Assessment of North Dakota's Services and Supports for Individuals with Disabilities

Submitted to the North Dakota Olmstead Commission

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November 30, 2022

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This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award with 100% funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

Executive Summary

The North Dakota Council on Developmental Disabilities engaged the Technical Assistance Collaborative Inc. (TAC) to conduct an assessment and an analysis of how North Dakota's organizations, systems, funding, services, and supports function to serve people with disabilities. The state's Olmstead Commission had determined that updated information and enhancements were necessary for an effectively working plan to support people with disabilities in the most integrated settings appropriate to their needs, as required under the landmark 1999 *Olmstead v. L.C.* United States Supreme Court decision. The purpose of the assessment is to assist the Commission in updating North Dakota's Olmstead Plan.

TAC consultants engaged in a multipronged approach to conducting the system assessment and analysis, including collecting and synthesizing both qualitative and quantitative data:

- We reviewed numerous key existing data summaries and reports.
- We conducted online research.
- We conducted key informant interviews and stakeholder listening sessions.
- We conducted an online survey to facilitate additional stakeholder input.
- We summarized and presented our findings, recommending action steps and potential data sources for subsequent updates and enhancements to North Dakota's Olmstead Plan.

The North Dakota Department of Health and Human Services (HHS) is the state agency primarily responsible for administering services and supports for individuals with disabilities across the age-span through six divisions and eight regional Human Service Centers. In addition, HHS operates state facilities that serve as a 'safety net' for individuals with intellectual and developmental disabilities, Autism Spectrum Disorder ASD, mental health disorders, substance use disorders, and traumatic brain injury (TBI). HHS administers federal and state funding resources.

TAC identified a number of strengths within North Dakota's human services system. The state was a primary adopter of Medicaid expansion, affording children and adults enhanced access to health care. North Dakota has benefited from federal matching revenues for the delivery of Home and Community Based Services waivers and the Money Follows the Person program. The state is one of only a handful that submitted and received approval for a 1915(i) Medicaid State Plan Amendment to provide home and community based services for individuals with serious behavioral health conditions and for individuals with TBI.

TAC also identified a number of challenges with North Dakota's human service system. The state continues to rely on institutional and segregated settings to serve individuals with disabilities. The state entered into a Settlement Agreement with the U.S. Department of Justice for allegedly failing to afford many people with physical disabilities the opportunity to live in integrated settings. The Aging and Adult Services Division has made some positive changes to support target population members in the community, but is having difficulty meeting requirements of the Settlement Agreement. Individuals who do not meet the criteria as Target Population Members continue to lack access to transition and community-based services and supports. Implementation of the 1915(i) State Plan Amendment is serving fewer than 100 of the estimated 11,000 potential beneficiaries. Stakeholders representing

children and adults with various disabilities report that services and supports are not accessible and that applying for benefits is cumbersome.

TAC has identified a series of recommendations for the Olmstead Commission to consider in updating the Olmstead Plan. Revising or eliminating administrative requirements unique to North Dakota should help individuals with disabilities to access needed benefits and to improve the pool of providers to deliver needed services and supports. The state can and should build on the successes experienced through the Money Follows the Person program and the Settlement Agreement. Most importantly, North Dakota must address the lack of data to oversee and manage the system. The greatest challenge TAC faced in conducting this assessment was the lack of timely, comprehensive data. TAC reviewed studies and reports generated by contracted entities that contained data analysis. Our assessment is that data exists; however, HHS lacks the capacity to analyze and use that data for monitoring and quality improvement within its service delivery system.

The ability to comply with *Olmstead* in North Dakota is beyond HHS. The Department needs ongoing support from the governor's administration and from the legislature. The Department also needs to collaborate with stakeholders to achieve the consensus necessary to move significant changes forward. Updating the Olmstead Plan provides the opportunity for all parties to work together, to build on the strengths of the system, and to identify the resources needed to fill the gaps that people with disabilities experience in their communities.

Chapter 1: Background and Approach

Background

In February 2022, the coordinator for the North Dakota Olmstead Commission contacted the Technical Assistance Collaborative, Inc. (TAC), regarding the Commission's interest in revising North Dakota's Olmstead Plan. The existing plan was written in 2002 and last officially updated in 2008. Members of the Commission determined that updated information and enhancements were necessary for an effectively working plan to support people with disabilities in the most integrated settings appropriate to their needs, as required under the landmark 1999 *Olmstead v. L.C.* United States Supreme Court decision. TAC responded favorably to the inquiry and entered into a contract in July 2022.

Title II of the Americans with Disabilities Act (ADA) of 1990 established a mandate to public entities to ensure that people with disabilities live in the most integrated settings possible. The *Olmstead* decision affirmed this civil right. In its ruling, the court strongly encouraged the development of 'Olmstead plans' to establish strategies that would support integration and also serve as a defense for states facing allegations of violating the ADA's integration mandate. According to the U.S. Department of Justice (DOJ), a comprehensive, effectively working plan must:

> "…do more than provide vague assurances of future integrated options or describe the entity's general history of increased funding for community services and decreased institutional populations. Instead, it must reflect an analysis of the extent to which the public entity is providing services in the most integrated setting and must contain concrete and reliable commitments to expand integrated opportunities."[1]

This report includes both an assessment and an analysis of how North Dakota's organizations, systems, funding, services, and supports function to serve people with disabilities. The report identifies key information that was used to inform the assessment and analysis, including the array of services and living arrangements, available funding and how it is spent, people served in various settings, and the structures in place to organize and deliver services. The report highlights TAC's assessment of strengths within the systems; gaps in services and supports that promote community integration; and challenges faced by state agencies, providers, and individuals with disabilities and their families. The report is intended to serve as a foundation for enhancements to the 2008 North Dakota Olmstead Plan, most notably by providing information that can help to establish baseline data and measurable outcomes.

[1] U.S. Department of Justice, Civil Rights Division (2011). Statement of the Department of Justice on enforcement of the integration mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. Retrieved March 25, 2021 from https://www.ada.gov/olmstead/q&a_olmstead.htm.

Approach

TAC consultants engaged in a multi-pronged approach to accomplishing the tasks outlined in the Scope of Work. Key strategies TAC used in developing and conducting the system assessment and analysis included collecting and synthesizing both qualitative and quantitative data:

- We reviewed several key existing data summaries and reports.
- We conducted online research.
- We conducted key informant interviews and stakeholder listening sessions.
- We conducted an online survey to facilitate additional stakeholder input.
- We summarized and presented our findings, recommending action steps and potential data sources for subsequent updates and enhancements to North Dakota's Olmstead Plan.

Data Collection

The data analysis involved conducting an environmental scan of recent studies, reports, and online documents; engaging and interviewing key state agency representatives; and conducting listening sessions with stakeholders.

Review of Existing Data Summaries and Reports

TAC evaluated and utilized quantitative data, as available, to inform our findings and analysis. TAC obtained data for this report from publicly available reports, including reports from the North Dakota Department of Health and Human Services (HHS) website, the Centers for Medicare and Medicaid Services (CMS) website, the U.S. Substance Abuse and Mental Health Services Administration's (SAMHSA) Uniform Reporting System, the Residential Information System Project, and other sources relevant to the populations of focus.

The Olmstead Commission provided numerous reports and policy, quality, and procedural documents for review. TAC also reviewed documents and literature found on various agency websites, as well as information provided by other stakeholders. These documents offered details on system indicators and issues being tracked by the programs, and policy and quality issues identified and monitored by leaders in various state agencies. A list of key documents provided or researched can be found in Appendix A.

Interviews

TAC conducted telephonic and virtual interviews with HHS staff and other recommended stakeholders. The purpose of these interviews was to review the analyses and recommendations made in previously commissioned reports on systems and services that support individuals with disabilities and to better understand the perspectives of the people who work within those systems, overseeing the delivery of services and supports. Staff were assured that their input would not be attributed to them directly to encourage their open participation. Please see Appendix B for a list of agencies and stakeholder representatives that TAC interviewed.

Stakeholder Listening Sessions

TAC held four virtual listening sessions with stakeholder groups, via Zoom, in October 2022 to inform our systems analysis. A total of 72 stakeholders participated in the listening sessions; TAC attributes this

low response in part to the short notice provided as a result of the compressed timeframe for obtaining input. Table 1 below shows a breakdown of listening session attendees by stakeholder group.

Table 1. Stakeholder Listening Session Attendees

Session	Date	Number of Attendees
State Council on Developmental Disabilities**	10/1/22	23
Families	10/4/22	14
People with Lived Experience	10/5/22	7
Providers	10/10/22	28
	Total	**72**

** DD Council members did not participate in polls due to the format of the meeting.

During each listening session, participants were asked similar questions regarding strengths, gaps, and challenges in the system for providers and for families and individuals with disabilities seeking services. They were also asked for their recommendations to strengthen the system.

Online Survey

TAC also posted the listening session polling questions as an online survey in attempt to garner additional stakeholder input. Eighty responses contributed to the analysis, with different stakeholder types shown in Table 2 below:

Table 2. Online Survey Response by Stakeholder Type

Stakeholder Type	Number of Respondents	Percentage of Total Respondents
Provider	55	65.48%
Person with a Disability	8	9.52%
Family Member	19	22.62%
Tribal Representative	1	1.19%
Other	12	14.29%
Total	95*	—

*Some respondents identified as representing more than one stakeholder group

Quantitative Data Utilized

TAC evaluated and utilized quantitative data, when available, to inform our findings and analysis.

The scope of work for this assessment did not allow for TAC's analysis of 'raw' Medicaid claims or encounters. However, TAC conducted in-depth reviews of publicly available reports, including reports

from the HHS website, the SAMHSA Uniform Reporting System, the Residential Information System Project, and other publicly available reports containing data relevant to the populations of focus. The accuracy of the findings and analysis in this report are largely dependent on the accuracy of that data.

Chapter 2: Summary of Key Findings and Relevant Information

This chapter presents findings based on available information across disability groups and key areas that were used to inform the analysis and recommendations offered in Chapter 4. The findings and relevant information are organized into the following topics:

- Demographics
- Key State Agencies Serving People with Disabilities
- Actions that Have Impacted System Improvement Efforts
- Services and Supports for Individuals with Disabilities

Demographics

The Technical Assistance Collaborative, Inc. (TAC) reviewed demographic data about North Dakota to provide context for our assessment of the system to support community integration for people with disabilities. North Dakota is the 19th largest[2] and 48th most populous[3] state (including the District of Columbia and U.S. territories). The largest city in North Dakota is Fargo, which had a population of 126,748 in 2020.[4] Fargo and West Fargo, along with Moorhead and Dilworth, Minnesota make up the Minnesota Metropolitan Statistical Area[5], also known as Fargo-Moorhead, and this area had a population of 248,591 in 2020.

The next most populous city in North Dakota is the historic city of Bismarck[6], which is the state capital and had a population of 73,651 in 2020. According to the City of Bismarck's Annual Comprehensive Financial Report for 2020[7], its top three employers are the State of North Dakota, Sanford Health, and Bismarck Public Schools. North Dakota is made up of three major geographic regions: the Red River Valley, the Missouri Plateau, and the southwestern part of the state which is made up of the Great Plains and the Badlands. Of North Dakota's 53 counties, 36 are considered to be frontier.[8] With 11.3 people on average per square mile, North Dakota's varied and mainly rural geography presents unique challenges to meeting the community integration needs of people with disabilities.

The United States Census Bureau estimated in 2020 that 355,103 people were employed in North Dakota, just under 50 percent of the population, which is a 5 percent increase from 2010. North Dakota's median household income was $65,315, slightly higher than the 2020 national median income of $64,994. The top industry in North Dakota in 2021 was government and government enterprises (17.8

[2] Wikipedia. (2022). List of US States and Territories by Area.
[3] Wikipedia. (2022). List of US States and Territories by Population.
[4] US Census Bureau. (2021). Quick Facts.
[5] Wikipedia. (2022) Fargo, North Dakota.
[6] Wikipedia. (2020). Bismarck, North Dakota.
[7] City of Bismarck. (2020). Annual Comprehensive Financial Report.
[8] Rural Health Information Hub (2020, January 21). *The Rural Monitor*: North Dakota Frontier Counties.

percent) followed by health care and social assistance (15.4 percent), and retail trade (11.2 percent).[9] From 1970 to 2020, nonfarm private (non-government) jobs increased about 20 percent, while farm jobs declined about 15 percent. From 2020 to 2021, the largest growing industries were mining, quarrying, and oil and gas extraction (+314.1 percent); transportation and warehousing (+104.8 percent); and agriculture, forestry, fishing, and hunting (+87.9 percent); while the only industries that had negative growth were information (-32.1 percent), other services (-7.2 percent), and utilities (-3.2 percent).

The Census Bureau estimates that the population of North Dakota was 774,948 people on July 1, 2021, a 15.23 percent increase since the 2010 census. Based on the 2020 data, of the people residing in North Dakota, 16.4 percent are 65 years and older; over 50 percent are between ages 18 and 64. According to the 2020 census, North Dakota is predominantly white (86.7 percent), followed by American Indian or Alaska Native (5.7 percent), Hispanic or Latino (4.4 percent), and Black or African American (3.5 percent).

According to the Centers for Disease Control and Prevention, in 2020, approximately 24 percent or 142,506 adults in North Dakota had a disability.[10] According to the Social Security Administration, there were 7,698 North Dakotans who received Supplemental Security Income (SSI) including 2,996 who also received Disability Insurance.[11] Individuals with disabilities who receive Old Age, Survivors, and Disability Insurance (OASDI) and/or SSI are most likely to need publicly supported disability services. Based on the 2020 U.S. Census, 11.1 percent of the population in North Dakota live in poverty compared to 11.6 percent nationally in 2021.[12]

Key State Agencies Supporting People with Disabilities

North Dakota Health and Human Services

In September, 2022 North Dakota consolidated the Department of Health and the Department of Human Services, in order to streamline operations and access to services. According to the North Dakota Department of Health and Human Services' (HHS) website, the Department strives to make North Dakota the healthiest state in the nation through streamlining paths to services, increasing quality and equity of services and programs, and providing opportunities for growth to their team members.[13] HHS has many resources for individuals of all ages who have intellectual/developmental disabilities (I/DD), physical disabilities, brain injuries, and visual and hearing impairments. These resources are offered through different divisions of HHS.

The goals of the newly consolidated department are to:

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[9] North Dakota Compass (2021). "All Jobs by Detailed Industry Share, North Dakota, 2021."
[10] U.S. Centers for Disease Prevention and Control (n.d.) Disability & Health U.S. State Profile Data for North Dakota. Retrieved November 30, 2022.
[11] Social Security Administration. SSI Recipients by State and County, 2020.
[12] U.S. Census Bureau. (2022). Poverty in the United States: 2021.
[13] North Dakota Department of Health and Human Services (n.d.). About Us. Retrieved November 30, 2022.

- Deliver one streamlined path to quality, equitable programs and services
- Continue to improve quality, effective, and efficient health and human services
- Create career growth and development opportunities for team members and build a one-team culture

The department is implementing an Integrated Eligibility System that allows an individual to apply for all benefits using one process. The Department is hoping this process will assist individuals in applying for benefits they may not be aware of.

Adult and Aging Services Division

The Aging and Adult Services Division administers programs and services that 1) help older adults and adults with physical disabilities to live in their own homes and communities, or 2) work with adults in long-term care settings. Programs include the Aging and Disability Resource Link, Dementia Care Services, Family Caregiver Support, the Long-Term Care Ombudsman program, Vulnerable Adult Protective Services, and a range of Older Americans Act services such as senior meals, Basic Care Assistance, and Home and Community-Based Services (HCBS). HCBS programs include Service Payments for Elderly and Disabled (SPED), Expanded Payments for Elderly and Disabled (Ex-SPED), an HCBS Medicaid waiver for this population, and the Program of All-Inclusive Care for the Elderly (PACE). The Adult and Aging Services Division works to protect the rights of, and ensure the safety and well-being of, all older adults and adults with physical disabilities.

The Division administers the Money Follows the Person (MFP) grant. The grant is part of the federal MFP rebalancing demonstration grant program intended to help older adults and people with disabilities by providing funding for one-time moving costs and arranging for the services and supports needed for people with disabilities to transition from a nursing home or an institution to the community.

Behavioral Health Division

The Behavioral Health Division offers support to North Dakotans at both the individual and community levels. The Division strives to ensure access to high-quality mental health and substance use disorder (SUD) services that reflect new technology and current knowledge, are grounded in evidence-based practices, and exist throughout all levels of the continuum, to meet the needs of all residents. This division is focused on supporting individuals throughout their lifespan through health promotion, prevention, treatment, and recovery.

The Behavioral Health Division is also responsible to serve individuals with traumatic brain injuries (TBI). The division operates the North Dakota Brain Injury Advisory Council, which aims to improve the quality of life for all individuals with a brain injury through assessment, awareness, prevention, research, education, collaboration, support services, and advocacy.

Developmental Disabilities Division

Developmental Disabilities (DD) Services "provides support and training to individuals and families in order to maximize community and family inclusion, independence, and self-sufficiency; to prevent institutionalization; and to enable institutionalized individuals to return to the community. To achieve this goal, the Developmental Disabilities Division contracts with private, nonprofit and for-profit organizations to provide an array of residential services, day services, and family support services." Services are accessed through eight regional Human Services Centers.

Services include DD Program Management (essentially case management), infant development, guardianship, early intervention, residential services, family support services, day services and employment services through Medicaid waivers, the Medicaid State Plan, and state funding. Residential services include Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), Residential Habilitation, and Adult Foster Care. Family Support services include In-Home Supports and Self-Directed Supports.

Division of Vocational Rehabilitation

The Division of Vocational Rehabilitation's mission is to assist North Dakotans with disabilities in finding and sustaining competitive employment opportunities and increasing independence. This Division also assists businesses with solutions to disability-related issues through consultations that help troubleshoot accessibility/employee issues, financial incentives, and staffing help, including recruitment and retention.

The Division of Vocational Rehabilitation also funds and operates Centers for Independent Living (CILs). The goal of Independent Living services is to "eliminate barriers and provide assistance to individuals with disabilities so they can live and work more independently in their homes and communities." Independent Living principles include Consumer Control, Consumer Needs-Based, Individualized Services, Community-Based Services, and Equal Opportunity."[14] All CILs provide independent living skills training, peer support, individual and systems advocacy, information and referral, and youth and institutional transition services.

Economic Assistance Division

The Economic Assistance Division operates a variety of public assistance programs to help qualifying North Dakotans in meeting their basic needs and moving toward self-sufficiency. Among these programs is the Basic Care Assistance program which helps people who are elderly, blind, or disabled to pay for services in a licensed basic care facility.

Medical Services Division

The Medical Services Division administers funding, processes enrollment, and provides information about the Children's Health Insurance Program (CHIP), Medicaid, Health Tracks, PACE, the Primary Care Case Management program, HCBS, and Qualified Service Providers. The Medical Services Division also offers Autism Services which help individuals and their families gain access to Medicaid services, waivers, vouchers, and other resources.

Regional Human Service Centers

The Department of Health and Human Services operates eight regional Human Service Centers (HSCs). HSCs are intended to provide a safety net that supports individuals and families with limited access to services or resources in their community. Each serves a designated multi-county area, providing counseling and mental health services, substance abuse treatment, and other human services.

- Telephone crisis services are available 24 hours a day.

[14] North Dakota Department of Health and Human Services (n.d). Centers for Independent Living.

- Team-based services include case management, therapy, rehabilitative services, addiction services, employment support, peer support, and medication management.
- Walk-in Assessments, Immediate Care and Referral Services are available Monday-Friday 8 a.m. to 5 p.m.

HSCs are staffed with state employees.

North Dakota Housing Finance Agency

The North Dakota Housing Finance Agency (NDHFA) aims to make housing affordable to all North Dakota residents. NDHFA offers home financing and rental assistance to low- and moderate-income families. NDHFA also acts as the Collaborative Applicant for the state's U.S. Department of Housing and Urban Development (HUD) Continuum of Care (CoC), whose geographic area encompasses all 53 of North Dakota's counties, cities, towns, and unincorporated areas, as well as the state's five federally recognized tribes.

County Services

The Human Service Zones (formerly known as county social service offices) are local offices in the counties with professionals on site who can help people who need Supplemental Nutrition Assistance Program (SNAP/Food Stamps); Temporary Assistance for Needy Families (TANF); heating assistance; Medicaid, including children's health services; basic care assistance; child care assistance; child welfare (foster care, child protection services); and/or referrals to other local resources and programs. These agencies are staffed with County employees.

Actions that have Supported System Improvement

Transition to Home and Community-Based Services

North Dakota began efforts many years ago to enhance services in the community for people with disabilities. The state was among the first to apply to establish HCBS waivers in the early 1980s.

The state also began in the 1980s, in response to a lawsuit, to downsize the state's Developmental Center, now the Life Skills and Transition Center. The Center's census has fallen from over 1,200 at one time to currently less than 70. Similarly, San Haven State Hospital, which treated more than 1,300 patients, closed in 1987. North Dakota State Hospital is the only remaining state-operated inpatient psychiatric facility, with a capacity of 100 beds. The state has also reduced nursing facility beds, from 7,071 in 1995 to 5,881 by 2019.[15]

Creation of an Olmstead Commission

In 2001, the North Dakota Olmstead Commission was created through executive order and charged with development of an Olmstead plan. The plan was intended to address provision of appropriate

[15] ND.gov. (n.d.) North Dakota skilled nursing homes. Retrieved November 30, 2022.

community-based placements for individuals with disabilities in a manner consistent with the needs and resources of the state.[16] In 2002, the Olmstead Commission held public meetings across the state to gather information on how to serve individuals with disabilities. The Commission developed a working plan that included historical information regarding efforts to serve individuals in less restrictive settings and a record of state actions to comply with the *Olmstead* decision. This plan was updated in 2008. Additional updates were proposed in 2010 and 2011 but it is unclear if these updates were formally adopted.[17]

Executive orders issued by the governor in 2010 and 2018 continued the Olmstead Commission and adjusted its membership. The 2018 executive order also provided that the commission could create subgroups for purposes of seeking expertise and input on community services and supports, health care, housing employment, education, and transportation. The 2018 executive order provides for the commission to consist of 10 voting members and 8 nonvoting members with a representative of the governor's office and a member representing the public to serve as co-chairs.

Olmstead Litigation and Settlement Agreements

In December 2015, the Civil Rights Division of the United States Department of Justice (DOJ) notified the State of North Dakota that it was investigating whether the state's long-term services were administered in the most integrated setting appropriate to individuals with physical disabilities. The investigation concluded that North Dakota was violating the Americans with Disabilities Act (ADA) and the Supreme Court's 1999 *Olmstead* decision by failing to afford many people with physical disabilities the opportunity to live in integrated settings. According to the DOJ's letter of findings, people with physical disabilities did not oppose living in the community and were capable of doing so, but could not access and maintain necessary community-based services and were therefore forced to enter, or were at serious risk of entering, nursing facilities to receive necessary services.

On December 14, 2020, North Dakota entered into a Settlement Agreement. The target population is individuals with a physical disability over the age of 21 who are eligible or likely to become eligible to receive Medicaid long-term services and supports and are likely to require such services for at least 90 days.

The Settlement Agreement indicated that North Dakota would begin in 2021 to provide opportunities for case management; person-centered planning; access to community-based services; education/information, screening, and diversion; in-reach; transition services; and housing services. An estimated 2,500 people with disabilities across the state could benefit from these expanded services.

Measures were taken by the Legislative Assembly towards meeting the Agreement. Measures included Senate Bill 2012 to provide for an appropriation to fund investments in home and community-based services, House Bill 1032 to make the SPED program more affordable, House Bill 1034 to require establishment of guidelines for nursing facilities to act as providers of in-home services, House Bill

[16] ND.Olmstead.gov (n.d.). The North Dakota Olmstead Commission. Retrieved November 30, 2022.

[17] ND.gov (2011). North Dakota Olmstead Plan 2011 Update.

1099 to expand the in-home service array, and Senate Bill 2124 to provide flexibility for specialization of home- and community-based case management services.

Medicaid Expansion

The North Dakota Medicaid expansion program has served its population since January 1, 2014, providing more people with access to health care, preventive services, and treatment. The Department of Health and Human Services (HHS) initially contracted with Sanford Health Plan to serve as the managed care organization (MCO). The expanded Medicaid program is available to individuals aged 19-64 with household incomes up to 138 percent of the federal poverty level. As of June 2022, North Dakota has enrolled 122,782 individuals in Medicaid and CHIP — a net increase of 75.45 percent since the first marketplace open enrollment period and related Medicaid program changes in October 2013. North Dakota has adopted one or more of the targeted enrollment strategies outlined in guidance issued by the Centers for Medicare and Medicaid Services (CMS) on May 17, 2013, designed to facilitate enrollment in Medicaid and CHIP.[18] Even with Medicaid expansion, North Dakota still has one of the lowest Medicaid penetration rates, between 11 and 12 percent.[19] This is likely due in part to the fact that North Dakota's income limit for Medicaid eligibility, 150 percent of the federal poverty level, is lower than in other states, which have determined eligibility up to 400 percent of the federal poverty level.

North Dakota implemented Medicaid expansion using a Medicaid MCO. The MCO payment of $14,107 per person is the highest in the country, 54 percent higher than the next highest state.[20] The state's original vendor, Sanford Health Plan, did conduct performance improvement efforts to identify and address individuals with significant opioid use disorders. Effective January 1, 2022, Medicaid expansion enrollees over the age of 21 were transitioned to Blue Cross Blue Shield of North Dakota.

Services and Supports for Individuals with Disabilities

Services for Children, Adults, and Older Adults with Physical Disabilities

Services to this population are offered through and/or managed by the Aging Services and Vocational Rehabilitation divisions of HHS, and in some cases by Medicaid. Many of these services are noted above in the agency descriptions.

Services for Children with Disabilities

Health Tracks (EPSDT)

Early Periodic Screening, Diagnosis and Treatment (EPSDT) is a Medicaid benefit that provides comprehensive and preventive health care services for children under age 21. EPSDT is intended to ensure that children and adolescents receive appropriate preventive, dental, mental health, developmental, and specialty services. In North Dakota the benefit is referred to as Health Tracks.

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[18] Medicaid.gov (n.d.). Medicaid & CHIP in North Dakota.
[19] Interview with Krista Freeman, Director, Medical Services Division, November 3, 2022
[20] Medical Services Budget – House Bill 1012, Traditional and Expansion, House Appropriations – Human Resources Division, Chairman Nelson Caprice Knapp, PhD Medical Services Director

Families participating in the listening sessions and online surveys shared their concerns that parents often are not aware of their rights to ask for EPSDT screening or additional services. Several shared their opinions that providers and doctors don't encourage parents to seek services due to the workforce shortage, and instead hold off on identifying emerging concerns until a child develops a disorder.

During the most recent legislative session the North Dakota legislature authorized a study of the Health Tracks benefit, prompted by concerns that the benefit was being underutilized. Stakeholders we interviewed raised concerns that EPSDT was not robust in North Dakota. Benchmarking indicates that North Dakota is in the bottom tier of peer states and below the national average for EPSDT screening and participation.

The preliminary report was made to the legislature in June 2022 and included recommendations for improvements in educating people about the benefit and in data collection. The Department is currently revamping the program to provide more outreach services to members and providers to increase EPSDT screening participation.[21]

Medicaid Waiver for Medically Fragile Children

The waiver provides institutional respite, program management or case management, dietary supplements, environmental modifications, equipment and supplies, in-home supports, individual and family counseling, and transportation for individuals who are medically fragile ages 3-17.

Children's Hospice Waiver

The waiver provides case management, respite, hospice, skilled nursing, bereavement counseling, equipment and supplies, expressive therapy, and palliative services for individuals who are medically fragile ages 0 to 21 years and who meet nursing home level of care. These waivers have a combined total of 55 slots.

Long-Term Services and Supports

Aging Services offers Basic Care Assistance, SPED, Ex-SPED, an HCBS waiver for this population, and PACE — and manages the MFP program.

Vocational Rehabilitation serves as the funding conduit for the state's four Centers for Independent Living. These centers provide training, transition assistance, peer support, information and referral, and in some cases also provide personal care assistance, housing assistance, and transportation.

Medicaid funds programs managed by the Adult and Aging Services Division, such as the HCBS waiver, and also pays for nursing facility care. Medicaid also operates a state plan personal assistance program (MSP-PC) and HCBS waivers targeted to medically fragile children.

Service Payments for the Elderly and Disabled

The SPED program is funded through state general funds and pays for a wide range of services and supports designed to help individuals remain in their homes rather than need care in a facility. Eligibility is based on functional need for assistance with activities of daily living (ADLs) or instrumental activities

[21] Alvarez & Marsal (2022). North Dakota developmental disabilities study report and oral presentation.

of daily living (IADLs) and having less than $50,000 in liquid financial assets. The need for assistance must also be expected to last three months or more. There are sliding fee cost-sharing requirements for persons with higher income/assets.

Services may include adult day care, adult foster care, chore service, homemaker service, emergency response, environmental modifications, home-delivered meals, respite, family home care, personal care, extended personal care, non-emergency transportation, and case management. Services must be provided by a Qualified Service Provider (QSP), which is an individual or agency that has met certain requirements and is enrolled with the Department. In November 2020, the Department reported the SPED program was serving 1,450 individuals at an average cost of $486 dollars per month. The annual cost for State Fiscal Year (SFY) 2021 was $5,767 per person.[22]

Extended Service Payments for the Elderly and Disabled

Ex-SPED is also state-funded, provides the same array of possible services, and is also based on a functional need for ADL or IADL assistance. However, persons must be Medicaid-eligible and have income at or below the Supplemental Security Income (SSI) level. The Department reported 141 recipients in November 2020, with an annual per person cost of $5,071 for SFY 2021.[23]

Medicaid Waiver for Home and Community-Based Services

This waiver is targeted to persons age 18 and above with age-related or physical disabilities. The waiver has a comprehensive menu of services including but not limited to adult day care, adult foster care, case management, homemaker and chore services, extended personal care, respite, environmental modifications, specialized equipment/supplies, emergency response, and non-emergency transportation. The waiver recently added a new service, Residential Habilitation; the service may provide up to 24 hours of supports in the person's home or in an Agency Foster Home. The Department reported 355 recipients in November 2020, and an annual per person cost of $32,111 for SFY 2021. The waiver is currently approved to serve over 600 unduplicated participants.[24]

Medicaid State Plan Personal Care Assistance

Personal care assistance provides help with ADLs and IADLs to Medicaid-eligible individuals. The program has three levels based on the amount of assistance needed. Persons at the top two levels must meet either nursing facility or intermediate care facility level of care. The three levels provide up to 120, 240, or 300 hours per month, respectively. Services are provided in the home, which may include a Basic Care facility. The Department estimated about 1,800 recipients, evenly split between persons living at home and in Basic Care facilities, at an annual per person cost of $26,591 for SFY 2021.[25]

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[22] Long-term Care Budget – House Bill 1012, House Appropriations, Chairman Nelson, Caprice Knapp, PhD, Medical Services Director and Nancy Nikolas-Maier, Aging Services Director

[23] Long-term Care Budget – House Bill 1012, House Appropriations, Chairman Nelson, Caprice Knapp, PhD, Medical Services Director and Nancy Nikolas-Maier, Aging Services Director

[24] Long-term Care Budget – House Bill 1012, House Appropriations, Chairman Nelson, Caprice Knapp, PhD, Medical Services Director and Nancy Nikolas-Maier, Aging Services Director

[25] Long-term Care Budget – House Bill 1012, House Appropriations, Chairman Nelson, Caprice Knapp, PhD, Medical Services Director and Nancy Nikolas-Maier, Aging Services Director

The Family Caregiver Support Program

The Family Caregiver Support Program provides information, assistance, counseling, support groups, training, respite care, and supplemental services, to help unpaid caregivers of older adults.

Program of All-Inclusive Care for the Elderly

PACE is a nationally recognized service model that provides a full range of health services to persons who meet a nursing facility level of care and are age 55 or older. Supportive services may be provided in an adult day setting, in the home, or in a facility, though the goal is to maintain persons in the community. North Dakota has one PACE provider which operates four sites, in the Bismarck, Dickinson, Fargo, and Minot areas, that serve a total of just under 200 people.

Money Follows the Person

MFP is a national Medicaid grant program that provides funding to assist persons with disabilities to transition out of institutions into the community. The North Dakota MFP program began in 2008. It provides transition coordinators who work with individuals who want to move, helping them locate needed services and housing. MFP funds can pay for moving expenses and other one-time costs not covered by other programs. According to program staff, just over 700 people have transitioned out of facilities since the program began, and that number is growing rapidly. Program staff reported 94 transitions in 2021 and estimated at least 100 individuals will transition in 2022.

Centers for Independent Living

North Dakota has four Centers for Independent Living (CILs) that provide services to individuals of all ages. The goal of Independent Living services is to "eliminate barriers and provide assistance to individuals with disabilities so they can live and work more independently in their homes and communities."[26] Independent Living principles include Consumer Control, Consumer Needs-Based, Individualized Services, Community-Based Services, and Equal Opportunity. All CILs provide independent living skills training, peer support, individual and systems advocacy, information and referral, and youth and institutional transition services. CILs may provide additional services as needed in their service area, including personal assistance services, housing and transportation assistance, and social/recreational activities. The CILs also employ the MFP Transition Coordinators funded by the MFP program.

Basic Care Assistance Program

The Basic Care Assistance program covers the cost of room and board for persons residing in North Dakota's state-licensed Basic Care facilities, congregate settings that provide custodial care for persons who have difficulty living independently but who do not require 24-hour medical or nursing care. These facilities are not Medicare- or Medicaid-certified. In addition to the Basic Care assistance, residents who meet financial and functional criteria may receive Medicaid State Plan Personal Care. The Department's budget presentation reported an average annual Basic Care payment of $35,235 per person in FY 2021.

[26] North Dakota Department of Health and Human Services. Centers for Independent Living.

Services for Individuals with Intellectual and Developmental Disabilities

Developmental Disability Program Managers

Developmental Disability Program Managers (DDPMs) function as case managers for individuals with I/DD. There are approximately 120 DDPMs who work out of 38 licensed provider practices. In 2020, they coordinated services for over 7,900 people, aged newborns to over 90 years old.[27]

Crisis Response

Crisis services are available to people with I/DD by calling 211. The caller will be connected to a specialized Developmental Disabilities CARES Response Team who can provide stabilization, support, and services coordination within 24 hours of the initial call. CARES Crisis Coordinators and applied behavior analysts are located throughout the state and work closely with the behavioral health mobile crisis teams from the state's regional human service centers. A sliding fee schedule is available based on an individual's ability to pay and insurance is accepted, if available.

Traditional IID/DD Medicaid Waiver

North Dakota's comprehensive IID/DD waiver is targeted to adults and children with I/DD. Waiver services for children include, but are not limited to, infant development; residential, day, and independent habilitation; in-home supports; equipment and supplies; and behavioral consultation. Waiver services for adults include residential, day, and independent habilitation; in-home supports; family support; extended home health equipment and supplies; environmental modifications; self-directed services; and behavioral consultation.

The waiver is approved to serve 6,380 participants in 2022, with that number increasing to 6,830 over the next three years. There are approximately 6,000 people currently enrolled in the waiver; the majority of enrollees are children. The average annual per person cost was $39,693 in FY 2018.[28] Total expenditures in FY 2020 were $268,528,805.[29] There is not a waiting list for the ID/DD waiver.

Intermediate Care Facilities

North Dakota has 108 licensed Intermediate Care Facilities for Individuals with Developmental Disabilities (ICF/IIDs). The current occupancy is about 460 persons, about 70 percent of whom reside in four- to six-person group homes. The state reports that its current policy is to limit licensure of any *new* facilities to homes that have a maximum of eight beds; reportedly, no currently licensed home, including homes that were licensed before the current policy, has more than twenty beds.

Life Skills and Transition Center

This state-operated facility has an average daily census of 68 individuals. Per the most current data identified by TAC, characteristics of individuals served are described in Tables 3 and 4 below.[30] Of the 68 admissions, 20 were identified as "short-term."

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[27] Presentation on House Bill 1012, House Appropriations | Human Resources Division, *Representative Jon Nelson, Chairman. ND Developmental Disabilities Division*

[28] University of Minnesota Residential Information Systems Project: North Dakota

[29] Alvarez & Marsal (2022). North Dakota developmental disabilities study report and oral presentation.

[30] University of Minnesota Residential Information Systems Project: North Dakota

Table 3. Ages of Individuals Served in the Life Skills Transition Center

Age	Number of Residents
0-18 years old	11
19-21 years old	4
22-39 years old	17
40-62 years old	21
65+ years old	15

Table 4. Severity of Disability of Individuals Served in the Life Skills Transition Center

Severity of Disability	Number of Residents
Mild	21
Moderate	14
Severe	8
Profound	16
Unknown	9

Autism Spectrum Disorder Services

Applied Behavioral Analysis (ABA) is a covered service in North Dakota for both Medicaid and commercial insurance. The Medicaid-covered service includes program oversight supporting comprehensive assessment; care plan development; referral; monitoring and follow-up; and skills training for qualifying individuals and their caregivers. Services can occur within the home, community, or a provider's facility. Individuals up to age 21 are eligible.[31] The Department requires that an annual Health Tracks/EPSDT screening with recommendations for ABA services be submitted yearly for continuation of services. The state follows Bright Futures screening recommendations, and MCHAT-R^{tm} is an approved screen in North Dakota. Reportedly, ABA services are increasingly being delivered in homes statewide to help prevent out-of-home placements.

[31] North Dakota Department of Health & Human Services (2019). Fact sheet: Medicaid Autism Applied Behavioral Analysis Service.

Autism Waiver

North Dakota is one of seven states with a special autism waiver in additional to an overall ID/DD waiver.[32] It serves persons ages 0-15. The waiver covers three services: case management, respite, and assistive technology. During the current budget cycle the state increased the number of waiver slots from 96 to 150. The expenditure in FY 2020 was $1,935,363; the 2021-2023 biennium appropriation was 1,955,531.[33] As of March 2022, there were 65 children on the wait list for the autism waiver.

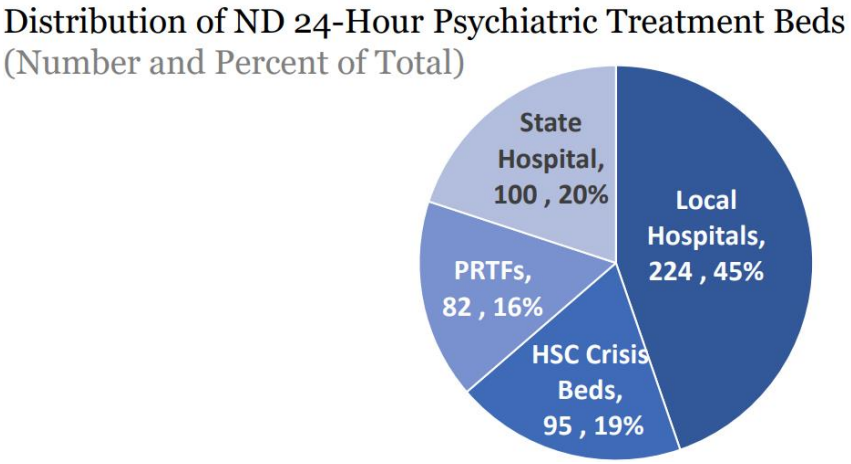
Autism Services Voucher Program

The Autism Services Voucher Program provides assistance to families of children with autism who do not participate in Medicaid. To qualify, household income for a family cannot exceed 200 percent of the federal poverty level. Vouchers help pay for respite care for family caregivers, assistive technology such as sensory or safety equipment, caregiver training, and other support services such as tutoring.

Services for Individuals with Mental Health and Substance Use Disorders

Services to individuals with the most significant mental health and substance use disorders (SUDs) are provided via the HSCs. Services include treatment and rehabilitative and social support services as well as targeted case management and crisis response. Services are funded with state and federal funds for non-Medicaid-eligible persons. HSCs may bill Medicaid for eligible recipients. The 1915(i) expanded Medicaid coverage for community-based services for children and adults who meet eligibility coverage. These services are delivered by contracted providers.

Figure 1. 24-Hour Psychiatric Treatment Beds in North Dakota[34]



[32] Alvarez & Marsal (2022). North Dakota developmental disabilities study report and oral presentation.

[33] North Dakota Department of Health & Human Services (2022). Medicaid autism waiver.

[34] Hughes, D., & Wieman, D. (2020). HSRI North Dakota hospital study. Cambridge, MA: Human Services Research Institute.

Services for Children with Behavioral Health Disorders

In 2019, 18,125 children were estimated to meet the definition of serious emotional disturbance (SED).[35] The children's system is working to ensure that residential treatment options are following current regulations and best practice guidelines, and to reduce out-of-state placements. One study found positive trends, with an increase in penetration rates for mental health outpatient treatment services for children and youth, and a greater proportion of children and youth outpatient services financed through Medicaid relative to HSC-funded services.[36]

Medicaid Benefits

Children enrolled in Medicaid are eligible for an array of services including Assessment and Diagnosis, Testing, Individual Therapy, Group Therapy, Rehabilitation Services, Speech Therapy, Occupational Therapy, Targeted Case Management, Transportation, Medication and Addiction Treatment Services. Additional home- and community-based services are now covered via the 1915(i) State Plan Amendment (SPA) to support children with behavioral health conditions, including Care Coordination, Training and Supports for Caregivers, Respite, Prevocational Training, Supported Education, and Family Peer Supports.

School-Based Mental Health Services

In 2018, the Simle Middle School (Bismarck Public Schools) was awarded state funding for a North Dakota Prevention and Early Intervention pilot grant. The goals of the grant were to demonstrate improvement in children's behavioral health in a school setting and to learn with schools how a fully integrated continuum of support could look in various schools throughout North Dakota. The 2019 legislative session established expansion of the pilot to include two additional schools serving rural and tribal schools. Effective July 1, 2020, $1,500,000 was made available to provide behavioral health services and support grants to school districts to address student behavioral health needs.

Services Available for Adults with Serious Mental Illness

In 2019, 30,258 North Dakotans were estimated to meet the definition of serious mental illness (SMI).[37] Individuals who meet SMI criteria are served through the HSCs while individuals with moderate to lower disorders receive services through private providers. HHS staff reported that Aging Services providers and I/DD providers are indicating the need to enhance their ability to serve people with co-occurring mental health needs, possibly as a result of the public system's targeting services to individuals who meet SMI criteria.

Services for Older Adults with Serious Mental Illness

In addition to community-based services through the HSCs there are 64 contracted gero-psych beds at 3 nursing facilities approved for Medicaid reimbursement. These beds are intended for older adults with medical needs whom the state hospital determines are inappropriate for admission.

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[35] Mental Health Advocacy Network (2021). HB 1012 – Behavioral Health [testimony].
[36] Human Services Research Institute (2018). North Dakota behavioral health system study: Final report.

[37] Mental Health Advocacy Network (2021). HB 1012 – Behavioral Health [testimony].

Services for Individuals with Substance Use Disorders

SUD Voucher Program

In July 2016, the Behavioral Health Division launched the state-funded SUD Voucher program to allow individuals to choose a provider and to address barriers to treatment, and increase the ability of people to access treatment and services for SUDs. Funding to support the SUD Vouchers increased from $.252M in 2017 to $7M in 2020. Since the program's inception, approximately 4,200 individuals have received services through the SUD voucher.[38] Recipients' outcomes measures in all four domains — Purpose, Health, Home, and Community — improved following services reimbursed through the SUD Voucher program.[39]

Recovery Housing Assistance Program

The Recovery Housing Assistance Program is a state-funded option for individuals wanting to initiate and sustain recovery efforts in a safe, stable living environment. Up to 12 weeks of an eligible individual's living expenses can be paid directly to a recovery housing provider. Recovery housing is intended to provide a safe environment, structured living, community integration, and a 24-hour support network.

Crisis Services for Children and Adults with Mental Health and Substance Use Disorders

Telephone crisis services are available 24 hours a day at no charge. If the crisis isn't resolved, a trained mobile crisis response team can be dispatched, though as of September 2022 there were only two teams available. In addition, walk-in and short-term, recovery-focused services, which could include one or more overnight stays, are available in the Bismarck, Fargo, and Jamestown regions. Services include withdrawal management, supportive therapy, and referrals to needed services. Efforts are underway to fully develop these facilities in all eight regions. Walk-in behavioral health screening is available at any HSC between 8:00 a.m. and 5:00 p.m. to assess an individual's situation and help them connect to services either at an HSC or with a community provider to prevent a future crisis.

In response to the impact of the COVID-19 pandemic, the Behavioral Health Division partnered with Lutheran Social Services to create Project Renew, a free crisis care program. The project offers trained crisis counselors to provide listening support, and to help connect individuals to resources if needed, including more formal clinical services.

Education/Employment Support

The 1915(i) SPA includes Supported Education and Supported Employment as covered benefits for eligible populations. However, Medicaid is the payer of last resort for services. Division of Vocational Rehabilitation (DVR) benefits must be accessed first.

Think College provides resources, technical assistance, and training related to college options for students with I/DD, and manages the only national listing of college programs for students with I/DD in the United States. Minot State University offers Think College in North Dakota.

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[38] North Dakota Department of Health & Human Services: Substance Use Disorder Voucher.
[39] North Dakota Department of Health & Human Services: Substance Use Disorder Voucher.

The Behavioral Health Division offers the evidence-based practice of Individual Placement and Support/Supported Employment (IPS/SE). In 2020, only 0.1 percent of individuals served by the state mental health authority reportedly received the service.[40] This number should be increasing since IPS/SE is an approved benefit for individuals with SMI and traumatic brain injury (TBI) as part of the 1915(i) SPA. Providers remain concerned, however, that DVR does not provide IPS/SE. Since individuals must access DVR services first, they may not have access to the services that would best assist them in obtaining competitive, integrated employment.

The Medicaid ID/DD waiver includes three employment support services:

- Supported Employment: Individual
- Pre-Vocational Services (described as day service)
- Small Group Employment for two to eight people; it is not clear from the description where this service occurs.

HHS estimated that in FY 2023, of the 6,380 total projected waiver recipients, 580 (9 percent) will receive Pre-vocational services, 409 (6.4 percent) will receive Individual Employment Support, and 378 (5.9 percent) will receive Small Group Employment Support.[41]

Services for Traumatic Brain Injury

Medicaid-eligible individuals with a brain injury may be covered for services under the Medicaid Waiver for HCBS or the 1915(i) SPA. Individuals may also qualify as a member under the Settlement Agreement. In 2018, the state established a Certified Brain Injury Specialist (CBIS) training program increasing the number of CBISs in the state from four to seventy-five. In 2020, $276,747 in State General Funds provided services to 269 individuals with TBI.[42]

Housing

North Dakota has a history of providing 'Housing First' to individuals experiencing homelessness, including individuals with disabilities. Examples include:

- The Fraser Permanent Supportive Housing (PSH) project[43] opened in May 2014. This program was the first of its kind in North Dakota. Individual single-room units are leased to youth ages 18-26 who have been determined the "hardest to house" individuals. Residents sign 12-month leases and work with staff on independent living skills, increasing their income potential, and developing positive rental history. There are 21 single units and 4 two-bedroom family units.
- Using Low-Income Housing Tax Credit (LIHTC) and other affordable housing supply resources, the state has supported the development of three supportive housing projects that have targeted 100 percent of their units to individuals experiencing long-term homelessness. Cooper House opened in 2010, LaGrave on First in 2018, and most recently, Edwinton Place Apartments.

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[40] U.S. Substance Abuse & Mental Health Services Administration: 2020 Uniform Reporting System Output Table for North Dakota.
[41] 1915(c) HCBS Waiver: ND.0037.R08.04 - Jan 01, 2021 (as of Jan 01, 2021) Page 193.
[42] Traumatic Brain Injury State Partnership Program (n.d). Grantee profile 2021-2026: North Dakota
[43] Fraser, Ltd (n.d.). Permanent supportive housing.

Edwinton is a PSH project that provides 40 individuals who have experienced long-term homelessness with a stable home and offers services to address the issues that may have contributed to their homelessness. Most of Edwinton's financing was provided by NDHFA. The state agency awarded $813,000 in federal LIHTCs to the project providing it with $7.2 million in equity. NDHFA also provided $1,026,147 from the National Housing Trust Fund, $460,000 from the Neighborhood Stabilization Program (NSP), and $500,000 from the state's Housing Incentive Fund. Edwinton is North Dakota's third PSH project to offer individuals Housing First.

- In September 2019, YWCA Cass Clay and development partner Beyond Shelter Inc. completed Grace Garden, a 30-unit PSH residence for once-homeless individuals and families, many of whom are domestic violence survivors.

The above projects are 'project-based' approaches to PSH, where more than 25 percent of the units are targeted to an intended target population.

Chapter 3: Strengths, Gaps, and Challenges

Strengths

Stakeholder Perceptions

Stakeholders identified a number of strengths within North Dakota's service systems. The most often expressed strength was that the preferences and choices of families and individuals with disabilities in services were honored. Respondents indicated there is access to supported education/employment programs, that there is adequate information about the array of available programs and supportive services including community-based services, and that services are accessible for people with disabilities through the use of interpreters, assistive devices, and physical plant accommodations.

Analysis of Findings

In addition to the stakeholders' responses, TAC identified the following system strengths based on our interviews and environmental scan.

Use of Federal Resources

North Dakota has historically utilized multiple federal authorities and funding sources to support persons with disabilities, including Medicaid Home and Community-Based Services (HCBS) waivers, Medicaid state plan services, the Program of All-Inclusive Care for the Elderly (PACE), and Money Follows the Person (MFP). More recently the state received approval to use a portion of American Rescue Plan Act funds to enhance HCBS.

Money Follows the Person

North Dakota was an early adopter of MFP. The state has transitioned more than 700 individuals from nursing facilities to the community.

1915(i) State Plan Amendment

In 2020, North Dakota added 12 new services to the Medicaid state plan to help children and adults with significant mental health and substance use disorders (SUDs) to live in the community. The 1915(i) state plan amendment (SPA) includes Care Coordination, Community Transitional Services to pay for one-time expenses, non-medical transportation, Supported Education, Supported Employment, Family Peer Support, Peer Support, and housing supports. Housing support services help people to obtain and maintain successful tenancy in independent living. Per the state's approved application, 1915(i) services can be provided to recipients in their own homes; in provider-owned and -controlled residential settings including Sober Living Homes, Group Homes, Foster Homes, Treatment Foster Homes, Transitional Living Homes; in nonresidential settings; and in the community at large.

The list of qualifying diagnoses is extensive and does not appear to pose a barrier to access. The original eligibility criteria included a World Health Organization Disability Assessment Schedule (WHODAS) 2.0 score of 50 or higher. The state received feedback that the score was 'too high' to qualify individuals for independent living and announced in July 2021 a proposed modification of the eligibility score to 25 or higher.

Administration for Community Living Grant

North Dakota was awarded an Administration for Community Living Traumatic Brain Injury (TBI) State Partnership Program grant. The aim of the grant is to establish a comprehensive system of support for people with TBI guided by a consumer-driven state plan. Additional aims of the grant include:

- Actively engaging individuals with brain injury and their family members in advocacy and outreach.
- Increasing Native American referrals to the resource facilitation program and partnering with tribal nations to enhance brain injury capacity and expertise through outreach and education and culturally specific materials.
- Partnering with behavioral health and criminal justice providers to implement standardized screening and referral to resource facilitation protocols for brain injury and symptom management education.
- Expanding access to brain injury educational materials and trainings to meet the diverse needs of individuals, family members, and various technical levels of providers.

State Funding Support

There appears to be legislative support for human services and systems, as evidenced by numerous state-funded programs and pilot initiatives. The state allocates significant funding for services that help people to remain in the community, such as the Service Payments for the Elderly and Disabled (SPED) and Extended Service Payments for the Elderly and Disabled (Ex-SPED) programs. Together these provide a core infrastructure of programs and services to support people in community-based settings. With a few exceptions in specialized areas or where the issue is a shortage of providers (discussed further below in this report) there are no waiting lists for services.

In addition to funding direct services, the legislature continues to fund multiple studies on the services provided in North Dakota. State agencies have also funded various studies. Findings and recommendations from these studies are identified throughout this report.

Impacts of the Settlement Agreement

In its January 2022 Biannual Report, the State reported transitioning 88 individuals since the effective date of the U.S. Department of Justice (DOJ) Settlement Agreement on December 14, 2020.[44] Sixty-one of those target population members (TPMs) who transitioned to community-based services were assisted through the State's MFP program.

Addressing the Workforce Crisis

North Dakota is experiencing the same workforce shortages within its human services and health care systems as every state in the nation.

The Division of Adult and Aging Services is taking steps to address issues to increase Qualified Service Provider (QSP) workforce capacity, perhaps the most significant being the creation of the Direct Service

[44] ND.gov. (2022). North Dakota settlement agreement report of the subject matter expert, March 2022.

Workforce/Family Caregiver Resource and Training Center (DSW/FC RC). The new center began operation in January 2022.[45] This "resource hub" will be operated through an initial three-year contract with the University of North Dakota School of Medicine and Health Sciences Center for Rural Health. Included in the scope of work for the DSW/FC RC is to:

- Conduct a needs assessment with individual and agency QSPs to determine current capacity and service gaps
- Assist QSPs with the enrollment and reenrollment process
- Provide QSP orientation
- Create and maintain accessible, dynamic education and training opportunities based on the needs of individual QSPs, QSP agencies, family providers, and individuals self-directing services
- Provide training support and technical assistance for Electronic Visit Verification (EVV) and billing
- Create communication tools for QSPs (a listserv and website) to provide relevant and accurate information in a continuous fashion to increase retention efforts
- Create mentoring and networking opportunities for QSPs, and
- Create recruitment strategies for QSPs.

In addition, Aging Services has made provisions to be able to pay family members of TPMs as QSPs to help keep their loved one at home. Funding sources include Medicaid, SPED, and Ex-SPED.

Promotion of HCBS

Since November 2021, Aging Services has been providing information and education on HCBS via twice-monthly webinars. These webinars explain in-home and community-based services funds from the Department of Health and Human Services (HHS) that give adults with physical disabilities and older adults options beyond nursing facility care. Individuals who could benefit from services, their family members, and community entities that work with older adults and adults with physical disabilities are encouraged to participate. By sharing more about available services, the state hopes to increase interest in HCBS and find individuals who may be interested in becoming service providers.[46]

Housing

As part of the Settlement Agreement, the state committed to providing, at minimum, the following number of PSH options for class members whose Person Centered Plans identify a need for PSH:

- 20 members within one year,
- Additional 30 members within two years,
- Additional 60 members within three years, and
- Additional PSH based on aggregate need.

[45] ND.gov. (2022). North Dakota settlement agreement report of the subject matter expert, March 2022.
[46] ND.gov. (2022). North Dakota settlement agreement report of the subject matter expert, March 2022.

Aging Services reported that PSH was provided to 28 TPMs in year one of the Settlement Agreement.[47] Given the lack of housing options in North Dakota, HHS sought consultation for the development of a Housing Access Plan.

Tribal Efforts

According to the January 2022 Biannual Report, one independent case manager was hired by the Standing Rock Sioux Tribe. The State has provided technical assistance and training to support this effort and is also supporting the development of HCBS services by tribal entities.[48]

Expansion of Preventive and Community-Based Behavioral Health Services

The state has taken steps to provide a more robust array of preventive and community-based behavioral health services. As previous reports have pointed out, strong systems for community education, prevention and early intervention, outpatient treatment, and community-based services are key to reducing institutionalization. The July 2022 project dashboard for the state's Behavioral Health Plan shows progress on almost all of the 13 aims and 28 goals prioritized by the Behavioral Health Planning Council.[49] Accomplished objectives include:

- Expanded funding for mobile crisis teams for children and youth in urban areas
- Financing for additional PSH
- Resourcing and beginning a pilot training on Crisis Intervention Teams for the Department of Corrections
- Submission, and CMS approval, of 1915(i) SPA for home and community-based behavioral health services
- Implementation of peer support services

Use of Evidence-Based and Promising Practices

HHS does offer several evidence-based practices (EBPs) to individuals who qualify for them.

Children, Adults, and Older Adults with Behavioral Health Disorders

- 38.4 percent of children served in North Dakota's behavioral health system receive therapeutic foster care compared to the national average of 1.7 percent.[50]
- EBPs for adults with serious mental illness (SMI) include Assertive Community Treatment (ACT), peer support specialists for children and adults; Illness Self-Management and Recovery, and Medication Management.
- 4 percent of adults served in the state's behavioral health system receive ACT compared to the US average of 1.8 percent.[51]

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[47] ND.gov. (2022). North Dakota settlement agreement report of the subject matter expert, March 2022.
[48] ND.gov. (2022). North Dakota settlement agreement report of the subject matter expert, March 2022.
[49] Human Services Research Institute (2022). North Dakota Behavioral Health Plan – Project Dashboard July 2022.
[50] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.
[51] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

- The expansion of medication-assisted treatment (MAT) has the potential to significantly reduce the risk of relapses, prevent overdoses, and reduce the need for higher levels of care if made more widely available to low-income individuals in the state.[52]

Housing Assistance

In September 2018, NDHFA launched the Opening Doors Landlord Risk Mitigation Fund to encourage property owners to lease apartments to individuals and families with poor credit, a history of evictions, or a criminal record. A care coordinator provides services including help to find and secure housing, monitoring tenancy, and mediating any disputes with the landlord. Opening Doors program participants are covered for up to 18 months. During that time, the landlord may receive compensation for damage or lost rent claim coverage for up to $2,000.[53]

The North Dakota Treasury established the ND Rent Help program to address housing instability in both rural and urban areas of the state. The program offers up to 12 months of assistance with past due, current, and future rent to prevent evictions and to promote stable housing. The program approved assistance for 1,684 qualifying renters between January 1 and July 19, 2021. These households lived in 38 of the state's 53 counties.[54]

Involvement of Families and People with Lived Experience

In 2021, legislation was passed increasing the survivor and family member representation on the state Brain Injury advisory council. Membership was realigned to have 50 percent of voting representatives be brain injury survivors.

Areas for Improvement and Gaps in Care

In our stakeholder listening sessions, participants were asked about the gaps in community-based supports for individuals with disabilities, including children, youth, adults, and older adults. The gaps most often identified are described in this section.

While TAC has identified many strengths within HHS's systems and services, our analysis also revealed areas for improvement within the system that should be addressed in order to support integrated community living for people with disabilities.

Systemic Issues

Early and Periodic Screening, Diagnostic and Treatment / Health Tracks

During its most recent session, the North Dakota legislature authorized a study of the Health Tracks benefit, prompted by concerns that the benefit was being underutilized. Stakeholder interviews raised concerns that Early and Periodic Screening, Diagnostic and Treatment (EPSDT) was not robust in North

[52] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

[53] North Dakota Housing Finance Agency (2018, September 13). Opening doors for households with rental barrier.
[54] ND.gov (2021, July 27). North Dakota renters can get help applying for rent assistance and other help.

Dakota. Benchmarking indicates that North Dakota is in the bottom tier of peer states and below the national average for EPSDT screening and participation.

Table 4. EPSDT Benchmarking[55]

	Screening Ratio *	Participant Ratio**	Average
Iowa	0.87	0.61	0.74
National	0.79	0.60	0.70
Idaho	0.81	0.58	0.70
Kansas	0.72	0.55	0.64
Wyoming	0.7	0.52	0.61
Minnesota	0.67	0.53	0.60
Nebraska	0.72	0.48	0.60
North Dakota	0.59	0.48	0.54
South Dakota	0.69	0.38	0.54
Montana	0.59	0.42	0.51

** Expected number of screenings / total screens received ** Total eligible who should receive at least one initial or periodic screen / total receiving*

The preliminary report was made to the Legislature in June 2022, and included recommendations for improvements in educating families as well as providers about the EPSDT benefit and requirements and in data collection. The Department is currently working on revamping Health Tracks to provide more outreach services to members and providers to increase EPSDT screening participation.

The Developmental Disabilities Division also offers Early Intervention screening services for infants and young children (0-3 years old) who have developmental delays. The assessments are free and a plan is developed with parents to meet the needs of their child and family, which may include services such as home visits, consultations, and parent coaching. It is not clear whether or how this screening aligns with the EPSDT screening process.

Expenditures for Institutional and Congregate Care

North Dakota ranked first in the United States in Federal Fiscal Year 2019 in the percentage of its overall Medicaid spending that supported Long Term Services and Supports (LTSS).[56] However, the state spends a disproportionate amount of these resources on institutional and congregate care settings. In that

[55] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.
[56] Mathematica (2021). Medicaid Long Term Services and Supports Annual Expenditure Report Federal Fiscal Year 2019.

same period, only 43.6 percent of spending supported HCBS, ranking 43rd in the U.S. at well below the national average of 58.6 percent.[57]

Expenditures for the intellectual/developmental disability (I/DD) population, shown in Table 6 below, are also skewed toward congregate care: 29 percent of state agency expenditures are for community-based ICFs, compared to the national average of 19 percent, while 71 percent of expenditures are for community-based waiver services, compared to the national average of 81 percent.[58]

Table 6. Annual Expenditures at Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs)[59]

	ICF (Non-State) Setting	Life Skills and Transition Center	DD Waiver
Recipients	460	68	5,157
Expenditures	$80,522,540	$25,936,900	$204,696,801
Average cost per person	$175,049	$381,425	$39,693

In FY 2020, the number of people served in ICFs dropped to 422, but the cost per person increased to $231,112 for total expenditures of $98,373,264.[60]

As shown in Table 7 below, North Dakota's per person spend for ICF/IIDs is higher than that of many peer states as well as the U.S. average. Table 8 shows that North Dakota also serves more children in ICF/IIDs than peer states do.[61]

[57] Mathematica (2021). Medicaid Long Term Services and Supports Annual Expenditure Report Federal Fiscal Year 2019.
[58] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

[59] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

[60] Presentation on House Bill 1012, House Appropriations | Human Resources Division, *Representative Jon Nelson, Chairman. ND Developmental Disabilities Division*
[61] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

Table 7. ICF/IID Annual Cost per Person in North Dakota Compared to Peer States[62]

	Total People Living in ICFs	% of People Living in ICFs	Total ICF Spend	% ICF Spend	Total People Served	Total Spend
North Dakota	460	7.57%	$80,522,540	29.25%	5,157	$275,335,784
Nebraska	382	6.59%	$68,761,528	18.73%	5800	$367,058,908
Montana	N/A	N/A	N/A	0.00%	2746	$113,619,580
Idaho	73	0.88%	$6,574,599	2.52%	8327	$260,486,457
Wyoming	72	3.01%	$23,217,840	19.18%	2394	$121,046,256
Minnesota	1,441	4.22%	$114,405,313	6.86%	34161	$1,668,719,713
Kansas	430	4.50%	$41,086,500	7.29%	9554	$563,481,120
Iowa	1,440	7.77%	$231,887,520	28.78%	18522	$805,652,614
South Dakota	176	4.41%	$31,807,072	21.52%	3,990	$147,774,447
National	70,046	5.35%	$9,635,527,760	18.64%	1,308,659	$51,685,458,530

Table 8. North Dakota Children Served in ICF/IIDs Compared to Peer States, 2018.[63]

State	ICF Utilization per 100,000 Residents
North Dakota	61.3
South Dakota	46.8
Minnesota	25.7
Nebraska	29.4
Kansas	18.9
Wyoming	5.3

[62] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

[63] Presentation on House Bill 1012, House Appropriations | Human Resources Division, *Representative Jon Nelson, Chairman. ND Developmental Disabilities Division*

Similarly, as shown in Table 9 below, the North Dakota State Mental Health Authority (SMHA) spends a greater percentage of its budget on institutional and other 24-hour care than on ambulatory community-based services.

Table 9. State Revenue Expenditure Data, FY 2020[64]

Services Setting	SMHA Expenditures	Percentage of Total SMHA Spend
Ambulatory Community Mental Health Expenditures	$40,026,159	45%
State Hospital Expenditures	$36,234,840	41%
Other 24-Hour Care	$7,959,586	9%
Other Psychiatric Inpatient	$2,770,865	3%
Total SMHA Expenditures	$88,068,163	100%

North Dakota utilizes state psychiatric hospital beds at a proportionately higher rate than other states across the country: state hospital utilization is .38/1,000 population in the U.S., but is .91/1,000 population in North Dakota. Readmission rates to the State Hospital are also higher than the national average: 9.2% within 30 days of discharge in the U.S., but 18.3% in North Dakota; 19.9% within 180 days of discharge in the U.S., but 34.2% in North Dakota.[65]

Length of stay for North Dakota State Hospital patients varies depending upon treatment needs but may range from just a few days for assessment and stabilization to many months for individuals with more complex treatment needs and placement difficulties. Most individuals do not receive treatment at the facility over a long period of time. These patterns of state hospital bed utilization align with studies that have concluded that the lack of psychiatric inpatient beds is not a major issue for North Dakota.[66] However, community-based inpatient beds may be filled with admissions from neighboring states, and system bottlenecks, inefficiencies, and limited information-sharing reportedly are viewed as barriers for Critical

[64] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

[65] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

[66] Schulte, R., Haglund, J., Victoria-Gray, E., Gion, D., & Vogeltanz-Holm, N. (2021). Acute psychiatric and residential care final report *and* Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report

Access Hospitals to admit public system clients, resulting in overutilization of The State Hospital for acute care. This is especially concerning as the State Hospital is in disrepair and proponents have suggested that it is necessary to invest millions of dollars to replace it.

A recent study conducted by the Human Services Research Institute (HSRI) found that admissions criteria for inpatient and residential services are not well defined, resulting in children and adult admissions to inappropriate levels of care, usually more intensive than needed, especially in the case of psychiatric residential treatment facilities.[67]

Homelessness

The state's 2020 report on homelessness cited a point-in-time study that found 541 people experiencing homelessness; 17 percent of these persons were chronically homeless and 19 percent suffered from SMI. Native Americans are overrepresented among those experiencing homelessness.[68] Reportedly, there are no homeless shelters or PSH units in the western part of the state.

It is well established that housing has a significant impact on health outcomes, and for people with disabilities in particular, housing shapes overall well-being.[69] Research has demonstrated that PSH is cost-effective for people experiencing homelessness who often have co-occurring medical or behavioral health conditions, and are frequent users of costly emergency and institutional services.[70] [71] [72] Overall, PSH results in positive outcomes in health, including behavioral health, as well as overall housing stability.[73] While there are PSH programs in the state (described earlier in this report), their capacity is insufficient to meet the need in North Dakota.

Satisfaction with Services

Stakeholders consistently expressed concerns with the quality of and satisfaction with services received. See Table 10 below for an assessment of outcomes by mental health service participants.

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[67] Hughes, D., & Wieman, D. (2020). HSRI North Dakota hospital study. Cambridge, MA: Human Services Research Institute.

[68] 2020 Point-in-Time Count ND-500 North Dakota Statewide CoC

[69] Taylor, L. (2018, June 7). Housing and health: An overview of the literature. *Health Affairs*.

[70] Culhane, D. P., Metraux, S., & Hadley, T. (2002). Public service reductions associated with placement of homeless persons with severe mental illness in supportive housing. *Housing Policy Debate, 13*(1), 107-163

[71] Larimer, M. E. (2009). Health care and public service use and costs before and after provision of housing for chronically homeless persons with severe alcohol problems. *JAMA, 301*(13):1349.

[72] Chalmers McLaughlin, T. (2010). Using common themes: Cost-effectiveness of permanent supported housing for persons with mental illness. *Research on Social Work Practice*, *21*(4):404–411.

[73] Rog, D., Marshall, T., Dougherty, R., George, P., Daniels, A., Ghose, S. S., & Delphin-Rittmon, M. (2014). Permanent supportive housing: Assessing the evidence. *Psychiatric Services, 65*(3):287-94.

Table 10. Mental Health Service Participants Assessment of Outcomes[74]

Source	North Dakota	U.S.
Adult Consumer Survey – Positive About Outcomes	56.5%	79.6%
Family/Child Survey – Positive About Outcomes	48.1%	74.6%

People with lived experience and their families expressed interest in being involved in key decision-making groups and in quality improvement efforts, suggesting that more data is needed on families' experiences. TAC shares this perspective and observes that North Dakota has not participated until recently in the National Core Indicators®. National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD) is a national effort to measure and improve the performance of public developmental disabilities agencies. The primary aim is to collect and maintain valid and reliable data about the performance of public I/DD systems and the outcomes experienced by participants in the system. Data collection consists of interviews with individuals receiving services and surveys of family members. While North Dakota is identified as a participating state, there are no reports issued up to and including 2020/21.

Gaps in Care

The gaps in care most often identified by stakeholders include:

- Inadequate staffing in community-based settings
- Inadequate support services and treatment options at all levels of care that are appropriate to people's needs including crisis services, supported employment/education and other community-based services
- Lack of services/supports in rural/frontier parts of the state
- Lack of transportation

Staffing shortages are addressed later in this report.

Services for Children

For children and youth, concerns center on the use of residential placements for those with lower level needs, and difficulty finding appropriate placements for those with the most complex needs. The failure to intervene earlier with community options is one factor thought to be driving inappropriate residential

[74] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

placements, as well as the experience that some facilities prioritize lower-level needs and are reluctant to serve children and youth with more challenging behaviors.

School-Based Services

In its 2018 study of North Dakota's behavioral health system, HSRI identified a lack of school-based services for children and youth with disabilities.[75] Based on available claims data, only 5 percent of all services of any type for persons under age 18 were delivered in a school-based setting, and 0.1 percent of youth SUD treatment services were delivered in school settings during FY 2017. The Behavioral Health Division has allocated funds earmarked for pilot school-based initiatives; while a step in the right direction, these pilots are not likely to fully meet the unmet need.

Participation in Services

A penetration rate measures the participation in services compared to the universe of potential service recipients. Penetration rates for mental health services in North Dakota are lower for every age group compared to other states in the Midwest. Penetration rates for mental health services and utilization of community mental health services in North Dakota are below the national average.[76]

Table 11. Community Mental Health Services Utilization in North Dakota Relative to the Nation

Penetration Rate	North Dakota	U.S.
Penetration/1,000 Population	18.87	24.58
Community Services Utilization/1,000 Population	18.49	23.98

The Behavioral Health Division and Medical Services each provide coverage for community-based mental health and SUD services. There do appear to be gaps in access to services depending on an individual's source of funding. For example, Peer Support is covered by Medicaid under the 1915(i), but given the low Medicaid penetration rate, may still be unavailable to individuals with mental health disorders who don't participate in Medicaid but would benefit from the service.

Lack of Adequate Crisis Response Services and Acute Psychiatric Inpatient Treatment

While the Behavioral Health Division's website indicates that mobile crisis response teams are available, information TAC reviewed[77] and stakeholder feedback indicate that first responders are often the front

[75] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

[76] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

[77] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

line of response for behavioral health crises, and that crisis stabilization units for adults are not available in all regions of the state.

Utilization of other psychiatric inpatient beds is lower in North Dakota (.46 percent) compared to other states in the country (1.47 percent).[78] Hospital emergency departments (EDs) in North Dakota are not adequately serving, and reportedly refusing to serve at times, people in behavioral health crisis or with acute psychiatric needs. One report found that of the 3,323 total hospital beds in the state, less than 8 percent were currently capable of treating acute behavioral health conditions in a resident's home community.[79]

This low service utilization could be linked to the lack of a pathway to appropriate community-based services. In Oklahoma, a recent technological innovation offers a form of self-directed care for individuals with behavioral health needs leaving EDs. To reduce the likelihood of returning to the ED or being admitted to inpatient psychiatric hospitalization, individuals receive computer tablets directly connecting them to behavioral health providers. Specifically, there are nearly 6,000 iPads in circulation to offer people in crisis an immediate method to connect with crisis line providers in Oklahoma. Reports show the tablet-based system is HIPAA-compliant, allows patients and first responders (e.g., law enforcement, emergency medical services, and fire departments) to remotely communicate face-to-face with a mental health professional, and lets providers conduct immediate assessments and referrals. The system saves responder time in transport and prevents unnecessary ED visits and inpatient hospitalizations that could disrupt patients' lives and work. The evidence of the system's success is mounting, with a 36-percent decrease in inpatient stays since its inception and an estimated savings of $5 million.

Services to Support Individuals with Traumatic Brain Injury

A person with a moderate or severe TBI may need ongoing care to help with their recovery. The consequences of severe TBI can affect all aspects of an individual's life, including relationships with family and friends, the ability to progress at school or work, doing household tasks, driving, and participating in other daily activities.[80] A moderate or severe TBI not only impacts the life of an individual and their family, but it also has a large societal and economic toll. The lifetime economic cost of TBI, including direct and indirect medical costs, was estimated to be approximately $76.5 billion nationally (in 2010 dollars).[81]

In 2016, the Behavioral Health Division contracted with the North Dakota Center for Persons with Disabilities at Minot State University to conduct a statewide needs assessment on the number of people with brain injury in the state, and the needs, services, and potential gaps for this population. Citing that

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[78] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

[79] Schulte, R., Haglund, J., Victoria-Gray, E., Gion, D., & Vogeltanz-Holm, N. (2021). Acute psychiatric and residential care final report.

[80] U.S. Centers for Disease Control and Prevention (2022, March 21). Get the facts about TBI.
[81] U.S. Centers for Disease Control and Prevention (2022, November 14). Moderate and Severe TBI.

report, applying the Centers for Disease Control and Prevention (CDC) prevalence estimates to North Dakota, an estimated range of 8,872 to 14,695 people with TBI live in the state.[82] The CDC has not refined or updated prevalence estimates since 2015. The CDC does gather annual data on TBI-related hospitalizations: In 2019, 223,135 individuals across the country were hospitalized for TBI-related injuries.[83] North Dakota's population represents approximately .23% of the nation's population. Applying .23% to the number of inpatient admissions, North Dakota would experience an estimated 513 individuals hospitalized for TBI-related injuries each year. Additional factors relevant to North Dakota include[84]:

- In 2019, American Indian or Alaska Native (AI/AN), Non-Hispanic persons had the highest average annual age-adjusted rate (23.1 per 100,000 population in 2019) of TBI-related deaths when compared to other racial and ethnic groups.
- Age-adjusted rates of TBI-related deaths per 100,000 population were second highest among people residing in the Midwest, 17.7 in 2019.

In the 2021 Executive Budget, funding for services and programs for individuals with TBI were cut reportedly due to anticipated Medicaid coverage for 1915(i) services. Some of the funding was restored, but given that services and state general funding for TBI services were reported as serving a fraction of the estimated population in need before the cuts, there are even fewer supports currently available. The North Dakota Brain Injury Network pre-vocational program and the Return to Work program experienced a combined reduction of a quarter-million dollars.[85] North Dakota no longer has a waiver targeted specifically for individuals with TBI.

According to legislative testimony, North Dakotans with TBI who also have a comorbid SMI/SUD encounter barriers to accessing wraparound case management and skills training services, while behavioral health services that support persons with TBI are scarce and disjointed.[86]

Services to Support Adults with Autism

Medicaid State Plan, waiver and voucher coverage for autism services is limited to children in North Dakota. Many adults in need of services do not meet eligibility criteria for ID/DD waiver services. According to state staff, an estimated 50 percent of individuals served at the Transition Center are adults and youth with Autism Spectrum Disorder.[87]

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[82] Report to the North Dakota Department of Human Services, Behavioral Health Division *and* North Dakota Center for Persons with Disabilities (2016). North Dakota Brain Injury Needs Assessment: Final Report.
[83] U.S. Centers for Disease Control and Prevention (2022, November 14). Moderate and Severe TBI.
[84] Centers for Disease Control and Prevention (2022). Surveillance Report of Traumatic Brain Injury-related Deaths by Age Group, Sex, and Mechanism of Injury—United States, 2018 and 2019. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.
[85] Mental Health Advocacy Network (2021). HB 1012 – Behavioral Health [testimony].
[86] Mental Health Advocacy Network (2021). HB 1012 – Behavioral Health [testimony].
[87] Mental Health Advocacy Network (2021). HB 1012 – Behavioral Health [testimony].

SUD Voucher Program

The Department reports that participation in the SUD Voucher program varies greatly across Human Service Centers, from 1.1 percent in Region 8 to 41.2 percent in Region 5. As of July 1, 2020, new individual and provider applications were suspended due to exhausted appropriations.[88] The Division of Behavioral Health continued to fund services for individuals who were in the program, serving 456 individuals as of January 11, 2021. From February 6 to December 11, 2020, 30.6 percent of expenditures were attributed to Partial Hospitalization and Residential Group Therapy services; only 0.3 percent of expenditures were attributed to Recovery Coaches or Peer Support.[89]

Paid Family Caregivers

As of November 2020, North Dakota and Hawaii were the only two states in the nation that did not have Paid Family Caregiving in Self Directed Programs for adults ages 65+ and adults with physical disabilities.[90] While Aging Services has started paying families of Target Population Members (TPMs) as caregivers to help address the direct service provider crisis, families of individuals not covered under the Settlement Agreement, for example individuals with I/DD, are not eligible to be paid caregivers.

Affordable, Accessible Housing

The cost of safe, stable housing in North Dakota is below the national average but is out of reach for individuals with disabilities with the lowest incomes. According to TAC's *Priced Out: The Housing Crisis for People with Disabilities* interactive web page, in 2022, a North Dakotan with a disability receiving SSI would have to pay 83 percent of their income toward rent for a one-bedroom apartment at the federal fair market rent established by the U.S. Department of Housing and Urban Development (HUD).

North Dakota provides rental assistance, landlord risk mitigation programs, and Housing Supports under the 1915(i) SPA. However, these resources are limited in their ability to help North Dakota's most vulnerable residents given the lack of affordable, accessible housing available to people experiencing homelessness and individuals with disabilities. Affordable, accessible housing is a critical support for individuals to live as fully included members of their communities.

HHS estimates that there are 3,000-4,000 homeless households throughout the state and that roughly 30 percent of those households have children under the age of five. In addition, people with disabilities in institutional settings are in need of housing in order to transition to the community: an estimated 100 individuals in state-run institutions; 2,800 people in nursing homes who have low level of need and could transition to the community; and an estimated 600 individuals in ICFs.

In 2021, HHS decreased funding for the Cooper House, LaGrave on First, Prairie House, and Gerridees Place supported housing programs. Advocates speculated that the Department anticipated the housing

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[88] North Dakota Department of Health & Human Services: Substance Use Disorder Voucher.
[89] North Dakota Department of Health & Human Services: Substance Use Disorder Voucher.

[90] Longtermscorecard.org (2020) Long-Term Services and Supports Scorecard *and* U.S. Centers for Medicare and Medicaid Services (n.d.) Emergency preparedness and response for Home and Community Based (HCBS) 1915(c) waivers.

support services would be covered under the newly approved 1915(i) SPA. Unfortunately, that was not the experience as many of the individuals served in these programs were not eligible for support under the SPA. The legislature did restore part of the decreased funding, but crucial housing support services are not sufficiently funded for non-Medicaid-eligible individuals.[91] Using new funding to expand scattered site PSH is important, but reducing project-based PSH programs before alternative units are available will only add to the housing crisis for people with disabilities.

Supported Employment

Family members reported their opinions that many providers are not oriented to supported employment or to asking people with disabilities if they want to work, and instead assume that they cannot or don't want to work. When individuals with disabilities are employed, families report the jobs are limited to working in fast food restaurants or stocking shelves. There is a need for more creative job development and the promotion of people with disabilities as viable workers. The Council on Developmental Disabilities has used its Facebook page to create a public awareness campaign, but agrees that more can be done to continue to change the perception that people with disabilities can't work.

Transportation

There is little to no non-emergency medical transportation to assist individuals who live in the community to access basic things like grocery shopping or attending worship services. Reportedly, private transportation companies have few accessible vehicles. Uber exists in many communities but there are not enough drivers with vehicles that can accommodate people with disabilities. Transportation is lacking for people who live in residential settings as well, due to staff shortages. Stakeholders reported that residential staff must remain onsite to ensure that ratios adhere to regulations, and therefore can't transport people offsite.

The lack of access to stable housing, employment, and other upstream services both increases the risk that a person will experience a behavioral health crisis, and negatively affects their ability to recover from one.[92]

In 2019, the Department of Transportation (DOT) developed a statewide transportation plan called "ND Moves." This plan is intended to serve as a guide and a resource in the development of state and local transportation systems and programs.[93] [94] Meetings were held around the state to gain input for the

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[91] Mental Health Advocacy Network (2021). HB 1012 – Behavioral Health [testimony].

[92] Martone, K., Arienti, F., Gulley, J., & Post, R. (2022). *The role of supportive housing, case management, and employment services in reducing the risk of behavioral health crisis*. Technical Assistance Collaborative Paper No. 8. Alexandria, VA: National Association of State Mental Health Program Directors.

[93] North Dakota Department of Transportation (n.d.) Statewide public and active transportation plan. Retrieved November 30, 2022.

[94] North Dakota Department of Transportation (n.d.) Statewide public and active transportation plan. Retrieved November 30, 2022.

transportation plan. Participants were asked to identify the most significant barriers in accessing transit systems in their areas. Stakeholders reported that there was not enough funding or prioritization for public transit, that bus services were too infrequent to meet the needs, and that in some communities there was no transit service. The DOT's findings indicated that mobility was a top issue for most people with disabilities and that it often determines the extent to which they can participate in the community and retain employment. DOT indicated they found no clear geographic pattern that emerged in the analysis of transit as it relates to people with disabilities.[95]

System Challenges

Stakeholders participating in the listening sessions and online survey shared perceptions about several challenges in supporting individuals with disabilities to live as inclusive members of their communities. The needs most often identified were:

- Increased staffing in community-based service settings
- Improving the adequacy of crisis response services, particularly for children and youth, and for adults across the state (not just in urban areas)
- Training providers to care for persons with higher levels of need

While TAC's assessment concurs that North Dakota is faced with these challenges, we also identify others below that are negatively affecting the state's ability to support individuals with disabilities in the community.

Workforce Crisis

Stakeholders identified the lack of adequate staffing in community-based service settings as the greatest challenge for North Dakotans with disabilities. This perception is consistent with compliance issues with the Settlement Agreement. Workforce issues are not new to the state or isolated to the Settlement Agreement; North Dakota has had shortages of mental health professionals for years. Currently, Ward, Morton, Burleigh, Grand Forks, & Cass are the only counties in North Dakota that are not Mental Health Professional Shortage Areas.[96] Examples of the impacts of the shortage of direct service workers include:

- Individuals and families report that even after QSP services are approved, they are unable to receive services due to their inability to find an available provider.
- Critical Access Hospitals have reported issues with their inability to admit people with complex needs and to connect admissions to aftercare services as a result of staff shortages.[97]

[95] North Dakota Department of Transportation (n.d.) Statewide public and active transportation plan. Retrieved November 30, 2022.

[96] University of North Dakota School of Medicine & Health Sciences, Center for Rural Health (n.d.). North Dakota mental health professional shortage areas.

[97] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

- HHS reported the Life Skills and Transition Center cannot meet census reduction targets because of continuous pressures to support high-acuity individuals as provider of last resort.[98]
- I/DD service providers report a workforce shortage for their direct care workers; providers are unable to accept or to continue serving high-acuity individuals, especially individuals with dually-diagnosed behavioral health concerns, because of their inability to properly staff.

The human services system is largely dependent on staff to deliver services, from clinical and medical professionals to aides and paraprofessionals. Like every other state in the country, North Dakota is experiencing this national workforce crisis.

In addition to the Aging and Adult Services Division's workforce efforts, the Behavioral Health Division and MFP program are supporting Human Services Research Institute's (HSRI) continued implementation of the 2018 behavioral health study. Aim 7 of the 13 areas for improvement is to *Engage in targeted efforts to recruit and retain a qualified and competent behavioral health workforce*.[99] HSRI is moving forward with proposals to increase staff recruitment and retention. These proposals should help to address the behavioral health worker shortage, though they are reportedly not as well-funded as Aging Services' workforce efforts. A local initiative the stakeholders identified as having promise is the Peer to Peer Disability Leadership Class in the Bismarck Public Schools. Reportedly the class has generated a 60-percent rate of students entering a disability-related field.

Adequate Funding

Stakeholders had different perceptions about the need for funding. While many indicated the need for additional funding, others suggested that existing funding would go further if it were spent on different services. A few stakeholders reported that some programs actually return funds at the end of the year.

There are reported state funding shortfalls referenced in this report as a result of implementing Medicaid coverage for the 1915(i) services. Examples include Housing Supports and Supported Employment for individuals with mental health disorders, and vocational services for individuals with TBI. Per the HHS Savings Plan, $4 million in state funding for these services was cut in anticipation of federal Medicaid revenues, however Medicaid revenue was not generated to the degree anticipated; as of November 2022, 240 people were enrolled with 64 receiving 1915(i) covered services. Stakeholders expressed concern that the funding has yet to be "right-sized" due to the slow uptake of participating providers and eligible service recipients.

Implementation of Study Recommendations

The legislature continues to fund multiple studies on the services provided in North Dakota. TAC reviewed studies and recommendations on mental health services, I/DD services, autism services for children, and EPSDT screening for children and youth. Yet there appears to be little impact on the system as a result of these research efforts. Stakeholders consistently expressed frustration that

[98] Olmstead Commission testimony from Jessica Thomasson and Tina Bay.
[99] Human Services Research Institute (2022). North Dakota Behavioral Health Plan – Project Dashboard July 2022.

recommendations, clearly supported with data, are not implemented. There is little benefit to funding studies unless there is a willingness to follow through with recommendations.

Compliance with the Settlement Agreement

According to the DOJ subject matter expert (SME), North Dakota has made progress but is struggling with elements of the Settlement Agreement.

Case Management Capacity

Thirty percent of a case manager's time is spent on administrative functions, leaving 70 percent of their time for direct service.[100] Beginning in June 2022, the state must assign a case manager to every TPM, which increases the concern regarding case management capacity.

Cultural Competence

Cultural competence is key when working with Native American communities. Stakeholders have indicated to the DOJ and the SME that case managers need to be more culturally sensitive when working with members of tribes and that the person-centered planning process needs to better address cultural issues. In October 2021, training in cultural sensitivity for case managers was offered by the state. All 65 Settlement Agreement case managers have completed the training.

Person-Centered Planning

The Settlement Agreement, in Section VIII.I.3.a, required the state to complete person-centered planning (resulting in a comprehensive Person-Centered Plan that meets all the requirements listed) with 290 TPMs by the end of the first year (December 14, 2021), based on the effective date of the agreement. At least half of the Person-Centered Plans required to be completed (145) were with TPMs in skilled nursing facilities and at least another half with those at risk of going to a skilled nursing facility. The state did not meet this benchmark in year one, and has developed a schedule for the completion of fully compliant Person-Centered Plans to achieve or largely achieve the benchmarks established for both year one (290) and year two (an additional 290).[101]

Environmental Modifications

Environmental modifications have been identified by Aging Services as one of the significant gaps in the provision of housing to TPMs returning to community settings. State personnel have indicated that it is easier to complete home modifications through the MFP program, which can directly reimburse contractors for work that needs to be done and is completed. However, Aging Services must follow Medicaid requirements for those delivering such services to be providers so they can bill and be paid through the Medicaid Management Information System (MMIS). Reportedly, contractors are interested in entering into long-term agreements for this type of work rather than billing by the job as is necessary through MMIS.

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[100] ND.gov. (2022). North Dakota settlement agreement report of the subject matter expert, March 2022.

[101] ND.gov. (2022). North Dakota settlement agreement report of the subject matter expert, March 2022.

Data Collection

The Settlement Agreement, in Section XV, discusses requirements for North Dakota to enhance its data collection system for TPMs in Section XV.A and generate summary/aggregate data (Section XV.B) about the number of at-risk TPMs, skilled nursing facility TPMs, and those that have transitioned to the community. The interfaces for this information are complex, as four data systems are involved for assessment data, clinical data, service authorizations, electronic visit verification information, and claims data: Therap, Wellsky, the North Dakota Health Information Network, and MMIS. These data systems remain separate, and much of the data provided in the most recent Biannual Report by the state continues to be tracked manually outside of these interfaces, particularly as it relates to the assignment of case managers.

Services to Children with Autism Spectrum Disorder

Identifying children in need of Autism Spectrum Disorder (ASD) services is a concern in North Dakota, in part as a result of the low rates for EPSDT screening and follow-up participation in services. Another concern of importance to North Dakota is the under-identification of ASD among AI/AN children. A 2009 University of Minnesota study reported that AI/AN children with autism are 13 percent less likely to be identified than white children with the disability.[102]

North Dakota's ASD waiver covers limited services. TAC subject matter experts observed that waiver services necessary to support youth with ASD include Family Partner/Peer Support; Care Coordination, one of the biggest areas of need for families in order to access the multiple systems and agencies often needed to serve youth with ASD; and Assistive Technology for non-dedicated devices, to maximize the benefit by 'normalizing' use. In addition to its limited benefit, there is a waitlist for the ASD waiver capped at 150 slots.

North Dakota's IID/DD waiver offers strong support for children under three; however, stakeholder interviews and data analysis indicate there is a significant drop-off in services to children after age three, when young children still do not yet have access to additional school supports. Ninety-one percent of waiver participants who turned three during the 2018-2021 sample period did not continue beyond their third birthday (mix of denials and families who chose not to continue services). According to interviews with state staff, the ID/DD waiver regularly shows significant year-to-year turnover, with around 800 to 900 people moving off yearly, many of whom are age three.[103] Funding for the Autism Voucher program was eliminated in the 2021-23 legislative session, but was partially restored by the Senate, reduced from $1.3 million to $300,000.

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[102] Sullivan, A. (n.d.) Racial disproportionality in school-based identification of autism. Minneapolis, MN: University of Minnesota College of Education & Human Development

[103] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

Services to Individuals with I/DD

As stated earlier in this report, North Dakota currently spends more than its peer states and the national average on supporting people in ICF/IIDs and less per person on IID/DD waiver services.[104] In 2020, the North Dakota State Council on Developmental Disabilities contracted for a comprehensive review and analysis (CRA) of North Dakota's services, supports, and unmet needs in the intellectual and developmental disability (IDD) service system. The report focused on 1) Health and Healthcare, 2) Employment, 3) Education and Early Intervention, 4) Transportation, 5) Child Care, 6) Housing, 7) Informal and Formal Services and Supports, and 8) Recreation. System Challenges for individuals with I/DD identified in the report included but were not limited to:[105]

- Over 4,500 North Dakota residents with disabilities were uninsured
- The low number of MFP transitions for people with IDD (156 between 2007-2012)
- 33% of people with a cognitive disability live in poverty in ND
- 35% of alleged ADA violations are due to lack of accommodation
- Poor educational outcomes for students with IDD

Stakeholders and previous reports such as the "North Dakota Developmental Disabilities Study Report and Oral Presentation" by Alvarez & Marsal also note that the ID/DD eligibility process creates a barrier to services.[106] The process involves two discrete steps, qualification of an ID/DD diagnosis and determination of meeting ICF/IID level of care. Reportedly, level of care assessments are made regionally and there are differences in outcomes by region. TAC supports state officials in their efforts to transition to a more centralized system.

Currently, by regulation, North Dakota has a 1:60 ratio for developmental disabilities case management. This caseload size is far too large to provide meaningful, person-centered support. In addition, services are provided by state staff referred to as Program Managers. As a result of the current workforce shortage, the Department is using temporary employees to meet the required ratio. This increases the risk of turnover, disrupting continuity of relationships and knowledge base for people and their families. For employees, there is an inequity in that temporary employees are doing the same job as their state-employed peers but receiving lower pay and fewer benefits.[107]

Finally, the ability to self-direct is very limited, and the approach in North Dakota is not consistent with CMS' approach. TAC recognizes that individuals can be hired as QSPs, which may mirror a Self-Direction approach. However, these individuals must complete a rigorous process similar to agency providers, and

[104] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

[105] A Report to the North Dakota State Council on Developmental Disabilities, Comprehensive Review and Analysis for the 2022 – 2026 State Plan, Joanne Hoesel, May 2020.

[106] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

[107] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

the state still has to qualify them, which restricts the pool of QSPs and inhibits the benefits of self-direction.

Services to Individuals with Behavioral Health Disorders

Reliance on Long-Term Care Facilities

The in-depth analysis conducted by HSRI found that many individuals with behavioral health needs are receiving care in long-term care facilities, a majority of which are specifically designed for older adults.[108] Approximately 24 percent of individuals who received a behavioral health service in a long-term care facility in FY 2017 were under age 65.[109] In addition, gero-psych beds do not meet the needs of older adults with SMI; nursing home regulations prohibit the use of some medications and treatments required by individuals with psychiatric conditions. Reportedly, facilities that follow best practice care for this psychiatric level of need are fined or otherwise penalized based on the current regulations.

Case Management

HHS is focusing on options for how to change case management, both to assure adequate case-management resources while also addressing the independence of case managers from providers of other services as currently required under the 1915(i) SPA. The state employs over 800 case managers and the Human Service Zones have an additional 950 case manager positions. Within the Human Service Zones, case managers work primarily in child welfare, with additional case managers working in the regional HSCs.

Requiring separate, specialized case managers for each service or program an individual with complex needs receives is inefficient and difficult to staff in most parts of the state. Moving to a "generalist" case manager approach could help to alleviate staff shortages and increase access to services.

Low Utilization of 1915(i) Services

Both provider enrollment and recipient participation in 1915(i) services have been low. According to HHS's November 2022 report, provider participation was limited to 38 group providers and 126 individual providers.[110] According to that report, of the 240 Medicaid recipients enrolled to receive 1915(i) services, only 54 received Care Coordination and 10 received Peer Support services through August 2022. In its application to CMS, the state projected serving over 11,000 individuals annually.

HHS has identified a number of challenges the agency has faced in implementing the SPA.

- The requirement for **conflict-free case management** has been a barrier for implementation in the state, where provider capacity has been a historical problem. One of the largest providers of 1915(i) services elected to enroll as a provider of Care Coordination, prohibiting the agency from providing services such as Supported Employment and Peer Support to Care Coordination

[108] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

[109] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

[110] North Dakota Department of Human Services (n.d.) 1915(I) Enrollment and Service Delivery Report.

recipients. Other providers of these services are limited or nonexistent. HHS reports that the agency has submitted to CMS an amendment to the SPA that will help alleviate the need for conflict-free case management in all but the four most urban communities.

- **Eligibility criteria** for the services has been a challenge. Stakeholders provided feedback to HHS that the original WHODAS score for adults was too high. The Department responded by reducing the score from 50 to 25. The Department is also considering revising eligibility criteria for children to increase access to services. HHS observes that providers were at different stages of readiness to implement the new services. Nontraditional Medicaid providers did not have the knowledge or administrative infrastructure to enroll in the Medicaid program or to bill successfully for services. Many providers were historically grant-funded and needed to alter their business models to adapt to unit-of-service funding. The Department is devoting staff to provide technical assistance and training to providers.

Adequacy of Providers/Administrative Complexities

State officials and prior reports also note that the process for enrolling providers is cumbersome. One example stakeholders consistently shared is QSPs. Even MFP program staff reported that administrative complexities create barriers to having sufficient QSPs. The HHS requirement that only agencies can provide 24 hours of service per day precludes individual providers from offering this intensity of services. In addition, there are reported challenges with the two vendors under contract to process QSP applications.

Administrative complexities are reportedly contributing to the lack of providers for 1915(i) services. Though there are some group providers, the majority are individuals required to enroll as qualifying staff. Receipt of verbal versus written guidance for service delivery, lack of a written explanation for rejected claims, and the administrative costs and burden associated with reimbursement based on quarter-hour units of services were identified as reasons that many small providers in North Dakota are not willing to enroll in Medicaid, contributing to the lack of providers for these crucial community integration services and supports.[111]

The referral process for children and youth in need of referral for and admission to treatment was described by stakeholders as overly burdensome, causing delays in identifying children and youth.[112] Indigenous children with a medical diagnosis and assessment already completed by a qualified Indian Health Service professional are required to secure an additional assessment by the state before the child can receive services. This reportedly causes delays in transfer to appropriate care and treatment for the child, who is often in crisis.[113]

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[111] Obtained during 1915(i) service provider interview.

[112] Schulte, R., Haglund, J., Victoria-Gray, E., Gion, D., & Vogeltanz-Holm, N. (2021). Acute psychiatric and residential care final report.

[113] Schulte, R., Haglund, J., Victoria-Gray, E., Gion, D., & Vogeltanz-Holm, N. (2021). Acute psychiatric and residential care final report.

Disparities in Access to Services

Studies reviewed by TAC report disparities for LGBTQ2S+ youth and adults, Native Americans, and justice-involved individuals. Tribal children and families reportedly struggle to navigate the referral assessment requirements as described above.[114] Multiple tribal groups reported the lack of culturally appropriate services. LGBTQ2S+ youth and adults and Native Americans reported experiencing provider stigma, discrimination, and a lack of culturally sensitive services.[115]

One report found that Indigenous populations are overrepresented in HSC service settings, Medicaid data, and in child welfare and criminal justice settings, compared to census estimates.[116] Justice-involved individuals with behavioral health conditions face stigma and resistance from community-based programs, and some are sentenced for low-level crimes solely to gain access to treatment denied in the community.

Data reported by the Behavioral Health Division indicates that Native Americans represent 15.8 percent of the total number of service recipients, compared to the U.S. average of 1.8 percent. The Native American penetration rate per 1,000 population is also higher in North Dakota (53.7 percent) than in the Midwest Region (50.2 percent) and the U.S. (34.7 percent).[117] This data suggests that the rate of Native Americans receiving behavioral health services in North Dakota is high, but does not differentiate if the services received are community-based or state-hospital-based. Table 12 below does indicate that re-admission rates for Native Americans to State Hospital civil beds are higher in North Dakota than the national average. Readmission of almost one in three Native Americans within 30 days of State Hospital discharge, and one in two within 180 days of discharge, could be interpreted as indicating the lack of connection to community-based services and supports.

Table 12. State Hospital Civil Bed Readmission Rates for Native Americans in North Dakota and the U.S.[118]

Readmission periods	North Dakota	U.S.
Readmissions within 30 days	29.1%	10.4%
Readmissions within 180 days	50.5%	24.2%

[114] Schulte, R., Haglund, J., Victoria-Gray, E., Gion, D., & Vogeltanz-Holm, N. (2021). Acute psychiatric and residential care final report.

[115] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

[116] Human Services Research Institute (2018). North Dakota Behavioral Health System Study: Final Report.

[117] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

[118] U.S. Substance Abuse and Mental Health Services Administration. 2020 Uniform Reporting System (URS) Table For North Dakota.

Use of Data to Drive Systems Change

Major gaps in data collection and usage serve as a systemic barrier to understanding service utilization, needs and outcomes, and making measurable progress toward targets in the state's service systems. HHS does not have an integrated and standardized data management system that incorporates all service data. In addition to the lack of data on the provision of services, there is little data on outcomes. The SUD Voucher program is an exception.

Other examples of how data has been used to impact services are related to Medicaid expansion. According to the 2021 External Quality Review report, the managed care organization conducted two performance improvement plans (PIPs) per requirement of the North Dakota Medicaid Expansion Quality Strategy.[119] PIP topics included follow-up for mental health. For Measurement Year 2020, Sanford Health Plan received an overall validation score of 83 percent for Follow-Up for the Mental Health PIP. Sustained improvement was demonstrated in the mental health PIP's Engagement of Alcohol or Other Drug Treatment performance measure.

The 2021 External Quality Review report also noted that "opioid dependency infiltrated the North Dakota Medicaid Expansion population in 2017 and increased in an alarming and rapid rate in 2018."[120] Based on the results, HHS contracted with Qlarant to spearhead a focused study solely on opioid dependency among North Dakota Medicaid expansion enrollees. The objective was to explore and attempt to identify aspects that could lead to the prevention of continued upward trends in opioid dependence within the Medicaid expansion population and fight the public health emergency effectively. Data showed that the opioid dependence rate per 1,000 Medicaid managed care enrollees continued to rise. However, data was utilized to identify initial problems that needed to be addressed and to focus attempts on slowing the steady rise.

[119] Qlarant (2021). North Dakota Medicaid expansion program annual technical review report measurement year (MY) 2020. North Dakota Department of Human Services.
[120] Qlarant (2021). North Dakota Medicaid expansion program annual technical review report measurement year (MY) 2020. North Dakota Department of Human Services.

Chapter 5: Recommendations

It is clear that North Dakota has developed initiatives and identified funding sources intended to serve people in integrated settings in the community. Many of the findings and recommendations in this report will require bold and sustained action to develop a system that prioritizes community integration. It is also important to recognize that an Olmstead Plan should be a document that is implementable, and will be revisited periodically to build from successes, learn from failures, and adapt to changing circumstances. Based on the information and data presented throughout this report, knowledge of best practices, and the Technical Assistance Collaborative's (TAC) experience with states and systems across the country, this chapter identifies a series of recommendations for the Olmstead Commission to consider in the development of an initial, comprehensive Olmstead Plan. As the Commission considers which recommendations to incorporate into its Olmstead Plan, these recommendations should be refined to be more specific.

Stakeholders were asked to identify their recommendations for improving the services and systems that support individuals with disabilities in North Dakota. The top three recommendations from stakeholder groups were:

- Secure more state and/or federal funding.
- Provide a more comprehensive array of community-based treatment, therapeutic services, and supportive services that are appropriate to levels of care needed.
- Provide more opportunities for stakeholders to participate in/contribute to systems change.

TAC has organized its recommendations under three themes. These recommendations will be further informed by the *Olmstead* Commission as the actual plan development phase begins.

- Ensure that individuals with disabilities have access to the individualized array of community-based services and supports they want and need to live as integrated members of their communities.
- Increase access to integrated housing and community-based services through new resources and repurposed funding transferred from institutional and segregated settings.
- Address systemic challenges and eliminate barriers to services that support individuals to live meaningful lives as integrated members of their communities.

Access to Community-Based Services and Supports

Recommendation 1: Build on the Strengths of the Current System

North Dakota has elements within its service systems that are vital to community integration. The key will be to fully implement those elements across the systems that serve individuals, regardless of their disability or their level of need, to create a strong foundation for transitioning to and living successfully in the community.

1A. Build on successes in the Money Follows the Person program.

North Dakota should take steps to ensure that transition-related activities and services currently being provided through the Money Follows the Person (MFP) grant are integrated into the entire system of programs and services. This includes typical transition services such as paying for furniture and deposits, but also time-limited rental assistance. It is vital that these services continue beyond the MFP grant. The MFP administrator should identify barriers for people, for example individuals with I/DD, contributing to their low utilization of the MFP transition funds.

1B. Build on efforts and lessons learned from the Settlement Agreement.

North Dakota has made positive changes within its Aging Services system in order to meet requirements of the Settlement Agreement. While some of these changes may have resulted from additional funding, based on TAC's experience working with other states, some system changes can be made without additional funding. Likewise, these or similar changes to services and systems that support individuals with other disabilities can and should be implemented. Other systems can also benefit from lessons learned by other agencies under the Settlement Agreement, which can serve to mitigate further litigation.

Recommendation 2: Increase the Use of Evidence-Based and Promising Practices

Like many states across the country, North Dakota continues to use its limited resources to fund services and programs that lack efficacy. TAC encourages HHS to continue and to grow its efforts to increase evidence-based and promising practices for individuals with disabilities.

2A. Adapt evidence-based practices for rural communities.

Some systems are adapting evidence-based practices (EBPs) for rural communities. Oregon has adapted its Assertive Community Treatment (ACT) teams for rural and tribal communities through a Center of Excellence. The Oregon Center of Excellence for Assertive Community Treatment provides training and technical assistance to support new and existing ACT programs to equip care providers with knowledge and tools that support positive changes in the lives of the people they serve, including in rural areas.

2B. Support providers to pursue status as Certified Community Behavioral Health Centers.

Work with providers to pursue status as Certified Community Behavioral Health Centers (CCBHCs), the national gold standard of integrated behavioral health and primary care with a proven track record of improving health outcomes nationwide. Neighboring states including Iowa, Minnesota, Montana, and Nebraska have CCBHCs.[121]

2C. Leverage Cost-based Payment Systems

Explore opportunities to leverage the cost-based prospective payment systems (PPS) allowed for safety net providers such as Federally Qualified Health Centers and Rural Health Centers. PPS can provide more

[121] National Council on Wellbeing (n.d.). List of CCBHCs by state and counties.

adequate funding for a wide range of health and health-related services while putting the state in a position to both require and support the expansion of EBPs.

2D. Target Funding for Data Driven Approaches

HHS should target Medicaid and non-Medicaid funding to support best practices, promising practices, and evidence-based services, based on data that shows their effectiveness. HHS should strengthen providers' contractual language regarding the use of EBPs, incorporating research-based outcome measures.

2E. Adapt EBPs to Better Meet the Needs of Tribal Communities

Promote adaptations of EBPs to better serve tribal communities.

Recommendation 3: Eliminate Gaps in Community-Based Services

As described earlier in this report, North Dakota offers a robust service array, but addressing gaps in these services could reduce reliance on institutional care for individuals with disabilities.

3A. Address the age-related and diagnosis-related gaps in services for people with intellectual and developmental disabilities.

TAC supports North Dakota in consolidating Home and Community Based Services (HCBS) waivers that exclusively serve children into a cross-disability children's waiver and modernizing Level of Care criteria, both recommendations from the Alvarez and Marsal study.[122] Louisiana was able to improve access to services by consolidating four separate ID/DD waivers into one "tiered" waiver.[123] The state adopted a nationally recognized tool used to screen applicants for urgency of need. Those with the greatest need have timely access to more comprehensive services. In North Dakota, legislation has been drafted to create a cross-disability advisory council intended to participate with and provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver and level of care reform for the comprehensive developmental disabilities Medicaid HCBS waiver.[124] TAC recommends that to avoid further delay, creation of such an advisory council occur simultaneously with implementing waiver consolidation.

3B. Enhance capacity to serve higher-need individuals in more integrated settings.

Both the Alvarez & Marsal study and the Report of the Subject Matter Expert for the Settlement Agreement noted the need to have more services designed for persons with high and/or complex care needs. HHS is piloting some services for I/DD using American Rescue Plan Act (ARPA) HCBS funds. The Department also recently began a service that can provide 24-hour care in a non-institutional setting for individuals who are aging with physical disabilities. TAC recognizes this need and recommends that HHS seek to expand and continue these efforts, including seeking funding when ARPA funds expire. TAC also

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[122] Alvarez & Marsal (2022). North Dakota Developmental Disabilities Study Report and Oral Presentation.

[123] Louisiana Department of Health (2018, April 30). Update: Louisiana Department of Health eliminates waiting list for those with developmental disabilities.

[124] Bill introduced by Senator Hogan

recommends these efforts be part of a larger effort to examine the service package in HCBS waivers to ensure the ability to serve higher-need individuals.

3C. Ensure that services meet the needs of individuals with all disabilities.

Stakeholders noted people with specific disabilities who they felt lacked access to effective services due to eligibility rules or to limitations on the service package. Examples included persons with cerebral palsy, other developmental but not intellectual disabilities, and persons with brain injuries. HHS should examine whether current programs and services are meeting these needs.

Consider the use of out-of-state/cross-border providers to expand provider capacity, for example, treatment providers that specialize in serving children and adolescents.

Address regional variations to ensure that people with disabilities receive needed services regardless of where in the state they reside. Examples include I/DD level of care assessments and use of the SUD Voucher program.

TAC supports HHS in exploring options for expanding the ability of case managers to serve more than one population. Case managers could have access to consultation on how to support individuals with co-occurring needs using the Project ECHO approach. Cross-training and the use of learning collaboratives are additional resources to expand case managers' competencies.

TAC supports the Alvarez & Marsal report recommendations that the state fund the cost of eligibility assessments for families seeking I/DD services and that HHS pursue Medicaid Administrative claiming for these costs.

Expand the coverage for Community Transition Supports beyond move-in and household establishment for persons transitioning from Medicaid institutions to also cover individuals transitioning from other settings or situations such as incarceration, homelessness, aging out of foster care, or loss of housing due to natural disaster or other events.

In the case of brain injury, TAC does not have sufficient detailed information to comment on the need to revisit a waiver targeted to this population, however, Iowa offers a comprehensive package of services in its TBI waiver for consideration. At minimum, TAC recommends that state policies should acknowledge individuals with TBI as a population with distinct needs. To identify gaps, HHS should cross-walk services provided in North Dakota with TBI-specific service definitions and therapeutic interventions that reflect best and promising practices for treating, serving, and supporting individuals with TBI in community settings.

3D. Consider dedicating revenues to fund HCBS services for non-Medicaid-eligibles.

Government policies and philosophies toward dedicated funds vary widely from state to state. Nevertheless, such funds can be a way to increase spending on HCBS without negatively impacting existing providers. TAC recommends that the state examine and consider options in this area. As examples, ten states (Alabama, Arizona, California, Florida, Georgia, Kentucky, Louisiana, Massachusetts, Tennessee, and Texas) have brain and/or spinal cord injury trust funds that fund services to this population and in some cases may match federal dollars. These are often funded by surcharges on

traffic tickets.[125] As another example, Louisiana has a law that requires that a certain percentage of any excess state revenue during a fiscal year be deposited in a fund used to support I/DD services.

3E. Expand the use of technology.

States across the country, especially in rural communities, are expanding the use of technology to engage people and ensure access to services — from the provision of consultations in EDs to direct services by ACT teams, permanent supportive housing (PSH) programs, and case management. States are identifying resources to ensure that people have actual phones/tablets and internet access. HHS should evaluate the potential, for example, of Oklahoma's approach to using technology to respond to crises/ED visits.

The state will also need to develop strategies to expand broadband access, as this infrastructure is necessary to support the use of innovative technology.

3F. Provide services in non-traditional settings.

An additional strategy is to make services available for people in rural communities at locations where they can access the internet services, for example a library in a rural community.

Recommendation 4: Increase Access to Affordable Housing for Individuals with Disabilities

Both the risk of crises and the costs associated with recurrent service utilization can be reduced by helping individuals who frequently use EDs, psychiatric and medical inpatient units, and other emergency services to instead quickly access PSH.

4A. Quantify the Need

TAC was not able to secure data on the need for PSH and other types of supported housing in North Dakota. We recommend conducting a PSH needs assessment, if one has not been done recently, to inform solid funding requests for the creation of additional units. If the state is not prepared to conduct a more formal needs assessment, TAC offers for consideration a methodology that has been used in other states.

4B. Facilitate and expand coverage for housing supports.

Facilitate use of 1915(i) services by simplifying requirements and reducing administrative burden for providers. Challenges to be addressed include:

- Address challenges with provider enrollment.
- Allow agency enrollment rather than requiring each individual staff member to enroll.
- Clarify state policy and guidance in writing to avoid varied interpretations of staff qualifications and experience.
- Reduce administrative burden by replacing the quarter-hour unit of service reimbursement with a daily, weekly, or monthly rate.

[125] Relias Media (2022, November 23). 10 states now have TBI trust funds.

4C. Ensure consistent coverage for housing supports.

HHS should expand coverage of tenancy supports under Medicaid for individuals with I/DD and physical disabilities by strengthening covered benefits in applicable HCBS waivers.

4D. Implement training and certification that supports best practices.

In implementing and expanding housing supports, the state should ensure that provider training and certification requirements address the fundamentals of tenancy support, consistent with fidelity to PSH as an EBP.

Recommendation 5: Increase Competitive, Integrated Employment Opportunities

5A. Increase the use of supported employment.

Continue to increase the use of supported employment with the focus on decreasing and eliminating the use of sheltered employment settings.

5B. Better align DVR and Medicaid-covered employment services.

While DVR may initiate and fund the vocational assessment for individuals with SMI who are seeking competitive, integrated employment, upon determination that an individual is interested in and eligible for supported employment, a prompt referral should be made. Individuals should be referred for Individual Placement & Support/Supported Employment (IPS/SE) using Behavioral Health Division funding if they are not Medicaid-eligible.

5C. Continue to promote people with disabilities as viable candidates for employment.

Given the workforce shortages faced in all sectors, people with disabilities across the country are experiencing more opportunities for job interview and employment. Connecting employers with potential employees is key.

Increase access to integrated housing and community-based services

To rebalance a system in order to better support community integration requires both new and repurposed resources. Stakeholders identified the need to approach the North Dakota legislature for funding but expressed uncertainty that the legislature would allocate the amount of additional funding needed to support community integration. This section identifies a multi-pronged funding strategy to make community-based services and supports readily available to support community inclusion. HHS should also examine how new ARPA resources (e.g., through Medicaid expansion; enhanced Federal Medical Assistance Percentage for HCBS, mobile crisis and other services; and housing resources) could support the state's compliance with *Olmstead.*

HHS will need to take bold steps to reduce reliance on institutional and segregated settings in favor of more integrated living options for individuals with disabilities. The most challenging of these actions involves shifting resources from institutional settings to integrated community-based housing and services.

Recommendation 6: Reduce Reliance on Institutional Settings

An increasing number of individuals with disabilities are being served in integrated settings in recent years, but the system is still structured in a way that serves too many people in institutional settings. North Dakota must undertake a culture change to embrace community integration. The system must emphasize policy, financing, and programs designed to support individuals in integrated community-based settings, as opposed to pathways that lead toward institutional living.

6A. Clarify the role of institutional settings.

HHS has moved to transform the Life Skills and Transition Center away from residential care into a provider of specialized services and consultation to help support people in the community. This effort should continue with a goal of focusing on short-term stabilization rather than residential care.

TAC recommends the state also examine the gero-psychiatric units in nursing homes. Stakeholders noted that the individuals admitted to these facilities are trending more toward individuals with brain injury, Parkinson's, and other physical diseases rather than SMI. They are also tending to be younger persons whose social needs are not met in a nursing facility. TAC agrees with the Schulte Report that the state should consider changes to these units. More importantly, TAC recommends prioritizing consideration of community-based options that can divert individuals from admission to nursing homes.

6B. Alleviate the acute care demand on the State Hospital.

Update the North Dakota Administrative Code section 33-07-01.1 to reinforce that primary care hospitals must provide behavioral health emergency treatment and address psychiatric treatment needs for emergency stabilization. Hospital EDs must be trained and have transfer agreements in place and be expected to do what it takes to provide crisis assessments, appropriate behavioral health care, and stabilization for all patients who have acute needs no matter the diagnosis or presenting condition.

In addition, TAC concurs with HSRI that the need for inpatient capacity is largely influenced by the availability of community-based services. Building up crisis response, outpatient treatment capacity, PSH, and other community-based services in all regions of the state will help to offset inpatient need.

6C. Reconsider investment in a new State Hospital.

TAC is aware that the HSRI and Schulte studies support the need for a new state psychiatric hospital, and that HSRI recommends a hospital facility of 75 to 85 beds. Reportedly, there is a funding plan for the facility, though TAC has not reviewed the plan. Based on TAC's experience, the number of psychiatric inpatient beds needed can be reduced if a robust continuum of community-based services is implemented. These services would fill the need for rehabilitative services currently provided at Jamestown. A new facility will require an investment of millions of dollars, with little opportunity for a federal Medicaid match. Conversely, contracting for psychiatric inpatient beds or bed days at state university medical centers or other local medical facilities will allow federal match for the treatment costs for Medicaid-eligibles; allow people to receive treatment closer to their families and homes; and serve as a better investment of North Dakota's resources. If the Department determines there is still a need for some state-operated capacity, TAC recommends exploring the option for repurposing a small vacant building or buildings to provide longer-term care for individuals with complex needs.

6D. Extend and expand the moratorium on new or expanded facility bed capacity.

The North Dakota legislature has enacted a moratorium on the addition of new nursing facility beds which runs through July 31, 2023. TAC recommends extending this moratorium. TAC also recommends the state enact a moratorium on additional ICF/IID beds.

6E. Explore supporting in-home approaches.

Build on the Home Care program to cover additional populations. CareGiver Homes operate in six states, providing dedicated care teams who work closely with caregivers and families to address the daily challenges of caring for older adults and individuals with disabilities. The approach is Structured Family Caregiving (SFC), the first home and community-based model in the nation to receive the National Committee for Quality Assurance's (NCQA) highest level of accreditation for case management. SFC is an approved HCBS waiver service that pays for a live-in caregiver, who may or may not be a family member, and a nurse care manager, who checks on the recipient regularly via telehealth. Used primarily to support families of people with aging-related and physical disabilities, including to transition people out of nursing homes, the service has been extended to include recipients with developmental disabilities.

6F. Repurpose existing funds.

As noted earlier in this report, North Dakota devotes a higher than average percentage of its Medicaid dollars to long-term services and supports (LTSS), and provides significant state funding of LTSS programs as well. However, a significant portion of these dollars go toward paying for institutional or facility-based care. HHS reports its Medicaid rates for these settings are among the highest in the nation. This is especially true for the elderly and persons with physical disabilities. Stakeholders cited the need for additional funding as a priority. Rebalancing the system in order to support more community integration may indeed require additional funding, but repurposing existing resources will also help to meet the need. Facility-based rates should be lowered and HCBS rates should be increased to incentivize use of funding in support of *Olmstead.*

Intermediate Care Facilities

Since State Center services provided to Medicaid recipients are eligible for the Federal Medical Assistance Percentage (FMAP), HHS will realize modest savings in operational costs from facility downsizing or closures. Approximately 53 percent of funding for the Transition Center and community-based ICFs is federal, while about 47 percent of costs are funded by the state.[126] The HCBS waivers do not pay for room and board; if HHS were to transfer most or all state matching funds to develop community-based services, there would likely be a need for additional state funding to offset the reduction in federal match. However, repurposing funds that currently support institutional and congregate care to options that promote community integration will assist North Dakota in complying with *Olmstead* and reduce the likelihood of further *Olmstead* litigation.

[126] Presentation on House Bill 1012, House Appropriations | Human Resources Division, *Representative Jon Nelson, Chairman. ND Developmental Disabilities Division*

6G. Reduce reliance on community-based congregate care and segregated day service settings.

While the majority of HCBS services appear to be delivered in an individual's home, some stakeholders report that certain program policies and/or the shortage of direct support workers have the effect of forcing persons into day programs and other congregate settings. TAC recommends a review of program policies to make sure persons have an option to receive appropriate services in the home if they so choose.

6H. Maximize leveraging of state resources.

Resources that Support Individuals in Basic Care Homes

Allow Basic Care Assistance to support individuals in independent living by using funds for rental assistance. North Dakota spends considerable resources to support individuals with disabilities in Basic Care facilities, including paying for room and board using state dollars. According to the HHS Budget Presentation, requested funding for FY 21-23 was about $48 million. The average cost per person was roughly equivalent to the average cost in the HCBS waiver. To the extent that the individuals residing in these facilities and receiving the assistance could be cared for at home, in an apartment or in a smaller HCBS setting with waiver services, the state would generate additional federal dollars and free up state funds that could be used elsewhere to support integrated services.

Address systemic challenges and eliminate barriers to accessing services

TAC found additional systemic challenges and barriers that interfere with the ability of individuals to live in integrated settings. The following recommendations address several of these findings.

Recommendation 7: Create a Culture that Supports the Voices of Individuals with Lived Experience

7A. Maximize the use of supported decision-making.

While identified as a strength in North Dakota's I/DD system, The North Dakota State Council on Developmental Disabilities Comprehensive Review and Analysis report identified the opportunity to increase utilization among individuals with I/DD.[127]

7B. Support Participation in National Core Indicators®.

Participation in the NCI®/NCI-AD® are currently grant-funded through 2023 by HHS-associated entities: the state DD Council and the MFP program. Participation is long overdue but is just the first step. HHS should commit to funding ongoing participation and to utilizing the information obtained to improve the service system and services provided.

[127] A Report to the North Dakota State Council on Developmental Disabilities, Comprehensive Review and Analysis for the 2022 – 2026 State Plan, Joanne Hoesel, May 2020.

7C. Understand and respond to low consumer and family satisfaction.

The Behavioral Health Division should conduct listening sessions and focus groups with persons utilizing services and family members of children to better understand the low ratings on satisfaction and on perceived positive outcomes of services.

7D. Include people with lived experience as voting members of the Olmstead Commission.

Expand membership of individuals with lived experience and family members. TAC understands that the state is starting a Consumer/Family Advisory Committee to the Olmstead Commission, but an advisory committee does not have the authority to vote.

7E. Create a cross-disability advisory council.

TAC supports language in a recent bill proposing the creation of a cross-disability advisory council. The bill requires that a majority of the 15 voting members of the council be family members of individuals with a disability, or individuals with a disability who receive Medicaid HCBS.

Recommendation 8: Address Workforce Capacity and Shortages

Workforce capacity problems and shortages in direct service providers are national problems that are particularly acute in rural areas. HHS cannot resolve these issues alone, but there needs to be an intentional effort to increase the availability and capacity of the workforce to support integrated community programs.

8A. Build on recent workforce initiatives.

HHS has been innovative in using additional federal dollars from sources such as MFP and ARPA to tackle workforce issues. Among these efforts are:

- Establishing a QSP hub, an online resource center to assist with enrollment and training.
- Using ARPA funds to pay recruitment and retention bonuses to providers.
- Providing grants to organizations seeking to develop or expand HCBS.

TAC recommends the state take steps to ensure that ongoing projects such as the QSP hub continue if/when the federal funding ends.

8B. Develop rural mentorship programs.

A recent U.S. General Accounting Office report on behavioral health workforce issues identified the development of mentorships to promote awareness of opportunities in behavioral health as a potentially effective recruitment and retention strategy. For example, one study found that connecting students in rural shortage areas with behavioral health providers in other areas through virtual mentorship programs can improve recruitment.[128]

[128] U.S. Government Accountability Office (2022). Behavioral health: Available workforce information and federal actions to help recruit and retain providers.

8C. Allow family members to be paid workers in additional HCBS programs.

HHS currently allows family members to be paid workers in certain programs and services, provided they meet the enrollment requirements. Given the shortage of staff, this option should be extended to additional programs and services, while making sure appropriate requirements are in place.

8D. Ensure HCBS provider rates are adequate to support the direct support workforce.

TAC recommends that HHS take the necessary steps to adjust HCBS rates to cover any salary increases necessary to ensure that community-based wages and benefits are competitive with those of facility-based staff. Rate adjustments should be implemented with assurances that funds go to direct support wages.

8E. Professionalize the direct care workforce.

HHS should encourage providers to "professionalize" direct support roles. Direct support is often described as "entry level work" that is considered of little importance, when in reality, staff spend hours with individuals with disabilities and should be acknowledged, afforded a living wage, and shown respect for their work. HHS should also partner with the state's Workforce Development and Career and Technical Education departments to promote direct care work as a career opportunity.

8F. Consider staff extender approaches.

Determine if the Behavioral Health Aide program could be helpful with addressing workforce shortages in North Dakota. The program was designed for use in tribal communities, and other rural communities are exploring use of the model as well.

8G. Repurpose existing state and county staff.

Given the recent reorganization, TAC recommends exploring opportunities to reconsider how state and county staff are utilized across systems. One option is to streamline administrative functions in order to free up staff time to provide direct services such as case management. Another option is to cross-train case managers to serve more than one target population, increasing staff utility and efficiencies in more rural communities.

Recommendation 9: Address Administrative Complexities

9A. Simplify Medicaid administrative complexities for providers.

Facilitate use of Medicaid-funded services by simplifying requirements and reducing administrative burden for providers. Challenges to be addressed include:

- Simplifying processes for provider enrollment.
- Identifying options for agency enrollment rather than requiring each individual staff member to enroll. Many states allow nontraditional Medicaid providers to enter into relationships with providers enrolled in Medicaid or Third-Party Administrators to facilitate enrollment, submission of claims, and payment for services.
- Clarifying state policy and guidance in writing to avoid varied interpretations of staff qualifications and experience.
- Reducing administrative burden by replacing the quarter-hour unit of service reimbursement with a daily, weekly, or monthly rate.

9B. Simplify Medicaid administrative complexities for recipients.

HHS should facilitate access to services and benefits by reducing the administrative burden on people in need. For example, the SNAP application is 26 pages for that program alone, which could deter people in need from completing the process. HHS has implemented an integrated application for multiple benefits, but stakeholders question the positive outcome of this approach if the application process is overly time-consuming.

While these recommendations refer to specific initiatives, reducing administrative complexities will benefit providers, and more importantly service recipients, across services and systems.

Recommendation 10: Use Data for Evaluation and Quality Improvement

10A. Employ data analysts.

Collecting, reporting, and using data for systems evaluation is an area for improvement in North Dakota. Matching recipient data across funding streams and services is also a challenge. Stakeholders consistently shared the concern about the lack of data. However, TAC observed the use of data in the various commissioned studies and reports reviewed for this assessment. North Dakota agencies have data but reportedly lack the staffing dedicated to analyzing the data and using their analysis to help inform funding requests, policy, and planning. TAC strongly recommends that HHS and other state agencies be approved and funded to add dedicated data analysts to their staff.

10B. Integrate data across systems.

Data reporting and analysis must include all aspects of the system: state operated facilities, Medicaid-funded services; state/federal grant services; and HSCs. Integrating data sets is necessary to provide baseline information on services and expenditures, how various funding streams are utilized, levels of care, and types of services being used across the continuum and throughout the state.

10C. Use data for quality improvement.

When HHS has determined that accurate, comprehensive data is being collected, this data should be incorporated into all aspects of program monitoring, quality assessment, and quality improvement efforts. Performance-based contracting may be an option in the future, but will require considerable investment in the providers to adapt to a very different business model and service delivery approaches.

Recommendation 11: Eliminate Barriers to Care

11A. Reduce case manager caseloads.

The existing case manager to client ratios of 1:60 for I/DD and 1:55 for Aging do not allow for adequate access to care. North Dakota must reduce caseload sizes in order for investment in case management to have a positive impact on recipients and their access to services. One option is to fund more case managers. TAC also recommends expanding the capacities of underutilized case managers to serve more than one target population.

11B. Expand access to transportation in rural and urban communities.

HHS should partner with the Department of Transportation to develop innovative approaches to non-emergency medical transportation. People with disabilities must have transportation to live and work in their communities. Ride-sharing arrangements and mileage reimbursement to individuals willing to transport others are options for consideration

Chapter 6: Conclusion

North Dakota is faced with critical decisions about how best to meet the needs of its residents with disabilities. The Department of Health and Human Services (HHS) is required as a result of litigation to reduce its reliance on institutional settings for individuals with physical disabilities. The agency has also embarked voluntarily on implementing a Medicaid State Plan Amendment designed to create an array of services to support people with significant behavioral health disorders and traumatic brain injury in integrated settings. North Dakota has several home-and-community-based services waivers that support children and adults with a variety of disabilities, and was an early adopter of Medicaid expansion. These are significant steps for a largely rural state to take, that should serve to meet the needs of individuals with disabilities in the community.

However, multiple studies and feedback from stakeholders across every service system report ongoing limitations that are having unwanted impacts on the lives of people with disabilities. North Dakota is dealing with challenges similar to every other state in the country — a workforce shortage, increased complexities of individuals' and families' needs, increased housing costs, and deteriorating infrastructure — that are straining resources. In addition, there appears to be a rigid and overly conservative approach to administering services and resources that inhibits implementation and utilization. Perhaps the most significant detriment to progress is the lack of uniform data collection and analysis to assess system needs and drive improvement.

HHS can lead the way in making improvements, but cannot carry the responsibility for systems change on its own. The Department needs ongoing support from the governor's administration and from the legislature. The Department also needs to collaborate with stakeholders to achieve the consensus necessary to move significant changes forward. Updating the Olmstead Plan provides the opportunity for all parties to work together, to build on the strengths of the system and to identify the resources needed to fill the gaps that people with disabilities experience in their communities.

Appendix A: Key Documents Provided or Researched

Documents Provided

North Dakota Housing Finance Agency, 2020-2025 Statewide Housing Needs Assessment – Population and Housing Forecast

North Dakota Moves, Statewide Active and Public Transportation Plan

Permanent Supportive Housing presentation by ND HHS, Behavioral Health Division PDF

Centers for Medicare and Medicaid Services approved 1915(i) state plan amendment for North Dakota

1915(i) Enrollment and Service Delivery Report, July 1, 2022

North Dakota Behavioral Health Strategic Plan.

2018 Behavioral Health System Study final report

2022 Acute Psychiatric and Residential Care Final Report, April 28, 2021

HSRI North Dakota Hospital Study

North Dakota Behavioral Health Vision 20/20 (HSRI)

North Dakota Residential Treatment Capacity brief, October 2020 (HSRI)

July 2022 North Dakota Behavioral Health Plan Project Dashboard

North Dakota Person-Centered Practices Initiative

North Dakota Department of Human Services: Asset Map

North Dakota Advocacy Network, HB 1012 – Behavioral Health, March 15, 2021

Olmstead Plan 2002

Olmstead Commission 2008 Plan Update PDF

DOJ Settlement Agreement

North Dakota DOJ Settlement Agreement Implementation Plan, September 2021

North Dakota Settlement Agreement Report of the Subject Matter Expert, March 2022

North Dakota Olmstead Commission Meeting Minutes, May 12, 2021

North Dakota Olmstead Commission Meeting Agenda, Draft Plan, June 2021 PDF

North Dakota Olmstead Commission Meeting Agenda, July 2022

North Dakota Developmental Disabilities Study: Report and Oral Presentation (Alvarez & Marsal)

Helgerson EPSDT Study Report, Human Services Committee Presentation, June, 2022

All North Dakota HCBS Waiver Documents

Report to the North Dakota Department of Human Services, Behavioral Health Division

North Dakota Brain Injury Needs Assessment: Final Report, June 2016 (PDF)

North Dakota MFP Operational Protocol

North Dakota HCBS Settings Rule Transition Plan

North Dakota State Plan on Aging 2022-2026

Documents Researched Online

North Dakota HHS Budget Powerpoints for DD, Medicaid, LTSS

University of Minnesota, Residential Information Systems Project, Status and Trends through 2018, North Dakota State Info

State of the States in Intellectual and Developmental Disabilities

AARP/Commonwealth Foundation LTSS Scorecard for North Dakota

Genworth Cost of Care Survey PDF

KFF/MACPAC state LTSS spending reports

SAMHSA Uniform Reporting System, 2020 Table for North Dakota

North Dakota Legislature Financial Facts

Oct 6 Hearing North Dakota Legislature Human Services Committee

North Dakota DHHS Website

TAC's Priced Out Report

North Dakota Medicaid Expansion Program, Annual Technical Review Report Measurement Year (MY) 2020, Submitted by: Qlarant, September 2021

Children's Health Under Medicaid, A National Review of Early and Periodic Screening, Diagnostic, and Treatment Services 2015 – 2019.

Appendix B: Key Interviews

State Agency Staff Interviewed

TAC consultants interviewed the following staff members of North Dakota state agencies:

- Jessica Thomasson, Executive Director, Human Services
- Krista Fremming, Executive Director, Medical Services and Caprice Knapp, past Executive Director, Medical Services
- Jacob Reuter and Kayla Trzpuc, Money Follows the Person Program
- Tina Bay, Developmental Disabilities Services Director
- Nancy Nikolas Maier, Aging and Adult Services Director

Stakeholders Interviewed

TAC interviewed the following stakeholder representatives:

- Teresa Larsen, past Executive Director, North Dakota Protection and Advocacy Project
- Multiple staff from a provider of 1915(i) services

Appendix C: Abbreviations Used in this Report

ABA – Applied Behavior Analysis therapy
ACT – Assertive Community Treatment
ADA – Americans with Disabilities Act
AI/AN – American Indian and Alaska Native
ARPA – American Rescue Plan Act of 2021
ASD – Autism Spectrum Disorder
BHD – North Dakota Behavioral Health Division
CIL – Center for Independent Living
CM – Case Management/Manager
CMS – U.S. Centers for Medicare and Medicaid Services
DDD – North Dakota Developmental Disabilities Division
DDPM – Developmental Disability Program Manager
DOJ – U.S. Department of Justice
DPI – Department of Public Instruction
DVRS – North Dakota Division of Vocational Rehabilitation Services
EBP – Evidence-Based Practice
EPSDT – Early Periodic Screening, Diagnosis and Treatment
Ex-SPED – Extended Services Payments for Elderly and Disabled
HCBS – Home- and Community-Based Services
HCV – Housing Choice Voucher
HHS – North Dakota Department of Health and Human Services
HSC – Human Services Center
HSRI – Human Services Research Institute
HUD – U.S. Department of Housing and Urban Development
ICF – Intermediate Care Facility
ICF/IID – Intermediate Care Facility for Individuals with Intellectual Disabilities
I/DD – Intellectual and other Developmental Disabilities
IPS/SE – Individual Placement and Support/Supported Employment
LIHTC – Low-Income Housing Tax Credit
LTSS – Long-Term Services and Supports
MAT – Medication-Assisted Treatment
MCO – Managed Care Organization
MFP – Money Follows the Person
NDCDD – North Dakota Council on Developmental Disabilities
NDHFA – North Dakota Housing Finance Agency
PCP - Person Centered Planning
PSH – Permanent supportive housing

QSP – Qualified Service Provider
SAMHSA – Substance Abuse and Mental Health Services Administration
SED – Serious Emotional Disturbance
SFY – State Fiscal Year
SMI – Serious Mental Illness
SPED – Service Payments for Elderly and Disabled
SPH – State Psychiatric Hospital
SSI – Supplemental Security Income
SUD – Substance Use Disorder
TAC – Technical Assistance Collaborative
TBI – Traumatic Brain Injury
TPM – Target Population Member