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# services for persons with developmental disabilities

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# Services for Persons with Developmental Disabilities

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# Services for Persons with Developmental Disabilities

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 2015 through 2019. 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, 2020, there are approximately 33,000 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 this office.

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## **DHS and the Board for People with Developmental Disabilities (BPDD)**

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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. Until recently, all of these programs were administered by the Division of Long Term Care (DLTC), which was eliminated as part of the DHS reorganization in the 2015-17 biennial budget act.

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.

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## **Federal Law Guiding the Provision of Services**

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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.

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### **Medicaid Funded Services**

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*Card Services.* MA is a state and federally-funded 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 long-term 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.

Prior to the initial implementation of Family Care in five pilot counties in calendar years 2000 and 2001, all Wisconsin counties provided MA-funded 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 long-term 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, 2020, 23,079 of the 50,927 persons enrolled in Family Care (approximately 45%) 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, 2020, there were 48 ADRCs serving all 72 counties and 11 tribes, including 36 single-county ADRCs, 12 multi-county/tribe regional ADRCs, and six 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 September, 2020, 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 long-term 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 49 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, 2020, there were 21,794 individuals enrolled in IRIS, including 4,651 elderly individuals, 8,852 individuals with physical disabilities, and 8,291 individuals with developmental disabilities.

**Relocation and Diversion Initiatives.** DHS operates three programs that provide 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 2017-18 (the most recent year for which information is available) a total of 7,211 people have been relocated from ICFs-IID and nursing homes, other than the state centers, to alternative community-based residential settings. Of the 7,211 relocated individuals, 988 were living with a developmental disability. Additionally, during that same time period, 1,533 people were diverted from admission to a nursing home through DHS diversion programs.

The three relocation initiatives operated by DHS are the ICF-IID restructuring initiative, the community relocation initiative (CRI), and CIP 1A (community integration program). However, DHS indicates that with the expansion of Family Care, the use of traditional relocation measures has diminished. In 2017-18, the most recent year

for which data is available, there were a total of 282 people relocated from nursing homes under CRI, two individuals under the ICF-IID restructuring initiative, and none under the CIP 1A initiative.

In addition to the three relocation initiatives, DHS also operates the nursing home diversion program which provides support to people who are at imminent risk of entering a nursing home to be diverted from nursing home admission and remain in community settings. Under the diversion program, in 2017-18, two people were diverted from nursing home admission and remained in community-based settings. However, as with the relocation initiatives, the number of counties eligible for diversion slots, has decreased over time due to the expansion of Family Care and IRIS. As such, the diversion program was only available in the seven counties that still operated the CIP II legacy waiver program at any point in 2017-18.

DHS indicates that since people are being served in the community at a cost below that of institutional care, the relocation initiatives resulted in savings to the medical assistance program in 2017-18 of \$910,000 for the people relocated during the year, and an additional \$56,000 saved as a result of the nursing home diversion program during that same year.

**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 (\$2,658.33 per month for an individual and \$3,591.68 per month for a family of two in 2020). Income deductions for MAPP eligibility include but are not

limited to a substantial deduction for earned income, any impairment related work expenses (IRWE) that the individual or individual's spouse have, a variety of special exempt income deductions, and any medical or remedial expenses if the total monthly out of pocket expense is more than \$500.

*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 exist to allow the MAPP member to save excess earned income for retirement. 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, 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 (\$12,760 annually in 2020), 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 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.

*EBD Medicaid.* The income eligibility limit for medically indigent elderly, blind, or disabled individuals in the MA program is 100% of the FPL. In 2020, this equals monthly income of \$1,063.33 for a one-person household and \$1,436.67 for a two-person household.

As of October 1, 2020, 28,540 individuals were enrolled in MAPP. It is not known how many of these individuals had developmental disabilities.

**Katie Beckett Provision.** The Katie Beckett provision provides Medicaid eligibility 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 Medicaid-funded 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 September 1, 2020, 8,498 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.

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 for individually planned and coordinated supports, treatment, or other services that permit the child to remain living in the home or other community-based settings. In addition, CLTS waiver participants must also be eligible for Medicaid card services.

The financial eligibility criteria require that, in 2020, the child's income not exceed \$2,349 per month. Children with greater income may become eligible for Medicaid by meeting the calculated cost-share requirement to the CLTS income criteria.

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 (\$71,676 for a family of three in 2020) 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 un-

der CLTS.

As of September 1, 2020, 11,169 children were enrolled in the CLTS waiver program, including 6,828 children with developmental disabilities. As of September, 2020, an additional 1,247 children were on the CLTS waitlist, including 638 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.

*Waiting List.* DHS provides each county with a funding allocation to support CLTS services. Counties must serve children on a first-come, first-served 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. DHS expects to begin this transition in calendar year 2021.

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.

DHS anticipates that children currently on the waiting list will be enrolled by June, 2021. However, whether the waiting list is down to zero at that point will depend on various factors, including how many new children seek to enroll during the period and how fast counties can implement care plans for new children.

**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.

**Unified Intake.** Similar to the ADRCs that serve as a gateway for adults seeking long-term care services, CompassWisconsin: Threshold (CWT) offers families a way to apply for multiple programs for their children through a single application and eligibility process. CWT assists families in understanding and applying for the Katie Beckett provision, CLTS waiver program, and the GPR-funded Children's Community Option Program (CCOP). As of September, 2020, CompassWisconsin: Threshold was operating in 17 counties.

2019 Act 9 provided \$444,700 GPR in 2019-20 and \$416,500 GPR in 2020-21 in the Joint Committee on Finance's program supplements appropriation, for DHS to seek a statewide intake, application, and screening contract for children's long-term care services through Katie Beckett, CLTS, and CCOP. Further, Act 9 required DHS to submit a request under s. 13.10 of the statutes to seek the release of this funding. The Committee's intent in placing the funding in the Committee's program supplements appropriation was to have the Department consult with stakeholders, including advocates, families, providers, and the counties, regarding implementation of this provision prior to the release of the funds. The Department is yet to seek the release of the Act 9 funding located in the Committee's program supplements appropriation for this purpose.

Based on discussions with stakeholders, DHS determined that a statewide solution can be

operationalized locally with statewide standardization of information and monitoring. DHS expects to begin implementing these changes in July, 2021. Once implemented, this new solution will replace CompassWisconsin: Threshold statewide.

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### Institutional Services

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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 August, 2020, there were four facilities with 94 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 2016 through 2019. As shown in this table, the number of individuals in institutions decreased by 56 (12%) over this four-year period, from 471 on December 31, 2016, to 415 on December 31, 2019. Current facilities range in size from seven to 46 beds, excluding the state centers. Counties owned

three of the four ICFs-IID, which accounted for 93% of the licensed ICF-IID beds (87 of 94), excluding the state centers. Almost all the residents of ICFs-IID are eligible for, and enrolled in, the state's Medicaid program.

**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. These individuals have lived at the state centers many years. 2003 Wisconsin Act 33 required DHS to relocate NWC's residents to either a community-based 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 long-term care if he or she is determined to be in need of protective placement under Chapter 55 of the

**Table 1: People with Developmental Disabilities in Institutions as of December 31**

Institution Type	2016	2017	2018	2019
State Centers	361	348	330	324
Nursing Homes*	38	26	27	27
Non-State ICF-IIDs*	<u>72</u>	<u>64</u>	<u>60</u>	<u>64</u>
Total	471	438	417	415

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

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. Short-term 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, 2020, and the private pay reimbursement rates for each of the state centers for 2020-21. The population at the centers has declined significantly over the years. In 1970, nearly 3,700 persons resided in the state centers, compared to 307 as of July 1, 2020. This decrease is largely due to the state-initiated 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. This movement of residents into the community was further increased due to implementation of CIP 1A in 1983 and the phase-out of long-term care services at NWC.

**Table 2: State Centers Population and Daily Rates**

Facility	Population*	Private Pay Rate**	Intensive Treatment Services Rate**
CWC	181	\$1,063	\$1,303
NWC	12	1,624	1,303
SWC	<u>114</u>	1,060	1,303
Total	307		

\*Population as of July 1, 2020, including long-term and intensive treatment populations.

\*\*2020-21

Table 3 shows the total budget and the number of authorized, full-time equivalent (FTE) staff positions for each state center for 2020-21. 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

**Table 3: State Centers Budget and Authorized Full-Time Equivalent Positions, 2020-21**

	CWC	NWC	SWC	Total
<b>Program Revenues - MA</b>				
State Operations	\$67,486,000	\$16,200	\$41,986,000	\$109,488,200
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	255,700	0	1,700	257,400
Electric Energy	<u>36,600</u>	<u>28,000</u>	<u>42,300</u>	<u>106,900</u>
Subtotal	\$70,247,500	\$1,390,500	\$44,463,000	\$116,101,000
<b>Program Revenues - Other</b>				
Alternative Services	\$210,400	\$8,485,000	\$24,100	\$8,719,500
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	<u>176,200</u>	<u>1,179,300</u>	<u>187,300</u>	<u>1,542,800</u>
Subtotal	\$534,000	\$9,721,700	\$346,900	\$10,602,600
Total Funding (All Sources)	\$70,781,500	\$11,112,200	\$44,809,900	\$126,703,600
Total Authorized FTE Positions (All Sources)	800.10	118.50	523.00	1,441.60

limited by the amount budgeted by the Legislature for this purpose.

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### Non-Medicaid Community-Based Services

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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 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 2021, DHS will distribute approximately \$169.8 million (all funds) under the BCA. In 2019, counties reported spending approximately \$14.74 million of the BCA on services for persons with developmental disabilities.

**CCOP.** As part of 2015 Act 55, and effective January 1, 2016, the Family Support Program funding was merged with the portion of COP funding allocated to children, 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 2021 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 2019, Wisconsin’s Birth to 3 Program evaluated 24,827 children, including new and on-going participants, those who did not enroll in the program, and those who were found to be ineligible. Of these children, 12,725 were eligible, enrolled, and provided early intervention services through the Birth to 3 Program. In 2019, 2,363 of these children disenrolled from the program with average program participation lasting 9.5 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 2019 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 2019. Appendix 2 includes some services reimbursed by Medicaid (\$2.9 million). However, DHS conducts additional reconciliation to find payments made by Medicaid (\$4.1 million) and private payers (\$3.3 million), which leads to the higher total in expenditures by source, presented in Table 4.

In 2020-21, DHS awarded \$1.2 million in grants to 15 Birth to 3 Programs for purposes of piloting new strategies to improve outcomes for

**Table 4: Birth to 3 Program Expenditures, by Source, 2019**

Funding Type	Amount
Federal Part C Allocation	\$5,836,046
State GPR Allocation	5,789,000
Medicaid (estimated)	6,961,636
Community Aids (BCA)	4,692,521
County Funding	14,781,466
Parental Cost Share	543,517
Private Insurance	2,414,776
Other	<u>1,807,952</u>
Total	\$42,826,914

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. The initiatives supported by these grants will run through the end of 2021.

**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 48 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 2019, a total of 11,752 cases were closed by these benefit specialists, with an additional 13,138 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) eligibility (29%), MAPP (10%), Medicare Part D options and enrollment (18%), SSI and SSDI post-entitlement issues (7%), and Medicare Savings Programs (6%).

DHS allocated a total of \$10 million (\$6.3 million GPR and \$3.7 million FED) for DBS services in calendar year 2019. Costs are divided between GPR and FED, and depend on federal cost reporting submitted by ADRCs to the Department. In 2019, approximately 63% of these costs were supported with GPR, with the remaining 37% supported with federal funds. Most of these costs are for services provided by ADRCs (\$8.8 million in 2019), with the remainder for legal services and training (approximately \$1.2 million in 2019).

**Epilepsy Service Grants.** DHS allocates state funds to private, nonprofit organizations or county agencies that provide direct or indirect services to persons with epilepsy. Direct services include services provided to a person with epilepsy or a family member of a person with epilepsy, such as counseling, referral to other services, case

management, and daily living skills training. Indirect services include services provided to a person working with or on behalf of a person with epilepsy, such as service provider training, community education, prevention programs, and advocacy. By statute, DHS is authorized to provide up to \$150,000 annually in epilepsy service grants, with no one entity eligible to receive more than \$50,000 annually. Funding for the epilepsy service grants is budgeted in a larger community aids appropriation from which a number of smaller grant programs are funded.

**Supplemental Security Income.** The supplemental security income (SSI) program provides cash benefits to elderly, blind, and disabled individuals, many of whom have developmental disabilities. In August, 2020, approximately 119,900 Wisconsin residents received SSI and SSI related benefits. In 2020, eligible individuals living independently received up to \$877.78 in state and federal benefits, which they may use for any purpose. Participants also automatically qualify for coverage under the Medicaid program. Additional information on the SSI program is provided in the Legislative Fiscal Bureau informational paper entitled, "Supplemental Security Income."

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## Additional Resources

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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](http://www.dhs.wisconsin.gov/disabilities/dd.htm)*

Wisconsin Board for People with Developmental Disabilities

*[www.wi-bpdd.org](http://www.wi-bpdd.org)*

National Center on Birth Defects and Developmental Disabilities

*[www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)*

## APPENDIX 1

### Services for Individuals with Developmental Disabilities Reported County-Level Expenditures, All Funds Calendar Years 2015 through 2019

County	2015	2016	2017	2018	2019
Adams	\$2,502,713	\$3,103,376	\$3,000,650	\$2,190,403	\$907,736
Ashland	28,252	19,398	22,216	22,553	73,865
Barron	1,017,422	987,550	883,437	769,782	981,805
Bayfield	198,521	165,971	155,175	215,199	161,691
Brown	23,880,112	4,017,732	4,284,877	5,275,202	5,990,296
Buffalo	284,123	324,805	327,011	295,794	270,490
Burnett	196,067	168,028	230,052	187,323	207,832
Calumet	2,162,247	2,086,452	1,999,303	1,971,363	2,253,906
Chippewa	1,305,675	938,581	1,210,090	1,220,805	1,472,201
Clark	1,263,727	1,609,330	1,761,003	881,111	1,002,296
Columbia	1,817,243	1,797,326	1,425,699	1,574,178	1,878,025
Crawford	217,987	188,564	209,504	173,072	210,774
Dane	95,009,875	99,585,103	106,969,768	33,256,357	17,603,974
Dodge	2,739,414	346,846	1,514,472	2,232,706	2,761,525
Door	4,072,875	1,053,704	1,220,282	1,126,403	1,270,654
Douglas	907,855	813,659	880,324	1,077,102	1,447,902
Dunn	842,649	268,271	719,912	1,003,930	569,229
Eau Claire	1,474,354	2,692,706	1,555,410	1,580,277	2,059,237
Florence	426,056	408,059	307,158	139,249	146,943
Fond du Lac	3,490,861	3,685,520	3,750,752	4,173,152	5,052,370
Forest-Oneida-Vilas	13,003,906	12,736,114	7,714,931	1,805,869	2,216,524
Grant-Iowa	1,015,711	1,103,288	1,182,185	1,109,813	1,311,419
Green	221,928	232,712	196,690	285,107	436,879
Green Lake	1,052,459	1,347,221	1,588,559	1,711,722	1,710,958
Iron	**	10,787	67,649	48,088	36,762
Jackson	192,390	283,053	427,399	408,436	422,160
Jefferson	1,583,878	1,382,814	1,872,255	1,934,788	2,357,433
Juneau	557,150	522,439	490,717	499,727	568,608
Kenosha	2,467,615	2,432,863	2,004,173	2,096,836	2,369,787
Kewaunee	2,225,748	1,624,425	1,026,895	1,363,683	1,556,787
La Crosse	3,868,339	3,296,911	2,998,336	3,221,024	3,388,604
Lafayette	283,650	243,823	433,546	374,341	408,302
Langlade-Lincoln-Marathon	8,970,245	9,192,690	8,837,474	8,944,045	9,806,517
Manitowoc	2,478,830	1,784,815	1,661,665	1,869,061	2,271,380
Marinette	3,632,897	723,954	623,424	598,465	582,581
Marquette	314,892	149,982	149,982	166,338	222,564
Menominee	1,480,115	1,484,100	1,502,296	12,500	320,936
Milwaukee	10,035,923	20,922,742	18,124,260	17,585,795	17,714,302
Monroe	1,359,753	1,297,890	1,395,346	1,438,800	1,804,076
Oconto	6,307,391	2,777,850	2,395,263	2,617,232	2,789,477

**APPENDIX 1 (continued)**

**Services for Individuals with Developmental Disabilities  
Reported County-Level Expenditures, All Funds  
Calendar Years 2015 through 2019**

County	2015	2016	2017	2018	2019
Outagamie	\$3,659,414	\$3,901,530	\$4,871,738	\$5,975,358	\$7,015,330
Ozaukee	1,253,991	1,137,842	1,092,742	1,256,578	1,371,510
Pepin	138,405	184,631	343,659	228,455	208,299
Pierce	201,419	173,839	270,834	301,587	306,993
Polk	537,951	587,860	471,869	321,548	379,277
Portage	1,543,435	1,206,730	1,247,391	1,338,317	1,280,562
Price	256,036	285,807	221,964	337,721	570,730
Racine	2,897,396	2,831,960	2,700,240	2,635,982	4,374,592
Richland	145,578	74,881	63,648	122,038	112,639
Rock	31,102,007	185,373	53,314	4,611,137	4,011,522
Rusk	336,906	269,165	269,415	268,313	202,152
St. Croix	1,373,814	1,556,294	2,334,521	3,169,003	3,169,003
Sauk	1,204,591	1,157,103	983,035	1,512,239	1,504,312
Sawyer	282,621	288,544	406,532	497,803	470,676
Shawano	5,480,743	2,122,572	1,739,386	1,945,005	1,654,722
Sheboygan	2,612,295	2,449,878	1,922,308	2,045,913	2,918,130
Taylor	3,953,258	3,922,996	2,434,719	413,515	423,643
Trempealeau	1,150,169	1,197,766	951,015	974,738	211,883
Vernon	264,136	268,850	268,351	303,269	271,208
Walworth	359,297	566,110	677,900	721,479	1,174,769
Washburn	438,710	541,434	534,120	693,787	706,127
Washington	1,042,194	737,769	1,064,815	2,117,008	2,283,027
Waukesha	12,520,580	13,236,150	**	12,281,231	11,787,738
Waupaca	5,163,676	4,634,587	3,969,879	1,666,366	1,420,029
Waushara	284,394	338,364	795,542	886,148	968,735
Winnebago	4,592,532	4,660,611	4,584,545	4,701,639	5,001,664
Wood	<u>1,188,967</u>	<u>1,237,809</u>	<u>1,229,955</u>	<u>1,331,688</u>	<u>1,086,724</u>
Total	\$288,874,680	\$237,577,429	\$222,623,577	\$160,115,496	\$153,504,803

\* 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 2019

	Total Expenses	Children Served		Total Expenses	Children Served
Adams	\$ 135,919	45	Marquette	\$ 142,182	22
Ashland	119,203	24	Menominee	55,482	19
Barron	223,108	120	Milwaukee	5,005,874	2,883
Bayfield	84,657	20	Monroe	481,087	148
Brown	1,383,446	547	Oconto	353,673	85
Buffalo	100,381	22	Outagamie	879,532	341
Burnett	95,903	22	Ozaukee	570,410	153
Calumet	642,730	122	Pepin	109,092	19
Chippewa	503,925	133	Pierce	165,775	76
Clark	252,915	59	Polk	244,677	80
Columbia	274,344	81	Portage	507,774	141
Crawford	114,779	47	Price	112,804	23
Dane	2,674,273	903	Racine	817,457	416
Dodge	511,853	229	Richland	161,550	39
Door	304,178	54	Rock	1,528,231	392
Douglas	178,884	83	Rusk	97,110	17
Dunn	638,274	129	St. Croix	655,707	201
Eau Claire	501,695	236	Sauk	771,756	139
Florence	48,194	6	Sawyer	158,220	40
Fond du Lac	556,650	193	Shawano	375,560	113
Forest/Oneida/Vilas	640,339	137	Sheboygan	1,000,767	286
Grant/Iowa	233,720	100	Taylor	116,660	32
Green	141,425	79	Trempealeau	199,224	76
Green Lake	117,300	25	Vernon	155,793	56
Iron	25,719	8	Walworth	1,139,509	216
Jackson	147,998	31	Washburn	120,298	33
Jefferson	794,270	210	Washington	502,004	334
Juneau	243,845	59	Waukesha	1,183,107	549
Kenosha	620,800	430	Waupaca	487,863	94
Kewaunee	265,271	62	Waushara	166,326	34
La Crosse	512,300	238	Winnebago	781,342	282
Lafayette	86,748	34	Wood	<u>608,004</u>	<u>192</u>
Langlade/Lincoln/ Marathon	1,620,983	366	Total*	\$ 34,403,151	12,725
Manitowoc	686,598	239			
Marinette	265,677	101			

\*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.