# HCBS Access Act 2021

**Student Name**

# Introduction

In 1967 there were 194,650 individuals with an intellectual/developmental disability (I/DD) living in a state institution or intermediate care facility (ICF) across the country. This number dropped significantly to 21,103 in 2015. However, as of 2015 there are still 37 states across the nation who operate ICFs (Lulinski & Shea-Tanis, 2018). Even though there are fewer individuals with I/DD living in state institutions, there continues to be significant barriers for individuals with I/DD to access the services they desperately need to live as independently as possible within their home community. It is estimated that there are 850,000 individuals across the nation who are waiting to access home and community-based Medicaid services (HCBS).

Some individuals are forced to wait decades before services they are eligible for become available (Nursing and Therapy Services of Colorado, n.d.).

Senators Maggie Hassan, Sherrod Brown, and Bob Casey along with congresswoman Debbie Dingell introduced a discussion draft bill in March 2021 called the HCBS Access Act of 2021 and is requesting stakeholder feedback prior to introducing the bill to the United States House of Representatives. The HCBS Access Act is looking to amend title XIX of the Social Security Act to require coverage of home and community-based services under the Medicaid program. The purpose of bill is to require all states to provide home and community-based services by eliminating wait lists and empowering individuals to live and work in the most integrated settings as possible. This includes supporting unpaid family caregivers and developing the direct support professional workforce (HCBS Access Act, 2021).

# Contextual Analysis

## Economic Factors

According to the National Council on Disability, in 2009, “the average cost of care in large state institutions ranged from a low of $104,025 per year in Arkansas to a high of $375,000 in Tennessee, while the average Home and Community-Based Services (HCBS) Waiver cost ranged from $21,789 in Mississippi to $107,453 in Delaware” (Cost Variation within among States, para.2). Even though the cost of care varies greatly by state, the overall cost of care in large state institutions is much greater than providing care in the community. The cost of care within the community is less than in an ICF due to some individuals not needing the high level of care that is provided within the ICF. There are several services that are built into the framework of the institutional setting that not every individual requires (National Council on Disability, n.d.). This may include overnight awake supervision, physical therapy, occupational therapy, nursing, and psychiatric services. Additionally, through the person-centered planning process and empowering individuals, families, and other natural supports, it is likely that it will be determined that the high intensity services are no longer needed to meet an individual’s needs and goals (National Council on Disability, n.d.). Finally, the overhead cost of paid direct support professionals (DSP) is less in community settings than in an institution (National Council on Disability, n.d.). However, since the community-based DSP is paid less and is provided with less supervision, there tends to be higher rates of turnover (National Council on Disability, n.d.)

Many states are hesitant to close their institutions and transition to community-based services due to the transition costs involved. The cost saving efforts are only fully conceptualized when an entire institution closes and not when one individual transfers to a less restrictive service (National Council on Disability, n.d.). However, when institutions are closed there are significant steps that must take place to ensure a smooth transition of individuals back to the community setting. This includes developing a client specific transition plan to start the

process of teaching every individual the necessary skills to live independently. As part of the transition plan it is also vital to ensure that all necessary housing arrangements based on the individuals needs and preferences have been obtained including returning to the family home, renting, or purchasing apartments and homes, and opening adult foster care homes. In addition to securing housing, there also needs to be workforce development by recruiting and training all levels of staff including DSPs, supervisors, therapists, behavioral specialists, and care managers. To build these frameworks, there must be additional funding mechanisms in place which will result in duplication of costs to operate the institutions but also builds the foundation for community-based services.

Eliminating wait lists has the potential to greatly increase Medicaid costs. According to Ng and all (2014), “the increased adoption of state cost control policies have led to large increases in persons on waiver wait lists” (p. 21). The number of individuals on waitlists varies by state. The State of Michigan does not allow for waitlists for medically necessary behavior health services which includes home and community-based services. Conversely, Texas has the highest waitlist at 78%. The HCBS Access Act strives to eliminate the waitlist. Texas would have to significantly increase its budget for home and community-based services to serve the 78% of individuals currently on a waitlist for services (Cobo-Lewis, 2017).

Furthermore, the HCBS Access Act calls for states to increase their workforce to support the thousands of individuals who have the right to participate in home and community-based services. Workforce development will include increased wages and provide benefits for DSPs as well as additional training and recruitment (Unites States Congresswoman Debbie Dingell, 2021). Currently, home and community-based service programs are plagued with high turnover at upwards of 50% and open job vacancy rates (Guerrero, 2021). This causes the current

workforce to be overworked and experience high burn out rates which decreases the quality of care for vulnerable populations and has resulted in abuse, neglect, and fraud. DSPs are typically minority females and earn on average $11.52 per hour (Musumeci et all, 2021). The HCBS strives to increase this to a living wage and provide the necessary benefits to attract professionals to the ever-growing field.

The HCBS Access Act appropriates funds in the forms of grants to be distributed to states to develop mechanisms to achieve the goals outlined in the act. The amount of $200,000,000 is being requested through the bill for this current fiscal year (HCBS Access Act, 2021). These dollars will result in cost efficiencies and savings in the long run as home and community-based service are cost effective and have resulted in a slower rate of spending growth for those states which have already expanded HCBS (Fox-Grage & Walls, 2013).

## Public Opinion

The overall public view of the HCBS Access Act is positive. The COVID-19 pandemic has shined the light on the dangers and health disparities of individuals living in congregate settings such as ICFs and nursing homes (The Arc, 2021). COVID-19 ran rampant in those setting costing the lives of thousands of individuals which could have prevented if for greater access to home and community-based services. According to Fox-Grage and Walls (2013), “the vast majority of people in need of long-term services and supports (LTSS) want to live in their own homes and communities” (p. 1). Even though individuals prefer to live and work in their home community, there is currently no mandate for the states to provide HCBS. They are required to provide and cover services at restrictive levels of care such as ICFs or nursing homes but have allowed states to make HCBS optional which has resulted in significant waitlists (Guerrero, 2021).

Furthermore, the Association of University Centers on Disabilities (2021) called the HCBS Access Act “a chance to improve a critical system” (AUCD Policy Talk, title). When the necessary supports are not in place for individuals with disabilities, individuals do not have the opportunity to participate in meaningful activities which leads to increase depression and risk of hospitalization (AUCD, 2021). The HCBS Access Act builds upon the infrastructure that is already in place to ensure it is fully funded and those who are eligible have access to the critical services it provides.

The Autistic Self Advocacy Network (ASAN) praises the HCBS Access Act due to the steps it is taking to remove the barriers that are preventing vulnerable populations from accessing appropriate services. Many individuals especially those who are black, indigenous, and other people of color are be subjected to live in more restrictive settings such as an institution (ASAN, 2021). There are race and gender disparities as these individuals are typically placed on the waitlist and must wait a greater amount of time to access appropriate services and may ultimately not receive them as they are institutionalized or incarcerated first.

The National Council on Severe Autism (NCSA) submitted comments regarding the discussion draft of the HCBS Access Act. Although most advocacy organizations praised the draft, the leaders of the NCSA had different feelings towards the draft bill. The NCSA stated that they believe that the HCBS Access Act is focused on myths instead of facts. Many states have already closed their institutions and other restrictive settings to take on a more integrated approach. The NCSA believes that this was a disservice to those with a severe disability as those settings were best equipped to respond appropriately to behaviors and other challenges as they arise. Also, there are often less regulations and oversight in the community setting which results in staff and other professionals not appropriately trained and supervised to meet the needs of the

individual. This has led to an increase use in law enforcement assistance and psychiatric hospitalization. Furthermore, the NCSA believes that the HCBS Access Act presumes that all individuals with disabilities can be served in the community and can reach a certain level of independence. While in contrary, the NCSA stated that there are situations when individuals due to the severity of the disability and deficits in functioning cannot be appropriately served in their home community. Lastly, the NCSA indicated that there is currently not public support for adults with severe autism to live in traditional style family homes as the behaviors they exhibit prevent them from having access to appropriate housing options. Homes and neighborhoods typically do not accept individuals who exhibit severe physical aggression and property destruction. (Escher, 2021, NCSA)

## Current Programs and Services

The Centers for Medicaid and Medicare established a final rule for HCBS in January 2014. The final rule established a set of requirements for programs and services under the 1915(c), 1915(i), and 1915(k) waivers of the Social Security Act. The final rule requires that states develop a statewide transition plan to bring the state in compliance with the final rule. The final rule specifies the characteristics of a setting to ensure that the setting promotes access to the broader community in the most integrated way (Department of Health and Human Services Centers for Medicare and Medicaid Services, 2014). It also provides additional clarification as to the expectations of the person-centered planning process. The final rule initially provided states with 5 years to come in compliance, but it has been extended to 2023. This final rule is different from the HCBS Access Act as the final rule only applies to services under the 1915 waivers of the Social Security Act and is not required for all services.

In the state of Michigan, community living support, skill building, and supported employment services are the services included in the statewide HCBS transition plan. The state of Michigan requires that individuals participating in these services must do so in the most integrated settings and that there must be regular, at least once per week, access to the broader community (Michigan Department of Health and Human Services, n.d.). Medicaid policy in Michigan prohibits waitlists and all individuals meeting eligibility criteria must be provided with the services as described through the person-centered planning process within required timeframes.

## Negative Consequences

There are potential negative consequences to the HCBS Access Act. The HCBS Access Act will mandate states to eliminate waitlists for HCBS services and ensure that all individuals who are eligible receive the services and supports they need to lead meaningful lives in their home community. If the HCBS Access Act is implemented too quickly the infrastructure will not be prepared for the influx of individuals who require supports. This may include housing options and all the professionals including social workers, DSPs, therapists, and medical practitioners required to provide the services. It takes a significant amount of time to recruit and train staff who have a thorough understanding of the unique needs of individuals with IDD. If the staff have only worked within the structured walls of the institution, they may not be prepared for unique circumstances that will arise in the community setting and could comprise quality of care (National Conference of State Legislators, 2000). Furthermore, without community collaboration and education, communities and neighborhoods may be resistant to individuals with disabilities moving into their neighborhood and increase stigma associated with disabilities.

## Ecological Systems Theory

The HCBS Access Act is embedded into all levels of the ecological systems theory. The HCBS Access Act affects the microsystem as the expansion of home and community services will impact individuals’ direct support systems including family, peers, neighbors, and health care providers. Family and other care givers will reap the benefits for the HCBS Access Act as the care demands fall to families of those on wait lists. With the passage of the HCBS Access Act, families and caregivers will be provided a much-needed break from break. Health care providers will see an increase in patients with disabilities and may become overburdened with treating individuals with complex care needs. With the expansion of HCBS services, individuals will have more of an opportunity to develop friendships with both disabled and non-disabled peers as they will be more integrated into the community.

The HCBS Access Act will also affect the mesosystem as there will need to be significant collaboration between multiple agencies and the staff within the agencies, families, and the individual for the individual to be successful. There is the potential for the individual to be receiving supports and services from multiple agencies and professionals. For the individual to reach his goals, all care team members must be on the same page and be in regular communication. If they are not, this has the potential to harm the individual, decrease outcomes, lead to duplication of services, and waste of resources.

Lastly, an individual’s success is dependent on macrosystem. If the attitudes and values of the community do not align with the vision of the HCBS Access Act, there is the potential that individuals will fail. The premise of HCBS is that individuals are integrated in their home communities both in leisure activities and work opportunities. If individuals with disabilities are

not embraced and welcomed back into the community, the mission of the discussion bill will fail and will have significant consequences.

# Policy Recommendations

## Policy Change

The HCBS Access Act strives to eliminate waitlists for long term care services for individuals with intellectual/development disabilities so that they live the most integrated and full life possible. The HCBS Access Act plans to accomplish this by mandating states to do so by providing funding to build the infrastructure and developing the workforce to meet the needs. However, the HCBS Access Act does not specify where the federal and state funding will come from to achieve the goals of the act. It also does not mandate the closure of ICFs and what forms of housing and services will be available to assist individuals with living integrated lives.

The shuttering of state institutions needs to be the premise of any bill which aims to increase independence and integration. The cost of institutional care is as high as “$294,300 per person, per year while the average cost of a person served with Medicaid HCBS is $49,854 per person per year” (ASAN, 2021). The State of Michigan closed all its institutions over the past several decades along with 13 other states and all individuals were moved to various housing options. Prior to the closure of the ICFs, there was a strategic plan in place to address the housing needs of these individuals. This included enacting a transition plan to develop housing options for a variety of individuals and needs. These mainly included adult foster care homes which specialized in treating individuals with I/DD and were overseen by community mental health centers. The housing options cannot be a one size fits all approach as institutions tend to be. There needs to be a continuum of options based on the preference and needs of the individual. This may include living in the family home with the support of DSPs, living in an

apartment alone or with friends and staffing based on the needs of the individuals in the home, and living in small or large adult foster care setting. The individual must have choice in a variety of settings and the setting must be tailored to meet the needs of the individual.

## Policy Alternatives

State institutions offered a continuum of care and provided all services within the walls of the facility which included primary care, nursing, psychiatry, behavioral therapy, occupational therapy, speech and language therapy, and physical therapy. When the institutions are closed, these services will need to be accessed within the community which may place a strain on the health systems as they are not familiar with treating the complex needs of individuals with IDD. The funding mechanisms for the services are also not derived by the same source. For instance, in the state of Michigan Medicaid funding for home and community services is funneled through the community mental health centers but Medicaid funding for physical health needs is funneled through a Medicaid Health Plan. This leads to silos and stresses the importance of integrating care for physical and behavioral health. According to Jansen et all (2006), “an interdisciplinary approach is needed for comprehensive assessment, treatment, and management in order to meet goals to (a) reduce fragmentation and discontinuities in medical care, (b) improve patient satisfaction and outcome and (c) provide efficient and effective medical care” (p. 215). Policy must be drafted which integrates the funding sources for all Medicaid services by placing them all under one umbrella. This umbrella must have a focus on best practices with long term care as the needs for individuals with lifelong disabilities is different than other populations. This would create additional financial efficiencies and would rid of the duplication of services that typically exists when funding sources are in silos. Also, if the care team is under the same umbrella it will lead to better outcomes and greater satisfaction.

According to Sandjojo et all, “being independent is valued by people with ID and a greater level of independence has been related to increased feelings of happiness and satisfaction and higher quality of life” (p. 37). When individuals are given the opportunity to make choices about their lives and to increase their independence no matter how big or small, it leads to a better quality of life. The closing of institutions will provide the opportunity for individuals with I/DD to take back their lives and have power and control over the decisions they make, and the services provided. Closing of the institutions also provides individuals with access to the community and to live integrated lives. They would have the same opportunity to participate in meaningful activities as their non-disabled peers and community members. This would also impact the community as they would learn the power of acceptance and diversity.

## Social Work Values

Social work values are entrenched in the closing of institutions and ensuring the integration of individuals into their home community. Social workers strive to challenge social injustice which includes promoting self-determination and empowering individuals to make decisions about their lives. Social workers must also advocate for oppressed and vulnerable populations to ensure they are leading meaningful lives of their choice. This means that families, care givers, and professionals must not dictate the choices an individual makes but empowering them to live the best life possible. Additionally, social workers strive to respect the dignity and worth of an individual. Unfortunately, there are situations where adults with IDD are not treated as a person and are not treated with dignity and respect. Social workers also have the responsibility to cognizant of their role at both the individual and broader society level. This includes being a good steward of the public funds and developing efficiencies where possible as closing of institutions is cost effective.

# Conclusion

A draft discussion bill known as the HCBS Access Act aims to amend the Title XIX of the Social Security Act and mandate home and community-based services for Medicaid recipients. By mandating home and community-based services, states would no longer be able to place individuals who meet medical necessity for the services on waitlists. This would help to alleviate the strain that lack of access to services places on individuals and families and would increase individuals’ productivity and self-sufficiency as well as assist them to live and work in the most integrated settings possible. It is imperative that states are provided with the necessary time and resources to build the infrastructure. If they are not, than the heart of the HCBS will be lost and individuals will greatly suffer.

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