◊ Are they knowledgeable of respite services and other supports?

### **Supporting Community Integration**

People with IDD should be supported to live, work, and socialize in our communities the ways we want to. We should not be forced to engage in certain activities because others are engaging in those activities, or, conversely, be forbidden from engaging in certain activities because others do not want to engage in them. This is especially true for people with IDD who live in provider-owned settings.<sup>20</sup> The central questions of support for community integration should be “What does this person want to do as part of their community? How can we support them to do it?”

A common barrier to answering these questions is that people with IDD, especially those who have lived, worked, and been educated in institutions and other segregated settings for large parts of their lives may not know what they want to, or even can, do in the community. Someone who grew up going to school in a segregated special education classroom, graduated to work at a sheltered workshop or in an enclave, and who has lived large parts of their adult life in an institution, group home, or similar setting will not have had opportunities to explore their interests and preferences for community living, work, and social experiences. They very likely would have also been taught, implicitly or explicitly, that they do not have the cognition or autonomy to make such decisions for themselves. Remedying these barriers, through exposure to many different community settings, potential workplaces, and social events, should be the first priority.

If a person with IDD chooses to work, the assumption should be that we can work in a competitive, integrated job — that is, a job in the community alongside non-disabled peers, for which we receive a comparable wage and comparable benefits to our non-disabled coworkers. The job should also be one the person chooses based on our interests, not simply one we are assigned to based on what a vocational counselor or employment support worker thinks we will be good at. Vocational

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<sup>20</sup> The HCBS Settings Rule includes provider-owned residential settings, such as group homes, assisted living facilities, and apartment buildings that only rent to disabled and/or older people, as “community-based” and therefore eligible for HCBS funding. However, ASAN and other self-advocacy groups believe that such settings are often institutional in nature, despite ostensibly being located in the community (Autistic Self Advocacy Network, 2020; HCBS Advocacy Coalition, 2019; Self Advocates Becoming Empowered, n.d.).

Rehabilitation programs, as well as waiver-based employment services, can assist in counseling people with IDD who choose to work, both on finding a wanted and suitable job, and on how competitive integrated employment would affect our benefits. People with IDD who choose to work should also have access to job coaching and other forms of support on the job, for as long as we need support (APSE, n.d.; Autistic Self Advocacy Network, 2018; Disability Hub MN, n.d.). The same reasoning applies to people with IDD who do not work for pay but choose to volunteer in the community — we should be able to volunteer in the community settings we choose to and receive the level of support we need to successfully volunteer. While people with IDD may choose to work for pay or volunteer in our communities, we should not be mandated to; if a person would rather attend a day program or school or engage in other daily activities, they should be able to do that.

People with IDD should also be supported to engage in civic activities and exercise our rights. This includes the right to vote, the right to participate in civic life (such as attending city council meetings or attending political protests), and the right to join groups whose views we agree with. For example, if someone with IDD wants to sign up to speak on an issue at a city council meeting or attend a meeting of the local chapter of a political party, they should receive the support they need to do so. This support should happen regardless of whether support staff agree with the person's political or social views or why they want to attend an event. People with IDD have the same right to form opinions about political, civic, and broader social issues as anyone else, and have the same rights to express those opinions as anyone else. Furthermore, support staff should not attempt to dissuade a person with IDD from voting or try to influence their vote. As long as a person is legally able to vote, they have the right to vote privately and free of influence from anyone else.

Finally, support staff should assist people with IDD in finding and attending social, recreational, and educational events. As we have previously mentioned, support staff may inadvertently or purposely prevent people with IDD from forming social relationships. This is unacceptable. People with IDD have the same right to socialization, friendship, and relationships as anyone else. If an adult with IDD wants to go to a bar to meet people, or a person with IDD wants to find a local sports league or take a community college course, they should have the opportunity to do so with the support they need. Similar to civic engagement, this right applies even when support staff do not agree with a person's views or do not approve of their chosen activities. Support staff may not approve of an adult with IDD going to a bar with the intent of finding a date, or of a person with IDD choosing to play pick-up tackle football on the weekends, but that does not mean people with IDD should not have those opportunities and choices.

### Questions to Answer About Community Integration When Writing Behavior Support Goals

- Where does the person live right now?
  - ◇ Do they live in a place where they are free to go out into the community?
  - ◇ What barriers exist to the person living in the community on their own terms?
  - ◇ Where would the person live if they could live anywhere?
- What does the person like to do in the community?
  - ◇ What hobbies or interests does the person have? Can they join groups related to these hobbies or interests?
  - ◇ Who are the person's friends, partners, or other community connections? If the person has few or no relationships with other people in the community and would like to make more, how can you support them to do this?
  - ◇ What places does the person like to go in the community? What other places might the person like to go? How can they be supported to visit these places?
- If this person is interested in working or volunteering, what kinds of (volunteer) work would they like to do? How can you support them to find jobs or volunteer opportunities they would enjoy?
  - ◇ What types of work (paid or unpaid) has this person done in the past? What did they enjoy or not enjoy about past work?
  - ◇ Does the person have specialized education or vocational training? If so, would they like to pursue work in that field? Does the person want to pursue further education or training?
  - ◇ If the person does not have prior work experience and does not know what kinds of work they might want to do, how can they pursue work experience to figure out what they might want to do?

## Addressing Dangerous Behavior

Our final goal for behavioral support services is addressing dangerous behavior that does not rise to the level of crisis. We have left this goal for last because we know that addressing underlying needs and supporting mental health and community integration will go a long way in reducing or eliminating dangerous behavior.

### Defining “Dangerous Behavior”

In order to provide guidance on addressing dangerous behavior, we must first define what “dangerous” behavior entails. We use Emerson’s definition of “challenging behavior” as a basis for our definition of “dangerous behavior”:

[Culturally] abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities (Emerson, 1995).

Dangerous behavior, in our definition, is behavior that places the safety of the person engaged in the behavior or those around them at immediate and serious risk of physical harm or involvement with the criminal legal system. Behavior may or may not be “dangerous” based on how often and how long it occurs, and how intense it is when it occurs. For example, a person with pica eating a single piece of paper one time is not dangerous behavior because it does not pose immediate and serious risk of physical harm to them. However, that same person ingesting a large amount of paper over a short time, or eating metal objects that could puncture their digestive tract, would count as engaging in dangerous behavior because that does pose immediate and serious risk of physical harm to them.<sup>21</sup>

We see dangerous behaviors as falling into one or more of five basic categories: serious self-injury, physical aggression, pica, self-neglect, and behavior that poses a real risk of involvement with the criminal legal system. We expand on these categories below.

Nonsuicidal self-injury is defined as “the deliberate, self-inflicted destruction of body tissue without suicidal intent and for purposes not socially sanctioned, includes behaviors such as cutting, burning, biting and scratching skin” (Zetterqvist, 2015). For our purposes, we will expand this definition to include suicidal behavior, that is, behavior undertaken with the intent to kill oneself (Crosby et al., 2011, p. 21). We stress here that self-injury, in order to qualify as dangerous behavior, needs to carry a real and immediate risk of physical harm. Various interventions, especially behaviorist interventions, have defined “self-injury” so loosely as to be meaningless. A person gently tapping a pencil against their head is not engaging in self-injury. A person biting their hand such that it leaves a mark but does not break the skin or cause bleeding is not engaging in self-injury.

Physical aggression is defined as “behavior causing or threatening physical harm towards others ... [including] hitting, kicking, biting, using weapons, and breaking toys or other possessions” (Kaye & Erdley, 2011). Physical aggression does not have to be deliberate (e.g., someone who hugs their friends hard enough to cause injury) but it does need to cause or threaten to cause serious physical harm. Someone who gives their friend a gentle slap on the back is not engaging in physical aggression. They may be engaging in unwanted behavior, or behavior that is dangerous for other reasons (e.g., repeated unwanted touching that could legally be assault), but consensual horseplay without risk of serious physical harm does not constitute physical aggression. Moreover, someone who acts in what a reasonable person would call self-defense should not be labeled as engaging in dangerous behavior. This includes people who are reacting to being restrained. A person who kicks a staff member pinning them to the ground is only reacting to violence being done to them.

We have previously defined pica in this section as “eating non-nutritive, non-food substances over a period of at least one month” (Al Nasser et al., 2023), and specified that individual instances of ingesting non-nutritive, non-food substances may or may not count as “dangerous behavior.” However, we consider the symptoms of pica as an ongoing disorder to be dangerous behavior because the risk of the person ingesting either a single very dangerous object (e.g., a metal object with sharp edges) or multiple objects that together cause serious harm (e.g., eating large amounts of dirt, causing a bowel impaction) is high. We also stress here that pica is, quite often, caused by an underlying health condition, such as nutritional deficit, mental health conditions, pregnancy, or neglect (Pica, 2022; F. Williams et al., 2022). While all

<sup>21</sup> Pica is defined as “eating non-nutritive, non-food substances over a period of at least one month” (Al Nasser et al., 2023).

dangerous behavior should be investigated to find its root causes, it is especially important to do so in pica, as the cause often tends to be identifiable and treatable.

Various definitions of “self-neglect” exist, including those used by state Adult Protective Services agencies (*Statutory Provisions: Types of Abuse Defined in Adult Protective Services Statutes*, 2020). However, Pavlou and Lachs (2008, p. 1842) define a person engaging in self-neglect as someone who engages in one or more of the following activities:

1. Persistent inattention to personal hygiene and/or environment
2. Repeated refusal of some/all indicated services which can reasonably be expected to improve quality of life
3. Self-endangerment through the manifestation of unsafe behaviors (e.g., persistent refusal to care for a wound, creating fire-hazards in the home)

Self-neglect can be dangerous behavior if it poses immediate and serious risk of physical harm to the person. Pavlou and Lachs give the examples of someone who refuses to care for a wound or someone who creates fire hazards in their home. These would count because untreated wounds pose a serious risk of infection and sepsis and fire hazards in the home can lead to uncontrolled fires. But it is important to distinguish dangerous self-neglect from people having different definitions of “hygienic” or “clean.” A person who does not shower everyday or who sometimes leaves dirty dishes in the sink for a few days is not engaging in dangerous self-neglect. Similarly, just because a person with IDD has different standards of “clean” than the people supporting them (e.g., someone who does not want to wear deodorant or make their bed every morning, despite being asked to) does not inherently mean the person is engaging in dangerous self-neglect.

Pavlou and Lachs note that self-neglect is often associated with mental health conditions (e.g. depression, anxiety, schizophrenia) or cognitive or physical impairment (e.g., dementia, intellectual disability, mobility disabilities). Social isolation, low health literacy, and adverse life events (such as trauma or the loss of caregivers) can also drive self-neglect. Thus, looking for and addressing the root causes of self-neglect is key to addressing dangerous self-neglect. If a person is too depressed to get out of bed and shower, no amount of lectures or punitive behavior programs will motivate them to attend to their hygiene. Similarly, someone failing to engage in hygiene and cleaning activities due to their disability needs support to engage in these activities, not lectures or behavior programs. A person who cannot clean their house because they do not understand the steps to cleaning, or a person who cannot take a bath because their bathtub is physically inaccessible to them, will not benefit from being told how gross their house or body is. They need support and accommodations in order to attend to their house and themselves.

Finally, behavior can be considered dangerous if it carries a real risk of involvement with the criminal legal system, i.e., illegal behavior that carries the risk of arrest, trial, and legal punishment. Sexually aggressive or violent behavior falls in this category, as do fire-setting, theft, physical assault, some kinds of drug use, and threats of illegal activity. Even if there is no real victim in these cases (e.g., a person with IDD using illegal drugs in order to relieve stress), it is worthwhile to take steps to lessen the risk of involvement with the criminal legal system. The goal should be to de-escalate or re-route the behavior before it rises to the level of involvement with the criminal legal system. It is also important to note here that not all behavior that is technically illegal rises to the level of dangerous behavior on the grounds of involvement with the criminal legal system. Jaywalking, for instance, is illegal in many jurisdictions, but since the risk of arrest, trial, and legal punishment for jaywalking is so minimal, it would not be considered dangerous behavior.

### **Avoiding Overgeneralization of “Dangerous Behavior”**

Not every behavior that could possibly pose a danger to a person or those around them is dangerous behavior. Wandering or eloping (the act of leaving a place without permission/warning, often without a fixed destination) is commonly talked about as “dangerous behavior”; however, under our definition, wandering or eloping is not inherently dangerous. There are dangers a person might experience in wandering (e.g., stepping into oncoming traffic), but these dangers do not mean that all wandering or eloping is inherently dangerous.

Keeping a narrow definition of “dangerous behavior” and not overgeneralizing the term matters because the label of “dangerous behavior” is often used to justify applying restrictive and punitive interventions. Calling wandering or eloping “dangerous behavior” may lead to someone being physically or chemically restrained so that they cannot move



freely around their environment. Calling breaking personal belongings “dangerous behavior” may lead to someone being secluded in an empty room. Even if the overgeneralization of “dangerous behavior” does not lead to such clearly restrictive interventions as restraint and seclusion, it can lead to a person being placed in long-term behavioral interventions that do not actually address the roots of the problem.

It is important to note that just because a behavior does not rise to the level of “dangerous behavior” does not mean that a person cannot deal with the consequences of that. A person who destroys their roommate’s belongings during an angry outburst may be tasked with repairing or replacing the belongings. A person who calls their staff members names when they are annoyed with them may be asked to apologize to those staff members. People can, and arguably should, experience the natural consequences of their actions, but heaping additional punitive measures on a person for their behavior is wrong. It is helpful to look at how a person’s peers without disabilities would be treated if they engaged in similar behavior. To go back to the example of destroying a roommate’s belongings, an adult without a disability would probably have to repair or replace the belongings, but nobody would say that adult loses the privilege of getting to eat dessert for the rest of the week.

### Dealing with Dangerous Behavior

We stress that, to address dangerous behavior properly, one must address the root causes of the behavior. What needs underlie the behavior and how can those needs be met? As we have previously discussed, there are a wide range of needs someone can express through their behavior. These needs *must* be at least identified, and hopefully addressed, if the behavior is to decrease or stop.

Take, for example, someone who engages in serious self-injury by banging their head against a wall to the point they give themselves a concussion. There could be many reasons for this behavior. The person might be dealing with physical pain or discomfort, e.g., a severe case of head lice (Endow, 2019). They might be dealing with untreated mental illness or psychological distress. They may be trying to communicate something but not have a robust method of communication. They may be sensory-seeking and not understand that their current methods are dangerous to them. They may be bored or understimulated and looking for any activity that will change the monotony of their day. They may be in desperate need of friendship and social attention and have learned they will only get attention if they “act out.” All of these are causes that can be addressed and treated.

Here is another example: a person who masturbates in public places, thus placing them at risk of involvement with the criminal legal system. Griffiths, Quinsey, and Hingsburger write about this in their book “Changing Inappropriate Sexual Behavior: A Community-based Approach for Persons with Developmental Disabilities,” outlining the following reasons why a person might masturbate in inappropriate spaces (Griffiths et al., 1989; McLaughlin, 2020). (Some of the reasons apply to other kinds of sexual behavior more broadly, but all the reasons are worth considering in this scenario.)

1. Structural/environmental barriers: If a person with a disability is not given private places (a private bedroom, a bathroom) to engage in sexual activity, they will find other places to do it. Parents, family members, and support staff need to teach public vs. private places and give people with disabilities privacy.
2. Modeling: People with disabilities may mimic behavior that is modeled to them. The authors give the example of a parent putting their face in their child’s face to get the child’s attention. The child then repeats this behavior to a store clerk and is accused of assault.
3. Partner selection: Who exists as a potential romantic or sexual partner for the person? The authors give the example of a person with a disability asking their support staff on a date because there is no one else in their life for them to be attracted to. People with disabilities should be allowed to build close relationships, including intimate relationships, with others who are not support staff or housemates in a group setting.
4. Inappropriate courtships: People with disabilities may be interested in asking someone on a date or for sex but not have the social knowledge to do it appropriately. Someone who gropes or flashes another person nonconsensually may be trying to show affection but has never been taught how.

5. Sexual knowledge: A person with a disability may not know about how to appropriately and safely tend to their sexual needs. The authors give the example of a person who uses feces as lubricant while masturbating because they are not aware commercial sexual lubricants exist. Once the person is given access to commercially available lubricants, their problem ceases.
6. Learning history: People with disabilities may receive sexual education from a variety of sources, including inappropriate or incomplete sources. Further, and more formal or structured, sexual education may help resolve issues.
7. Perpetual arousal: A person with a disability may masturbate excessively or in inappropriate places because they are having trouble achieving orgasm. They may have been taught misinformation about masturbation and orgasm, e.g., that achieving orgasm or ejaculation is “dirty” or will make them sick.
8. Medical: A person with a disability may be sick or have medical or psychological issues causing them to masturbate inappropriately. Someone with a yeast infection, for instance, may masturbate or touch themselves inappropriately to try to relieve the discomfort.
9. Medications: Changes in medications can cause changes in sexual behavior or arousal.
10. Moral vacuum: People with disabilities may have been taught, implicitly or explicitly, that certain behaviors are acceptable even when those behaviors are not. Or, people with disabilities may have been taught that certain behaviors are acceptable in some situations but then overgeneralize those situations to others. For example, a child with a disability may have been taught that it is okay to hug people without permission, but as that child grows into an adult, they start to find people react badly when hugged with no warning.

All of these reasons are worth considering when someone engages in public masturbation. If a person is engaging in public masturbation because of a lack of knowledge or because they have no private place to conduct their business in, these things must be remedied. Even if the behavior does not have a conscious or willing cause (e.g., someone who masturbates compulsively because they have OCD), it still has some sort of cause that can be identified and addressed.

Even when the root causes of a behavior cannot be ascertained or addressed, it is still better to teach the person skills and coping strategies rather than manipulating them to stop the behavior. We have previously addressed that wandering is not inherently dangerous behavior, but someone who bolts out the front door of their house and into oncoming traffic so frequently they have been hit by cars is engaging in dangerous behavior. In this case, teaching the person safety skills around traffic and staffing so they always have a one-to-one staff member with them is preferable to restricting their motion so they cannot leave their house. Close observations of the person’s behavior, even if they cannot communicate their needs or motivations in ways others can understand, are also in order. If, for example, the person bolts when the house is excessively noisy, staff should try providing them with earplugs or establishing a quiet space for them to go to inside.

As we have stressed before, the root causes of dangerous behavior must be dealt with in order to resolve the behavior in the long-term. When the root causes of behavior are not addressed, the behavior is likely to reemerge later on. Furthermore, addressing only dangerous behavior without addressing the root may cause more harm and trauma than it prevents. People do not feel good or valued when others force them to change their behavior without addressing the causes of their behavior. Especially if someone is acting out of pain, fear, isolation, or discomfort, people around them forcing them to change their behavior without addressing the hurt causing their behavior comes off as callous and uncaring towards the person’s situation. People with IDD who engage in dangerous behavior still have thoughts and feelings, even if they cannot easily express their thoughts and feelings in ways others can understand. Communication barriers are difficult for everyone involved, most acutely the person trying to communicate. Even if support staff are not purposefully ignoring the person’s needs by addressing only the dangerous behavior, they still convey to the person that the person’s underlying needs are not as important as the person ceasing their behavior.

It is also important to remember that people have the right to dignity of risk and to harm reduction practices. Dignity of risk as a concept emphasizes that “people with IDD should have the autonomy to make choices or bring about change concerning their daily lives while leveraging support from individuals they select. Furthermore, they should have the opportunity to own the consequences of their choices” (Bumble et al., 2022). In other words, people have the right to take

risks, make mistakes, and learn from the consequences of their actions. Harm reduction is an umbrella term for practices that seek to lessen the harm of risky or dangerous activities while realizing that people will engage in those activities despite potential risks. Harm reduction is most often conceptualized around illicit drug use (Centers for Disease Control and Prevention, 2022). However, the term can apply to a wide variety of activities in different risk domains.

While the definition of what is a “reasonable” or “acceptable” risk will vary from person to person (e.g., the threshold of an “unreasonable risk” is typically lower for children than adults), adults without disabilities generally have broad leeway in deciding what is a reasonable or acceptable risk for them. Adults with disabilities, including adults with IDD, should be afforded the same right. If an adult with IDD decides it is an acceptable risk for them to smoke cannabis at their friend’s house, despite the drug being illegal, or to participate in extreme sports like competitive skateboarding, dignity of risk states that they should have the right to do just that. Children and young adults with IDD should be afforded the same age-appropriate risks as their peers — if an autistic 6-year-old wants to go to school without a sweater on a chilly day or a 15-year-old with Down Syndrome wants to stay out past curfew with their friends, they should be able to do those things and experience the natural consequences of their actions. People with IDD, like everyone else, have the right to decide what is an appropriate risk for us and to take risks, even if others in our lives do not approve.

Staff involvement, when it comes to people with IDD participating in potentially risky or dangerous behavior, should thus be less about enforcing a strict abstinence approach and more about helping people identify ways to reduce risks and harms. A 30-year-old woman with an intellectual disability who wants to have sex with her casual boyfriend runs the risk of pregnancy or contracting an STI, but so does any other 30-year-old woman who would like the same. Rather than telling the woman that she is absolutely not allowed to have sex with her boyfriend, her staff should explore ways to lessen the risk of harm with her. Discussing contraception, condoms and barrier methods, and other safer sex practices while accepting that this woman has a right to make her own choices about her body will produce much better and more harmonious outcomes than simply forbidding her from having sex.

There is no question that people with IDD can engage in challenging, risky, or even dangerous behavior. We do not dispute this. But we question methodologies and interventions that claim they can eliminate undesired behavior without addressing underlying causes. We feel that, at best, such approaches will result in misguided power struggles and are based in the deep infantilization and patronization of people with IDD. People have the right to compassion and care, even when we act in ways others find unacceptable and deeply unpleasant. The goal should not be to eliminate behavior for behavior’s sake but to give the person tools and skills to act in ways that contribute to their well-being and personal growth.

### **Questions to Answer About Dangerous Behavior When Writing Behavior Support Goals**

- Does this person engage in dangerous behavior?
  - ◊ If so, what kind of behavior? How is it defined?
- How is this person treated if they engage in dangerous behavior?
  - ◊ If consequences are involved, are those consequences similar to ones non-disabled people might face for the same behavior?
- What reason might someone have for engaging in dangerous behavior? How can support be tailored to address the root cause of the behavior?
- What accommodations or modifications could be made to this person’s life to help them avoid dangerous behaviors?
- Is this person given the chance to take risks?
- Has this person been educated about harm reduction?
- Have support staff been trained on dignity of risk and harm reduction?

## Appendix B: Selected List of Crisis Support Planning Resources

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Here we have collected a range of resources for crisis support planning that we encountered while writing this paper. We have organized these into five categories: Psychiatric Advance Directives, General Mental Health Crisis Planning Tools, IDD-Specific Mental Health Crisis Planning Tools, Health Care Passports, and Miscellaneous Tools. Tools developed by groups led by people with lived experience around IDD and/or mental health disabilities are marked with an asterisk (\*).

### Psychiatric Advance Directives

- Mental Health America: Creating a Psychiatric Advance Directive: <https://www.mhanational.org/creating-psychiatric-advance-directive>
- National Resource Center on Psychiatric Advance Directives: <https://nrc-pad.org/>
- SMI Advisor: My Mental Health Crisis Plan app: <https://smiadviser.org/getmyapp>

### General Mental Health Crisis Planning Tools

- \* Fireweed Collective: Crisis Toolkit: <https://fireweedcollective.org/crisis-toolkit/>
- \* Fireweed Collective: Madness & Oppression: Paths to Personal Transformation and Collective Liberation: <https://fireweedcollective.org/publication/madness-oppression-paths-to-personal-transformation-and-collective-liberation/>
- Mental Health America: Think Ahead: Mental Health Crisis Plan: <https://screening.mhanational.org/content/think-ahead-mental-health-crisis-plan/>
- Mental Health Minnesota: Crisis Plan for Your Support System: <https://screening.mhanational.org/content/worksheet-crisis-plan-for-your-support-system/>
- \* Oakland Power Projects of Critical Resistance: SAGE Response to a Psychosocial Crisis: <https://docs.google.com/document/d/1DFE6KTf6EZkURLGyBo3ojLvpuzhAiM4BLSdGkG7Tdso/edit>
- \* Project LETS: Anti-Carceral Crisis Plan: [https://drive.google.com/file/d/1cXgw\\_a3oJMkuhN3KUiu\\_H5B\\_PKVzTEoc/view](https://drive.google.com/file/d/1cXgw_a3oJMkuhN3KUiu_H5B_PKVzTEoc/view)
- Wellness Recovery Action Plan: <https://www.wellnessrecoveryactionplan.com/what-is-wrap/>

### IDD-Specific Mental Health Crisis Planning Tools

- Missouri Department of Mental Health: Crisis Safety Plan Assessment and Template for Plan: <https://dmh.mo.gov/media/pdf/crisis-safety-plan-assessment-and-template-plan>
- North Carolina Department of Health and Human Services: Crisis Prevention and Intervention Plan Training: <https://www.trilliumhealthresources.org/sites/default/files/docs/Provider-documents/Crisis-Prevention-intervention-plan-training.pdf>
- Surrey Place Center: A Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities (DD) for Primary Care Providers and Caregivers: [https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/04/Guide\\_to\\_Understand\\_Bx\\_Probs-2.pdf](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/04/Guide_to_Understand_Bx_Probs-2.pdf)
- Elspeth Bradley and Yona Lunsky/Surrey Place Center: Risk Assessment Tool for Adults with DD in Behavioural Crisis: [https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Risk\\_Assessment\\_Tool.pdf](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Risk_Assessment_Tool.pdf)
- Melhas et al./Surrey Place Center: About My Health: Learning about the healthcare and communication needs of adults with intellectual and developmental disabilities: <https://ddprimarycare.surreyplace.ca/wp-content/uploads/2021/03/5.1-About-My-Health-new.pdf>
- Vanderbilt Kennedy Center for Research on Human Development: Health Care for Adults with Intellectual and Developmental Disabilities Toolkit for Primary Care Providers: Crisis Prevention and Management Planning: <https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/crisis-prevention/>



- \* Ambitious about Autism: What's Your 'Normal'? Toolkit: <https://www.ambitiousaboutautism.org.uk/sites/default/files/youth-participation/toolkit/Ambitious-about-Autism-know-your-normal-toolkit.pdf>
- \* Ren Koloni, The Link Center: What To Do When I Don't Feel Okay: Big Ideas Guide: <https://www.nasddd.org/wp-content/uploads/2023/11/What-To-Do-When-I-Dont-Feel-Okay.pdf>

## Health Care Passports

- Elizabeth Perkins/Florida Center for Inclusive Communities: My Health Passport: [http://flfcic.fmhi.usf.edu/docs/FCIC\\_Health\\_Passport\\_Form\\_Typeable\\_English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf)
- Virginia Department of Behavioral Health and Developmental Services: My Care Passport: <https://dbhds.virginia.gov/wp-content/uploads/2022/09/DBHDS-My-Care-Passport-9.25.22.pdf>

## Miscellaneous Tools

- \* Mia Mingus/Bay Area Transformative Justice Collective: Pods and Pod Mapping Worksheet: <https://batjc.wordpress.com/resources/pods-and-pod-mapping-worksheet/>
- Oregon ISP: One Page Profiles: <https://oregonisp.org/1ppa/>
- Parents Helping Parents: Introduction to One-Page Descriptions: <https://www.php.com/elearning/introduction-to-one-page-profiles/>

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