

Informational Paper #51

Services for Persons with Developmental Disabilities

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Chapter 51 of the Wisconsin statutes defines a developmental disability as "a disability attributable to brain injury, cerebral palsy, epilepsy, autism, Prader-Willi syndrome, intellectual disability, or another neurological condition closely related to an intellectual disability or requiring treatment similar to that required for individuals with an intellectual disability, which has continued or can be expected to continue indefinitely and constitutes a substantial handicap to the afflicted individual."

The federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 created a somewhat different definition that applies to several federally-funded programs, including Medicaid. Under the Act, a developmental disability is defined as "a severe, chronic disability that is attributable to a mental or physical impairment or combination of impairments, is manifested before age 22, is likely to continue indefinitely, and requires a combination of individually planned and coordinated services, supports, or other forms of assistance of lifelong or extended duration." In addition, the disability must result in "substantial functional limitations in three or more of the following areas of major life activity: (a) self-care; (b) receptive and expressive language; (c) learning; (d) mobility; (e) self-direction; (f) capacity for independent living; or (g) economic self-sufficiency."

State and county agencies administer several programs that support individuals with developmental disabilities in Wisconsin. Appendix 1 shows the total amount each county reported spending for county-administered programs that serve persons with developmental disabilities for calendar years 2017 through 2021. The expenditure totals include a combination of state, federal, and county funds, but do not include expenditures for programs not administered by counties, such as Family Care.

Most of the programs that provide long-term care services to people with developmental disabilities are provided as part of the state's Medicaid program. Consistent with federal policy and court decisions, Wisconsin has increasingly relied on Medicaid's home and community-based services (HCBS) waiver programs to serve this population outside of institutional settings. However, only individuals who meet the more restrictive federal definition of what constitutes a developmental disability are eligible for services provided under Medicaid's HCBS programs.

As of October 1, 2022, there are approximately 35,000 adults with developmental disabilities receiving one or more long-term services supported by the state's Medicaid long-term care programs. However, this number does not include Medicaid recipients with developmental disabilities who rely solely on Medicaid fee-for-service benefits for long-term care services, since these individuals are not required to complete a functional screen as part of their eligibility requirements.

This paper describes services available to individuals with developmental disabilities in Wisconsin that are provided through the state's Medicaid program, and other non-Medicaid services administered by the Department of Health Services (DHS) and counties. Other agencies, including the Department of Workforce Development and the Department of Public Instruction, administer programs to meet the vocational and educational needs of people with developmental disabilities. These programs are described in other informational papers prepared by the Legislative Fiscal Bureau. DHS and the Board for People with Developmental Disabilities (BPDD)

DHS and its contracted entities, such as counties and managed care organizations, administer most of the state's health programs that serve people with developmental disabilities, while BPDD's mission is to advocate on behalf of individuals with developmental disabilities, foster inclusive communities, and improve the disability service system.

DHS. Most Medicaid funded long-term care services are administered by the DHS Division of Medicaid Services. However, the DHS Division of Care and Treatment Services operates the three State Centers for People with Intellectual Disabilities, and the DHS Division of Public Health operates the DHS Bureau of Aging and Disability Resources.

Several councils and committees provide advice to DHS relating to these programs, including: the Governor's Autism Council, the Children's Long-Term Support Council, the Governor's Birth to 3 Interagency Coordinating Council, the Governor's Committee for People with Disabilities, the state's Long-Term Care Advisory Council, and the IRIS (Include, Respect, I Self-Direct) Advisory Committee. These councils and committees each have different membership structures and missions, as designated by statute or established by the Governor or DHS Secretary.

BPDD. BPDD is a state board attached to the Department of Administration that works in conjunction with Disability Rights Wisconsin (DRW) and the Waisman Center (the state's University Center for Excellence in Developmental Disabilities), as a part of the Disability Policy Partnership. Each of these agencies is authorized under the federal Developmental Disabilities Act to improve the quality of life for persons with disabilities and their families through public policy, and each organization is charged with a unique mission and set of responsibilities to carry out this objective.

BPDD's mission is to promote a consumer and family-directed system of services and informal supports that enable people with developmental disabilities to exercise self-determination and be independent, productive, and integrated in the community. The responsibilities of BPDD include developing and monitoring a state plan for advocacy and systems change; advising DHS, the Governor, and the Legislature; administering programs funded by BPDD; and advocating for people with developmental disabilities.

Federal Law Guiding the Provision of Services

The state's policies with respect to services for people with developmental disabilities are based on federal law, including federal Medicaid statutes as they relate to Medicaid-funded services, the Developmental Disabilities Assistance and Bill of Rights Act of 2000, and the Americans with Disabilities Act of 1990 (ADA).

In addition, court decisions, including the 1999 U.S. Supreme Court decision Olmstead vs. L.C., have affected the implementation of state and federal law. On June 22, 1999, the United States Supreme Court held in Olmstead that unjustified segregation of persons with disabilities constitutes discrimination in violation of the ADA, and that public entities must provide community-based services to persons with disabilities when: (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.

In its decision, the Supreme Court explained that its holding reflects two "evident judgments." First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life." Second, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

In light of the *Olmstead* decision, Wisconsin currently offers home and community-based services through the Medicaid-funded Family Care, IRIS, and the Children's Long-Term Support (CLTS) Waiver Program, as well as several programs not supported by Medicaid (MA) funding.

Medicaid Funded Services

Card Services. MA is a state and federallyfunded entitlement program that provides primary, acute, and long-term care services to qualifying individuals with limited resources. Under the program, recipients are entitled to receive primary and acute care services and certain long-term care services, identified in the state's MA plan (commonly referred to as "state plan services" or "card services") as long as the services are medically necessary and provided within the limitations set by state and federal law and policy. These services include most medical services provided by non-institutional providers such as physicians and dentists, hospital services, drugs, and care provided by nursing homes.

Individuals with developmental disabilities may be eligible for Medicaid card services either because they meet income standards to qualify for coverage under BadgerCare Plus (MA coverage for individuals and families with low income) or because they meet income, asset, and functional eligibility requirements to qualify for elderly, blind, or disabled Medicaid coverage (EBD Medicaid). In order to qualify for EBD Medicaid, a person must be 65 years of age or older, blind, or disabled. For purposes of EBD eligibility, a disability is defined as "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." Disability determinations are conducted by the DHS Disability Determination Bureau (DDB). For more information regarding MA eligibility and benefits, see the Legislative Fiscal Bureau's informational paper entitled, "Medical Assistance and Related Programs (BadgerCare Plus, EBD Medicaid, Family Care, and SeniorCare)."

Long-Term Care Waiver Services. Wisconsin has also obtained several waivers to federal Medicaid law that permit the state to provide certain types of long-term care services, in addition to card services, to persons with disabilities and elderly individuals who require long-term care services. These services are commonly referred to as "waiver services," to distinguish them from card services.

Family Care provides community-based longterm care services through managed care organizations (MCOs), which manage enrollee care and provide some Medicaid card services and other long-term care services. The state also offers a self-directed long-term care program called IRIS, as an alternative to managed care.

As of July, 2018, Family Care and IRIS services are available to qualifying residents in all of the state's 72 counties. Most recently, Family Care services expanded to qualifying residents in Florence, Forest, Oneida, Taylor, and Vilas counties starting in July, 2017, Dane County, beginning in February of 2018, and Adams County beginning in July, 2018. Qualifying individuals are entitled to receive services under these programs no later than three years after Family Care and IRIS services are first made available in their county of residence. In February, 2021, the last person waiting to join one of Wisconsin's long-term care programs was enrolled in IRIS, thereby eliminating the waiting list for eligible adults.

Prior to the initial implementation of Family Care in five pilot counties in calendar years 2000 and 2001, all Wisconsin counties provided MAfunded home and community-based long-term care services to qualifying persons with developmental disabilities through the legacy waiver programs. These programs included: (1) the community integration program 1A (CIP 1A); (2) the community integration program 1B (CIP 1B); (3) the intermediate care facilities for individuals with intellectual disabilities (ICF-IID) restructuring initiative; and (4) the non-waiver community options program (COP). Individuals who met the functional and financial eligibility requirements were entitled to receive Medicaid card services, including care provided by nursing homes. However, counties maintained waiting lists for individuals seeking to enroll in home and community based waiver programs as a means of receiving community-based long-term care services. However, as Family Care has expanded to additional counties, the statewide number of individuals on waiting lists for home and community-based longterm care services has decreased significantly, since home and community based long term care program waiting lists only remain in counties still in their initial Family Care start-up period.

Certain individuals who earn income through work, are enrolled in a certified health and employment counseling program, or are involved in competitive, supported, or sheltered employment and who would not otherwise meet the financial eligibility standards for non-institutional Medicaid may be eligible for Medicaid-funded benefits through the MA Purchase Plan (MAPP). Children with long-term disabilities may also receive Medicaid card services through the Katie Beckett provision and long-term supports and services through the Children's Long-Term Support (CLTS) waiver program.

The remainder of this section provides additional information regarding some of the Medicaid-funded waiver programs serving people with developmental disabilities.

Family Care. Family Care is a comprehensive long-term care program that was created to improve the quality of long-term care services individuals receive, provide individuals with more choices and greater access to services, and be a cost-effective system for delivering long-term care services in a community setting.

Under Family Care, DHS makes monthly capitation payments to MCOs, which provide comprehensive long-term care services for enrollees through their contracted health care providers. Family Care includes some long-term care card services in addition to the more extensive waiver services. Acute medical services, such as inpatient and outpatient hospital and physician services, are not funded as part of the capitation payment. Consequently, providers submit reimbursement claims for these services to the state Medicaid program, rather than the enrollee's MCO.

In order to be eligible for Family Care, enrollees must meet both functional and financial eligibility criteria. In general, enrollees must be at least 18 years of age and their primary disability must be a condition other than mental illness or substance abuse. An individual meets the functional eligibility criteria if the person has a condition that is expected to last at least 90 days or result in death within 12 months after the date of application and if one of the following applies: (a) the person's functional capacity is at the nursing home level, meaning they require ongoing care, assistance, or supervision; or (b) the person's functional capacity is at the non-nursing home level, but the person is at risk of losing his or her independence or functional capacity unless he or she receives assistance from others.

As of September 1, 2022, 25,040 of the 57,013 persons enrolled in Family Care (approximately 44%) were people with intellectual or developmental disabilities.

As a part of the long-term care reform initiatives that created Family Care, the state began funding services provided by aging and disability resource centers (ADRCs). ADRCs offer the general public a single source of information and assistance on issues affecting elderly individuals and people with disabilities. ADRCs employ options counselors to present information on the choices individuals have to meet their long-term care needs, and serve as an entryway to publicly funded long-term care programs.

Individuals with developmental disabilities and their families often seek assistance from ADRCs when their life circumstances change, such as the declining health or death of a caretaker, or at the time an individual is transitioning from school-based programs to adult services.

As of October, 2022, there were 47 ADRCs serving all 72 counties and 11 tribes, including 34 single-county ADRCs, 13 multi-county/tribe regional ADRCs, and seven tribal aging and disability resource specialist agreements.

IRIS. IRIS was originally implemented in response to the Centers for Medicare and Medicaid Services (CMS) in the U.S. Department of Health and Human Services (DHHS) who required the state to offer an alternative to managed care in order to provide individuals with sufficient choice in obtaining Medicaid-funded long-term care services. The IRIS program is a self-directed support waiver under the Medicaid home and community based services (HCBS) waiver authority, through which individuals may self-direct their

long-term care supports and services through management of a designated budget amount. Like Family Care, IRIS is available statewide.

DHS contracts with IRIS consulting agencies (ICAs) and fiscal employment agencies (FEAs) to assist enrollees in managing their services. ICAs are responsible for assisting each enrollee in developing an individualized support and service plan. The services included in the plan must remain within the individual's approved budget, must be allowable under the federal Medicaid waiver, and must ensure the individual will be healthy and safe. FEAs assure that all services are paid according to an individual's plan and assist each enrollee in managing all fiscal requirements, such as paying providers and assuring that employment and tax regulations are met.

As of October, 2022, DHS had contracts with seven ICAs and four FEAs, each responsible for serving different geographical regions of the state.

To be eligible for IRIS an individual must meet functional eligibility requirements, and reside in an eligible living arrangement, such as a home, apartment, adult family home limited to four beds, or residential care apartment complex.

The services available under IRIS are limited to the home and community-based services not available through Medicaid card services. This differs from Family Care, which covers all longterm care services, including those otherwise available through the Medicaid card. Instead, IRIS enrollees continue to receive these services through their Medicaid card. IRIS enrollees have the option of self-directing their personal care services with the help of the ICA. Currently, approximately 53 percent of IRIS enrollees choose this option.

IRIS enrollees are provided an annual budget based on their functional needs and a comparison to historical service costs of other IRIS participants with similar needs. The enrollee then develops an individual support and service plan. Once the plan is reviewed and approved by the ICA, the person may use funds from his or her individual budget to obtain the services needed on a fee-for-service basis.

Individuals are not permitted to use any of their individual budgets to pay for room and board. Enrollees work with an IRIS consultant to develop an appropriate individual support and service plan that fits their individual budget. While individuals enrolled in IRIS have control over an annual budget, only services that are received and authorized as rendered are paid to providers by DHS.

As of October 1, 2022, there were 24,582 individuals enrolled in IRIS, including 5,570 elderly individuals, 9,484 individuals with physical disabilities, and 9,528 individuals with developmental disabilities.

Relocation and Diversion Initiatives. DHS provides people with physical and developmental disabilities, as well as the elderly, who reside in nursing facilities and ICFs-IID, the opportunity to relocate to community-based settings. From 2005-06 through 2020-21 (the most recent year for which information is available) a total of 8,079 people have been relocated from ICFs-IID and nursing homes, other than the state centers, to alternative community-based residential settings. Of the 8,079 relocated individuals, 1,040 were living with a developmental disability.

The statewide expansion of Family Care has significantly altered the way people transition from institutional settings to the community. DHS considers a transition to be a situation where a person was living in a nursing home and transitioned to the community as part of their enrollment in Family Care or another home and communitybased program. However, transitions that occur entirely within the Family Care program are not reflected in the DHS data, for example a Family Care member who moves to a nursing home due to a health condition can remain enrolled in Family Care. Using the Department's definition, in 2020-21, there were 122 total transitions, including 16 individuals (approximately 13%) for people with developmental disabilities. Of the total 122 transitions, 23 individuals had been in a nursing home for more than a year.

DHS indicates that since people are being served in the community at a cost generally below that of institutional care, these relocations result in savings to the medical assistance program.

MA Purchase Plan (MAPP). MAPP permits adults determined to have a disability under SSI standards (disregarding the individual's ability to work), including adults with developmental disabilities, to remain eligible for Medicaid if their earnings would otherwise disqualify them from coverage under the state's Medicaid program.

Income. An individual may qualify for MAPP if the individual's net household income is less than 250% of the federal poverty level (FPL) for the size of the individual's household (\$2,831.25 per month for an individual and \$3,814.58 per month for a family of two in 2022). Income deductions for MAPP eligibility include: verified impairment related work expenses, verified outof-pocket medical or remedial expenses, and the current cost of living adjustment disregard from January 1 through the date the FPL is effective for that year, if applicable.

Assets. An individual may qualify for MAPP if the individual's non-exempt assets do not exceed \$15,000.

Independence accounts are exempt accounts that allow MAPP participants to save excess earned income for retirement. MAPP enrollees can save up to 50% of their gross earnings in an independence account. If the participant earns more than this amount, he or she will have to pay a penalty. Existing retirement accounts may be registered as Independence Accounts once an individual is eligible for MAPP, but the account's balance prior to MAPP eligibility will not be exempt (i.e. the amount will be counted toward the \$15,000 asset limit), only the amounts accrued while the individual is eligible for MAPP may be exempt. If the individual opens an account, such as a savings account, to serve as an Independence Account, the account may only be established and registered while an individual is eligible for MAPP.

Assets accrued in an independence account are excluded when determining eligibility for MAPP, Family Care, IRIS, the Family Care Partnership program, SSI-related Medicaid, and Medicare Savings Programs (MSPs).

Premium Structure. A participant whose individual income exceeds 100% of the FPL for a single-person household (\$13,590 annually in 2022), will pay a premium equal to 3% of his or her adjusted earned and unearned income that exceeds 100% of the FPL plus \$25. If a MAPP enrollee owes a premium and does not pay, that individual's MAPP enrollment is suspended for three months. MAPP coverage resumes again if the individual: pays the premiums; has a change in circumstances, such as a change in income or a temporary waiver that no longer requires the person to pay a premium; or waits until the three months end and asks that MAPP coverage resume. Alternatively, the individual may ask for a temporary waiver of the premium. If DHS determines that a temporary difficulty has occurred that makes paying the premium a hardship on the individual, the premium must be waived.

Work Requirement. In order to be found eligible for the program, MAPP participants must meet a work requirement. Currently, participants are required to engage in a work activity at least once per month or be enrolled in a health and employment counseling (HEC) program. An individual is also considered to be working if he or she is engaged in in-kind work in lieu of employment, meaning he or she receives something of value as compensation for a work activity.

As of October 1, 2022, 33,965 individuals were enrolled in MAPP. It is not known how many of these individuals had developmental disabilities.

Katie Beckett Provision. The Katie Beckett provision of federal Medicaid law permits states to provide Medicaid coverage to children who live at home and have substantial medical conditions, including developmental disabilities, severe emotional disturbance, physical disabilities, and chronic mental illness. Under the provision, children, who would not otherwise qualify for Medicaid coverage while living at home due to the income of their parents, may obtain Medicaidfunded services if they meet other eligibility criteria. For these children, the parents' income and assets are not considered in determining eligibility.

In order to be eligible for MA under this provision, a child must meet all of the following criteria: (a) be under 19 years of age; (b) require an institutional level of care at home that is typically provided in a hospital or nursing facility; (c) be provided safe and appropriate care; (d) not have income in their name that exceeds the current standards for a child living in an institution; and (e) not incur a cost of care at home that exceeds the cost Medicaid would pay if the child were in an institution.

As of October 1, 2022, 7,811 children in Wisconsin were enrolled in MA under this provision.

CLTS Waiver Program. The Children's Long-Term Support (CLTS) waiver program provides services and supports for children with significant physical and developmental disabilities and severe emotional disturbance, residing in an allowable setting.

In order to be eligible to participate in the CLTS waiver program, children must meet functional and financial eligibility criteria. The functional criteria require a child to have a physical disability, developmental disability, or severe emotional disturbance that is diagnosed medically, behaviorally, or psychologically. The impairment must be characterized by the need an institutional level of care, which means a child or youth has a level of need for care and services that would qualify for comprehensive, inpatient care in an intermediate care facility for individuals with intellectual disabilities (ICF/IID), psychiatric hospital, nursing home, or hospital, that is reimbursable by MA. In addition, CLTS waiver participants must also meet nonfinancial and financial eligibility criteria for Medicaid card services.

Although the income of the child's parents is not considered in determining program eligibility, some families are required to contribute to the cost of services based on their annual income and family size. In accordance with state law, families with income that exceeds 330% of the FPL (\$75,999.13 for a family of three in 2022) are required to share in program costs on a sliding scale based on income.

The supports and services provided under the CLTS waiver program are similar to those available under other Medicaid HCBS waiver programs. However, some of the services that are necessary for adults, such as home-delivered meals, adult day care, and services provided by residential care apartment complexes and community-based residential facilities, are not available to children under CLTS.

As of September 30, 2022, 17,009 children were enrolled in the CLTS waiver program, including 11,484 children with developmental disabilities. As of September 30, 2022, an additional 1,715 children were eligible for the program and could begin receiving services based on available funding, but were waiting for the county agency to enroll them in the program, including 958 children with developmental disabilities. This figure excludes children with multiple or unknown disabilities.

Children may continue receiving services under the waiver until they reach the age of 22, as long as they continue to meet functional and Medicaid eligibility requirements, and reside in an eligible living setting, after which they would need to receive services under an adult HCBS waiver program. However, most children receiving CLTS services will transition to IRIS or Family Care upon turning 18. Counties can prevent a disruption in services for children already receiving services under CLTS by planning for their transition to Family Care or IRIS.

County waiver agencies (CWAs) help confirm program eligibility and enroll children in CLTS, as follows: (1) CWAs complete the CLTS functional screen; (2) if a child is eligible, the CWA enters the child's data in the Program Participation System (PPS); (3) on a first-come, first-served basis, DHS confirms that the child has funding and is ready to enroll; and (4) the CWA enrolls the child in CLTS and updates PPS.

Waiting List. DHS provides each county with a funding allocation to support CLTS services. Counties must serve children on a first-come, firstserved basis, so long as funds are available. In the past, some counties served additional children by supplying the non-federal share of matching funds to obtain federal matching funds on CLTS services.

Historically, counties kept their own waiting lists for CLTS services. However, the federal Centers for Medicare and Medicaid Services (CMS) has required that the state transition to a statewide enrollment process managed by DHS.

To facilitate the transition to a statewide waiting list, 2017 Wisconsin Act 59 authorized DHS to require counties to continue to provide funding that the counties had previously been contributing to partially support program costs, and required counties to cooperate with DHS to determine an equitable funding methodology and county contribution mechanism for contributing local funds to support CLTS services. The state may establish a waiting list for CLTS services when the state does not have sufficient funding to provide services to all eligible individuals.

Recent Funding Increases. The 2017-19 biennial budget act (2017 Act 59) provided DHS with an additional \$14.2 million (all funds) in 2017-18 and an additional \$25.4 million (all funds) in 2018-19 to fund CLTS services for children who were on the waiting list. These amounts were calculated based on the number of children on the waiting list for services at the time Act 59 was deliberated. However, the waiting list for CLTS services has subsequently grown. Since the funding budgeted for this effort was sum certain, rather than sum sufficient, the waiting list was not eliminated.

The 2019-21 biennial budget act (2019 Act 9) provided funding for an estimated 10,637 children to be enrolled in CLTS by June, 2021, at a cost of \$136 million (all funds). However, actual expenditures totaled \$112 million (all funds) in 2019-20, \$17 million below budget in spite of program enrollment already surpassing the total anticipated number of enrollees projected for the end of 2020-21. On July 1, 2020, (the start of 2020-21), 10,972 children were enrolled in the CLTS program, while an additional 1,198 remained on the waiting list.

The 2021-23 biennial budget act (2021 Act 58) provided an additional \$27,145,000 (\$10,084,000 GPR and \$17,061,000 FED) in 2021-22 and \$40,019,600 (\$15,878,800 GPR and \$24,140,800 FED) in 2022-23, above the amount budgeted for the program in 2020-21 in Act 9, to support program costs in the 2021-23 biennium. This funding was based on the assumption that 14,542 children would be enrolled in the program by June, 2023, with average monthly enrollment in the program totaling 13,272 in 2021-22 and 14,212 in 2022-23.

Current enrollment (17,277 as of October, 2022) has exceeded estimates under Act 58. As

previously indicated, as of September 30, 2022, 1,715 children have funding from the state but are waiting for the county agency to enroll them in the program. However, since current average enrollee costs have been lower than the Act 58 estimates, no eligible children have been denied services due to the lack of available funds.

Autism Treatment Services. Prior to calendar year 2016, all MA-supported autism treatment services were provided as part of the CLTS waiver program. In 2014, CMS modified its policy regarding these services and notified states that, if they wished to receive federal financial participation to support the cost of these services, they should be provided as state plan services, rather than as waiver services. In 2016, DHS began transitioning these services from waiver services to state plan services and, as of January, 2017, all autism treatment services are provided as state plan services.

Institutional Services

Several facilities offer institutional care for Wisconsin residents with developmental disabilities. The largest facilities, including the state centers, are certified by CMS as intermediate care facilities for individuals with intellectual disabilities (ICFs-IID), and must meet federal Medicaid care and treatment standards.

An ICF-IID provides care and active treatment to residents with developmental disabilities who need medical, nursing, or psychiatric supports to acquire skills for personal independence. This certification makes these facilities eligible for federal cost sharing under the state's Medicaid program. However, as state and federal policies encourage counties to provide care to persons with developmental disabilities through community-based services rather than institutional care, the number of these facilities has decreased over time. For example, excluding the three state centers, at the end of 2005 there were 26 facilities, with 990 total licensed beds, serving individuals with developmental disabilities in Wisconsin. As of October, 2022, there were four facilities with 92 licensed beds, excluding the three state centers.

Table 1 provides information on the various types of institutions that serve persons with developmental disabilities in Wisconsin from December, 2018, through December, 2021. As shown in this table, the number of individuals in institutions decreased by 51 (12%) over this four-year period. Current facilities range in size from five to 46 beds, excluding the state centers. Counties owned three of the four ICFs-IID, which accounted for 95% of the licensed ICF-IID beds (87 of 92), excluding the state centers. Almost all the residents of ICFs-IID are eligible for, and enrolled in, the state's Medicaid program.

Table 1: People with Developmental Disabilitiesin Institutions, as of December

Institution Type	2018	2019	2020	2021
State Centers Nursing Homes*	330 27	324 27	296 21	286 24
Non-State ICF-IIDs*	60	64	65	56
Total	417	415	382	366

*Nursing home and ICF-IID populations include fee-for-service MA populations, but exclude individuals with traumatic brain injuries.

State Centers. The DHS Division of Care and Treatment Services operates three residential facilities for the care of persons with developmental disabilities: Northern Wisconsin Center (NWC) in Chippewa Falls; Central Wisconsin Center (CWC) in Madison; and Southern Wisconsin Center (SWC) in Union Grove.

Currently, two of the three state centers, CWC and SWC, serve individuals with developmental disabilities on a long-term basis. Most of these individuals have lived at the state centers many years. 2003 Wisconsin Act 33 required DHS to relocate NWC's residents to either a communitybased setting or to another ICF-IID, but authorized the facility to continue to provide short-term services.

In recent years there have been no new admissions for long-term care to the state centers. However, if there were, the statutes require that, within 30 days after a person is admitted for long-term care, DHS and the county or appropriate MCO identify the support services that would be necessary for the individual to successfully live in the community. In addition, a person over the age of 18 may only be admitted to a state center for longterm care if he or she is determined to be in need of protective placement under Chapter 55 of the statutes. Community support plans are reviewed annually in a Watts review for all long-term residents at the state centers. The Watts review determines whether each person is in the least restrictive environment appropriate for their needs and abilities.

As counties' and MCOs' capacity to support individuals in the community has increased, there has been a shift from long-term extended care admissions to short-term admissions at the state centers.

An individual may be admitted to one of the state centers on a short-term basis to receive an evaluation, assessment, crisis intervention services, or to allow the county and provider adequate time to redesign a community support plan. Short-term programs are the intensive treatment programs (ITPs) at all three state centers and the medical short-term care program at CWC. Shortterm admissions provide services to individuals who need active treatment that includes aggressive, consistent implementation of a program of specialized and generic training, treatment, and health services. These types of admissions require the approval of the local community board or appropriate MCO, the director of the state center, and the parent or guardian, unless the admission is ordered by a court. A short-term admission is typically for a 30- to 90-day period, but may be extended to 180 days with mutual agreement of the referring entity and the director of the state center. Short-term admissions are typically voluntary admissions.

The state centers provide residents with services that may not otherwise be available to them and assist them in returning to the community. These services include: (a) education, training, habilitative, and rehabilitative services for residents; (b) behavioral evaluation of individuals at the request of county community program boards and county developmental disabilities boards; (c) assistance to county boards to enable them to better meet the needs of developmentally disabled persons; and (d) short-term care to individuals, including ITP services, to help prevent long-term institutionalization. In addition to these services, the state centers may offer dental, mental health, therapy, psychiatric, psychological, general medical, pharmacy, and orthotic services.

Table 2 shows the populations of the state centers as of July 1, 2022, and the daily private pay reimbursement rates for each of the state centers for 2022-23. The population at the centers has declined significantly over the years. In 1970, nearly 3,700 persons resided in the state centers, compared to 279 as of July 1, 2022. This decrease is due to several factors, including the state-initiated

Table 2: State Centers Population and DailyRates

			Intensive
		Private	Treatment
Facility	Population*	Pay Rate**	Services Rate**
CWC	167	\$1,595	\$1,857
NWC	11	2,382	1,857
SWC	<u>101</u>	1,323	1,857
Total	279		

*Population as of July 1, 2022, including long-term and intensive treatment populations. **2022-23 movement to relocate state center residents into the community that began in the early 1970's as the centers' mission shifted from primarily a residential to a treatment approach; the creation of Medicaid-supported home and community-based long-term care waiver programs, beginning in the early 1980s and culminating with the with the statewide implementation of Family Care; the implementation of state policies and practices consistent with the U.S. Supreme Court's 1999 *Olmstead* decision; and the discontinuation of long-term care services at NWC, beginning in 1983.

Table 3 shows the total budget and the number of authorized, full-time equivalent (FTE) staff positions for each state center for 2022-23. As noted, most of the program revenue funding for the state centers is comprised of payments through the state's Medicaid program. However, unlike Medicaid payments to other ICFs-IID, Medicaid payments to the state centers are based on the actual eligible costs of operating each facility, as limited by the amount budgeted by the Legislature for this purpose.

Non-Medicaid Community-Based Services

While the Medicaid program is the primary source of public funding for services for individuals with developmental disabilities, counties receive funding under other programs administered by DHS. Some of these programs are partially supported by Medicaid funds.

Community Aids. DHS distributes state and federal funds to counties under the community aids program for community-based social, mental health, developmental disability, and substance abuse services. Counties receive both a basic county allocation (BCA), which they may expend for any of these eligible services, and categorical

	CWC	NWC	SWC	Total
Program Revenues - MA				
State Operations	\$76,009,700	\$16,200	\$44,819,500	\$120,845,400
Utilities & Fuel	2,160,900	1,346,300	2,032,600	5,539,800
Institutional Repair and Maintenance	308,300	0	400,400	708,700
Institute Operations	269,400	0	1,700	271,100
Electric Energy	36,600	28,000	42,300	106,900
Subtotal	\$78,784,900	\$1,390,500	\$47,296,500	\$127,471,900
Program Revenues - Other				
Alternative Services	\$214,700	\$8,752,000	\$24,100	\$8,990,800
Extended Intensive Treatment Surcharge	50,000	0	50,000	100,000
Farm Operations	0	0	50,000	50,000
Activity Therapy	77,400	17,800	17,500	112,700
Gifts and Grants	20,000	39,600	18,000	77,600
Interagency and Intra-agency Programs	176,200	1,225,500	186,900	1,588,600
Subtotal	\$538,300	\$10,034,900	\$346,500	\$10,919,700
Total Funding (All Sources)	\$79,323,200	\$11,425,400	\$47,643,000	\$138,391,600
Total Authorized FTE Positions (All Sour	rces) 787.30	118.50	512.25	1,418.05

Table 3: State Centers Budget and Authorized Full-Time Equivalent Positions, 2022-23

allocations, including funding for the community mental health services block grant, substance abuse prevention and treatment block grant, and Alzheimer's family and caregiver support program, each of which is designated to provide specific services and programs. Additional information on the community aids program is provided in the Legislative Fiscal Bureau's informational paper entitled, "Community Aids/ Children and Family Aids."

BCA. Counties use the BCA, in combination with funding from other sources, to support a wide range of human service programs, including services for individuals with developmental disabilities. Counties may use the basic county allocations for any allowable community aids service. In 2023, DHS will distribute approximately \$169.8 million (all funds) under the BCA. In 2021, counties reported spending approximately \$15.7 million of the BCA on services for persons with developmental disabilities.

CCOP. As part of 2015 Act 55, and effective January 1, 2016, state funding for several county-administered programs that provided services to

children with special needs, including children with developmental disabilities, was combined to form the children's community option program (CCOP). CCOP provides supports and services to children living at home or in the community who have one or more of the following long-term disabilities: developmental disabilities, physical disabilities, or severe emotional disturbance. For calendar year 2023 DHS plans to distribute \$10,994,500 GPR to counties and nonprofit agencies to support CCOP services.

Eligibility Criteria. In order to be eligible for CCOP, the child's disability must be characterized by a substantial limitation on functional ability in at least two of the following areas: self-care, receptive and expressive language, learning, mobility, and self-direction. Further, the child must meet the following eligibility criteria: be under 22 years of age; be a resident of Wisconsin with intent to remain; live in a home or community setting; and require a level of care typically provided at an ICF-IID, a nursing home, or a hospital.

Covered Services. CCOP funding can be used to provide a range of services and supports that

allow the child to remain in the home or community. Allowable services are selected based on an individualized assessment of the child's needs and a service plan completed by the local county CCOP agency, in consultation with the child's family. Some examples of covered services include home modifications, respite care, adaptive equipment, transportation, care management, and communication aids. Parents may be required to pay a sliding scale fee, based on the family's income and service costs. CCOP is a payer of last resort, as such CCOP funding cannot be used to replace services that are available through Medicaid, HCBS waiver programs, schools, income maintenance programs, or private insurance.

Early Intervention Services for Infants and Toddlers with Disabilities (Birth to 3). The Birth to 3 Program, authorized under Part C of the federal Individuals with Disabilities Education Act (IDEA), utilizes state, federal, and local funds to support a statewide, comprehensive program of services for infants and toddlers with disabilities, and their families. Program goals established in federal law include enhancing the development of children with developmental disabilities, minimizing the need for special education, and decreasing rates of institutionalization.

Counties are responsible for administering the program based on state and federal guidelines. Specific county responsibilities include establishing a comprehensive system to identify, locate, and evaluate children who may be eligible for the program.

An early intervention team, comprised of a service coordinator and staff working in at least two different disciplines related to the child's suspected areas of need, evaluates children referred to the program to determine their eligibility for the program. A child qualifies for the program if he or she is younger than three years old and has a significant developmental delay of 25% or more or a physician-diagnosed and documented condition likely to result in a developmental delay.

Once eligibility is determined, the early intervention team conducts an assessment to further identify the unique needs of the child and the family. The results of the assessment are used by a team of professionals, the service coordinator, the parents, other family members, and an advocate (if requested by the parent), to develop the individualized family service plan (IFSP). The plan must include a statement of the expected outcomes, how those outcomes will be achieved, a timeline for the provision of services, the manner in which services will be provided, and the sources of payment for the services. Eligible children are ensured the provision of core services at no cost to the family. Core services include evaluation, service coordination, and the development of an IFSP.

The services Birth to 3 Program participants most frequently use include mandatory service coordination, communication services, special instruction, occupational therapy, and physical therapy. Children in the program may also receive audiology services, assistive technology services, family training, counseling and home visit services, nursing services, certain medical services, nutrition services, psychological services, sign language and cued language services, social work services, transportation, and vision services.

In 2021, Wisconsin's Birth to 3 Program evaluated 8,337 children, including new and ongoing participants, those who did not enroll in the program, and those who were found to be ineligible. Of these children, 7,165 were eligible, and of those, 6,755 enrolled in, and were provided early intervention services through the Birth to 3 Program. For children exiting the program in 2021, the average length of time in the program was 334 days, or about 11 months.

The program is funded from several sources, including the federal IDEA grant, state GPR, county funds, community aids, Medicaid, private insurance reimbursement, and parental cost sharing. Table 4 shows the calendar year 2021 reported expenditures for the Birth to 3 program from all sources. Appendix 2 provides total expenditures reported by the counties for Birth to 3 and the number of children each county served in calendar year 2021. Expenditures as represented in Appendix 2 are based on unaudited county-reported expenditures, which typically lack certain cost information available to DHS, such as full annual Medicaid expenditure amounts. The amount of estimated Medicaid expenditures represented in Table 4 is instead based on DHS analysis of claims based-data, which leads to the higher total in expenditures, presented in Table 4.

Table 4: Birth to 3 Program Expenditures, bySource, 2021

Funding Type	Amount
County Funding	\$13,355,910
State GPR Allocation	6,660,909
Federal Part C Allocation	6,050,890
Medicaid (estimated)	5,997,599
Community Aids (BCA)	4,770,658
Parental Cost Share	313,526
Private Insurance	296,842
Other	<u>1,040,236</u>
Total	\$38,486,570

In 2020-21, for the period of July 1, 2020, through December, 31, 2021, DHS awarded \$1.2 million in grants to 15 Birth to 3 Programs for purposes of piloting new strategies to improve outcomes for participating children. DHS received more than 30 grant applications, submitted either by individual counties or county consortia. Grantees are required to report back to DHS on measures developed for their projects, which will subsequently be used by DHS to determine program innovations Wisconsin might want to implement statewide.

Applications for these grants had to: target the social and emotional needs and development of children in the Birth to 3 program; design a program that would, at a minimum, help children that enrolled in Birth to 3 because of incidents of

abuse, neglect, or exploitation; include efforts that are meant to benefit overall family health and help families better care for their child; and aim to reduce future incidents that would cause the child to reenter the child welfare system.

In addition, as a result of the COVID-19 pandemic, the program was allocated \$3,720,800 in federal American Rescue Plan Act (ARPA) onetime funds, made available beginning July, 2021 through December, 2023. As such, the implementation of these grants is still underway.

Disability Benefit Specialists. The disability benefit specialist (DBS) program provides assistance and information to people with disabilities between the ages of 18 and 59 (individuals 60 years of age or older can receive similar services from elder benefit specialists). Benefit specialists work in all 47 aging and disability resource centers (ADRCs), covering all 72 counties. Great Lakes Inter-Tribal Council also employs three DBS to serve tribal members. The DHS Office for the Deaf and Hard of Hearing employs a DBS to serve individuals who use American Sign Language. DBS provide services such as help with program applications, discussions about program choices to meet the individuals' needs, and, at times, representation in appeals processes for certain programs.

In 2021, 19,514 cases were closed by these benefit specialists, with an additional 6,873 information-only contacts. While the majority of clients served had either a physical disability or a mental illness, seven percent of DBS clients had a developmental disability and no other diagnosis. The most common issues addressed by DBS are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) (72.8%), Medicaid for the elderly, blind or disabled (11.1%), Medicare options and enrollment counseling (9.5%), Medicare savings programs (4.8%), and other issues within the scope of the program (3.7%). DHS allocated a total of \$10.2 million (\$6.1 million GPR and \$4.1 million FED) for DBS services in 2021-22. Costs are divided between GPR and FED, and depend on federal cost reporting submitted by ADRCs to the Department. In 2021-

22, approximately 60% of these costs were supported with GPR, with the remaining 40% supported with federal funds. Most of these costs are for services provided by ADRCs, with the remainder for legal services and training.

Additional Resources

Additional information on these and other issues regarding services for persons with developmental disabilities can be found through the following resources:

- Wisconsin Department of Health Services www.dhs.wisconsin.gov/disabilities/dd.htm
- Wisconsin Board for People with Developmental Disabilities www.wi-bpdd.org
- National Center on Birth Defects and Developmental Disabilities www.cdc.gov/ncbddd

APPENDIX 1

Services for Individuals with Developmental Disabilities Reported County-Level Expenditures, All Funds* Calendar Years 2017 through 2021

County	2017	2018	2019	2020	2021
Adams	\$3,000,650	\$2,190,403	\$907,736	\$758,924	\$809,512
Ashland	22,216	22,553	73,865	97,687	44,286
Barron	883,437	769,782	981,805	931,474	1,051,974
Bayfield	155,175	215,199	161,691	167,524	166,849
Brown	4,284,877	5,275,202	5,990,296	6,318,784	7,008,397
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Buffalo	327,011	295,794	270,490	229,980	453,252
Burnett	230,052	187,323	207,832	150,440	250,880
Calumet	1,999,303	1,971,363	2,253,906	2,378,875	2,442,078
Chippewa	1,210,090	1,220,805	1,472,201	1,565,838	544,436
Clark	1,761,003	881,111	1,002,296	1,189,983	1,198,566
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Columbia	1,425,699	1,574,178	1,878,025	2,109,621	2,249,494
Crawford	209,504	173,072	210,774	206,660	184,415
Dane	106,969,768	33,256,357	17,603,974	20,239,129	23,529,775
Dodge	1,514,472	2,232,706	2,761,525	3,484,381	3,787,232
Door	1,220,282	1,126,403	1,270,654	1,235,168	1,673,011
Douglas	880,324	1,077,102	1,447,902	2,036,494	2,576,324
Dunn	719,912	1,003,930	569,229	591,025	965,023
Eau Claire	1,555,410	1,580,277	2,059,237	2,341,204	2,825,311
Florence	307,158	139,249	146,943	163,605	68,329
Fond du Lac	3,750,752	4,173,152	5,052,370	5,301,268	4,900,635
Forest-Oneida-Vilas	7,714,931	1,805,869	2,216,524	2,585,407	4,523,088
Grant-Iowa	1,182,185	1,109,813	1,311,419	1,457,296	1,607,811
Green	196,690	285,107	436,879	571,705	756,403
Green Lake	1,588,559	1,711,722	1,710,958	1,101,167	1,965,732
Iron	67,649	48,088	36,762	20,280	11,479
Jackson	427,399	408,436	422,160	205,815	436,003
Jefferson	1,872,255	1,934,788	2,357,433	2,273,499	2,952,495
Juneau	490,717	499,727	568,608	643,393	637,736
Kenosha	2,004,173	2,096,836	2,369,787	2,187,279	3,956,889
Kewaunee	1,026,895	1,363,683	1,556,787	1,439,748	1,794,076
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La Crosse	2,998,336	3,221,024	3,388,604	3,588,771	4,164,378
Lafayette	433,546	374,341	408,302	439,991	394,325
Langlade-Lincoln-Marathon	8,837,474	8,944,045	9,806,517	8,070,030	8,301,877
Manitowoc	1,661,665	1,869,061	2,271,380	2,551,834	1,529,318
Marinette	623,424	598,465	582,581	474,119	503,546
Marquette	149,982	166,338	222,564	109,108	281,915
Menominee	1,502,296	12,500	320,936	41,210	99,032
Milwaukee	18,124,260	17,585,795	17,714,302	22,982,451	26,731,916
Monroe	1,395,346	1,438,800	1,804,076	2,230,616	2,934,804
Oconto	2,395,263	2,617,232	2,789,477	2,793,206	3,023,250
Como	2,375,205	2,017,232	2,107,711	2,175,200	5,025,250

APPENDIX 1 (continued)

Services for Individuals with Developmental Disabilities Reported County-Level Expenditures, All Funds* Calendar Years 2017 through 2021

County	2017	2018	2019	2020	2021
Outagamie	\$4,871,738	\$5,975,358	\$7,015,330	\$7,236,273	\$8,660,379
Ozaukee	1,092,742	1,256,578	1,371,510	1,072,020	831,216
Pepin	343,659	228,455	208,299	200,005	234,774
Pierce	270,834	301,587	306,993	172,614	220,899
Polk	471,869	321,548	379,277	271,855	273,872
Portage	1,247,391	1,338,317	1,280,562	1,433,452	1,990,300
Price	221,964	337,721	570,730	587,940	570,368
Racine	2,700,240	2,635,982	4,374,592	4,531,220	5,239,404
Richland	63,648	122,038	112,639	79,621	86,594
Rock	53,314	4,611,137	4,011,522	4,289,113	5,839,919
Rusk	269,415	268,313	202,152	183,159	346,399
St. Croix	2,334,521	3,169,003	3,169,003	797,507	993,280
Sauk	983,035	1,512,239	1,504,312	1,721,536	2,210,109
Sawyer	406,532	497,803	470,676	540,159	567,323
Shawano	1,739,386	1,945,005	1,654,722	1,191,251	1,396,188
Sheboygan	1,922,308	2,045,913	2,918,130	2,766,185	3,110,346
Taylor	2,434,719	413,515	423,643	369,515	575,243
Trempealeau	951,015	974,738	211,883	237,309	202,418
Vernon	268,351	303,269	271,208	296,372	343,681
Walworth	677,900	721,479	1,174,769	1,454,075	436,607
Washburn	534,120	693,787	706,127	882,321	1,233,673
Washington	1,064,815	2,117,008	2,283,027	2,417,929	2,854,236
Waukesha	**	12,281,231	11,787,738	14,991,075	15,214,773
Waupaca	3,969,879	1,666,366	1,420,029	1,991,580	1,179,968
Waushara	795,542	886,148	968,735	515,926	677,436
Winnebago	4,584,545	4,701,639	5,001,664	5,438,909	4,676,565
Wood	1,229,955	1,331,688	1,086,724	1,115,377	1,220,906
Total	\$222,623,577	\$160,115,496	\$153,504,803	\$164,049,287	\$184,522,728

* Data obtained from the Human Services Revenue Reports (HSRR) collected by DHS. Family Care expenditures are not reported.

**No data reported.

APPENDIX 2

Birth to 3 Expenditures and Number of Children Served, By County Calendar Year 2021

	Total Expenses	Children Served		Total Expenses	Children Served
Adams	\$177,903	38	Marquette	\$136,607	22
Ashland	85,044	12	Menominee	58,961	18
Barron	394,631	135	Milwaukee	5,431,736	2373
Bayfield	68,905	11	Monroe	583,473	137
Brown	1,214,603	450	Oconto	326,403	70
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Buffalo	89,250	25	Outagamie	926,688	323
Burnett	93,833	33	Ozaukee	579,099	180
Calumet	657,927	88	Pepin	91,017	18
Chippewa	517,992	148	Pierce	220,406	76
Clark	184,030	46	Polk	219,903	57
Columbia	297,690	93	Portage	621,031	146
Crawford	141,674	24	Price	118,478	19
Dane	2,875,130	799	Racine	845,415	423
Dodge	473,448	216	Richland	195,102	43
Door	295,667	46	Rock	1,331,004	392
Douglas	150,650	46	Rusk	96,283	13
Dunn	678,575	108	St. Croix	670,791	189
Eau Claire	487,361	209	Sauk	780,801	110
Florence	44,622	7	Sawyer	118,703	32
Fond du Lac	704,757	220	Shawano	355,614	111
Forest/Oneida/Vilas	,	104	Sheboygan	766,484	309
Grant/Iowa	238,867	94	Taylor	131,597	30
Green	149,984	81	Trempealeau	193,455	69
Green Lake	113,405	24	Vernon	170,706	47
Iron	34,810	13	Walworth	1,095,220	192
Jackson	106,870	25	Washburn	103,739	21
Jefferson	763,993	202	Washington	536,497	351
Juneau	229,294	60	Waukesha	1,268,506	497
Kenosha	638,000	314	Waupaca	541,621	93
Kewaunee	223,120	52	Waushara	165,676	33
L . Course	401 201	222	XX7	015 774	220
La Crosse	491,381	223	Winnebago	815,774	230
Lafayette	85,808	16	Wood	618,635	197
Langlade/Lincoln/	1 (0(012	250	Π 4 14	435 000 554	11 480
Marathon	1,606,912	352	Total*	\$35,900,754	11,479
Manitowoc Morinatta	675,054 274,855	244			
Marinette	274,855	100			

*Total expenses include Birth to 3 costs, including costs for early intervention services, service coordination, administrative costs, outreach, and other costs, as reported by the counties.