



Informational Paper 50

**Services for Persons with
Developmental Disabilities**

Wisconsin Legislative Fiscal Bureau

January, 2009

Services for Persons with Developmental Disabilities

Prepared by

Cory Kaufman and Sam Austin

Wisconsin Legislative Fiscal Bureau
One East Main, Suite 301
Madison, WI 53703

Services for Persons with Developmental Disabilities

The state of Wisconsin provides a wide range of treatment and rehabilitation services for persons with developmental disabilities, mental disorders, alcoholism, and other drug abuse problems. State law expresses the intent to maintain a unified system of prevention of these conditions, and the provision of services to ensure access to minimally restrictive treatment alternatives, while providing continuity of care.

This paper provides information on state programs that provide services to individuals with developmental disabilities and their families.

Background

Chapter 51 of the Wisconsin statutes defines a developmental disability as:

"a disability attributable to brain injury, cerebral palsy, epilepsy, Prader-Willi syndrome, autism, mental retardation, or another neurological condition closely related to mental retardation or requiring treatment similar to that required for mental retardation, which has continued or can be expected to continue indefinitely and constitutes a substantial handicap to the afflicted individual."

This section describes the symptoms and causes of several of the most prevalent developmental disabilities -- intellectual disability, epilepsy, cerebral palsy, and autism.

Intellectual Disability. The American Association on Intellectual and Developmental Disabilities describes intellectual disability as significant limitations in intellectual functioning and in

adaptive behavior as expressed in conceptual, social, and practical adaptive skills. In addition, intellectual disability refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. Historically known as "mental retardation," intellectual disability is the most common type of developmental disability.

Intellectual disability can be caused by any condition that impairs development of the brain before birth, during birth, or in the childhood years. Several hundred causes of intellectual disability have been discovered, but the cause remains unknown in one-third of those affected. The three major known causes of intellectual disabilities are Down syndrome, fetal alcohol syndrome, and Fragile X syndrome.

Epilepsy. This neurological condition involves a disturbance in the normal pattern of brain activity, causing strange sensations, emotions, and behavior and sometimes convulsions, muscle spasms, and loss of consciousness. Epileptic seizures that affect part of the brain (partial seizures) or the entire brain (generalized seizures) cause these physical changes. The cause of the condition is not known for most people with epilepsy. However, incidents that interfere with brain function, such as head injuries, a lack of oxygen during birth, brain tumors, genetic conditions, and infections such as meningitis or encephalitis, may cause epilepsy.

Cerebral Palsy. This group of chronic disorders of movement or posture appears early in life and is generally caused by a non-progressive irritation or injury to the brain. The causes of cerebral palsy include prenatal maternal diseases or infections, prolonged or abnormal deliveries, birth trauma, prematurity, and several post-natal causes such as respiratory distress or infection.

Autism. Autism is a spectrum disorder affecting each individual differently, and at varying degrees. This spectrum includes autistic disorder, pervasive development disorder not otherwise specified (PDD-NOS), Asperger syndrome, Rett syndrome and childhood disintegrative disorder (although some controversy exists on which conditions should be included). Typically appearing in children under three years of age, autism is characterized by three main types of symptoms -- impaired social interaction, problems with verbal and non-verbal communication, and unusual or severely limited activities and interests. In addition, autistic behavior frequently includes abnormal responses to sound, touch, or other sensory stimulation. The causes of autism are unknown, although it appears to be a physiological rather than a psychological disorder.

Evidence suggests that some developmental disabilities can be prevented, primarily through proper perinatal care. Developmental disabilities are commonly associated with low-birthweight and premature babies and may also occur due to exposure and ingestion of lead, head injuries resulting from accidents and child abuse, use of alcohol or other drugs during pregnancy, and periodontal disease.

The Role of Counties in Providing Services

In Wisconsin, counties are responsible for the well-being, treatment, and care of residents with developmental disabilities, and must ensure that persons in need of immediate emergency services receive these services. Each county establishes its own policy and budget for these services. Wisconsin's statutes assign counties the responsibility for the program needs of persons with developmental disabilities only within the limits of available state and federal funds, and

county funds required to match these funds. Counties may limit service levels and establish waiting lists to ensure that expenditures for services do not exceed available resources. Some counties may offer services to persons with developmental disabilities that are not defined by rule, such as supported employment services. State policy has also emphasized individualized services for the needs of each client.

For these reasons, the type and amount of community-based services available to persons with developmental disabilities varies between counties. However, rules promulgated by the Department of Health Services (DHS) require that all counties meet certain minimum service standards to be eligible for state financial assistance for community-based services. These rules (DHS 61) apply to the following sixteen service areas:

- Information and referral;
- Follow-along;
- Diagnostic;
- Evaluation;
- Counseling;
- Education;
- Recreation;
- Training;
- Treatment;
- Sheltered employment and work activity services;
- Day care;
- Personal care;
- Domiciliary care;
- Special living arrangements;
- Transportation; and
- Protective services.

In an effort to ensure that a minimum array of services is available in all counties, the state distributes funding to counties for a variety of programs and services that complement and support these basic services. Most of this funding is provided under the state's medical assistance (MA) program.

Medical Assistance-Supported Community-Based Services

Some low-income individuals with disabilities are eligible for federal and state supplemental security income (SSI) benefits. For many individuals with developmental disabilities, SSI payments are the only income they receive. Recipients often use these benefits to pay room and board in community-based settings and for any other personal expenses common to community life. Eligibility for SSI provides categorical eligibility for medical assistance (MA), a state and federally-funded entitlement program that provides primary, acute, and long-term care services to certain low-income individuals.

Individuals with developmental disabilities whose income and resources exceed the SSI limits may also qualify for MA by "spending down" to the medically needy income and asset levels. Disabled individuals who are working or enrolled in a certified job counseling program or involved in competitive, supported or sheltered employment may also qualify for MA by meeting the qualified working and disabled individuals (QWDI) or the MA purchase plan (MAPP) criteria.

Under the MA program, recipients are entitled to receive MA card services, such as physician services, dental services, home health and case management services, as long as the services are medically necessary and are provided within the limitations set by state and federal law and policy. In addition, the MA program offers persons with a developmental disability and in need of long-term care several comprehensive program options. These programs include the MA home- and community-based waiver programs, the state-funded community options program, and Family Care. Children with a developmental disability have access to the Children's Long Term Support Waiver. Certain children may also be eligible for

MA under the Katie Beckett provision, while working disabled adults may qualify under the MAPP or QWDI criteria. These programs are summarized in this section and described in more detail in the Legislative Fiscal Bureau Informational Paper entitled "Medical Assistance, BadgerCare Plus, SeniorCare, and Related Programs."

Federal law authorizes the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, to waive certain MA requirements to enable states to provide home- and community-based services to persons who would otherwise require care in an institution. In Wisconsin, there are seven such programs that operate under seven federal MA waivers: (1) the community integration program IA (CIP IA); (2) the community integration program IB (CIP IB); (3) the community integration program II (CIP II); (4) the community options waiver program (COP-W); (5) the brain injury waiver (BIW); (6) the children's long-term support waivers (CLTS), which includes the intensive in-home autism waiver; and (7) the community opportunities recovery program (COR). Five of these programs, CIP IA, CIP IB, BIW, and CLTS, provide services particularly catered to persons with developmental disabilities.

In addition, the Family Care program, which provides a similar package of community-based services plus certain long term support-related MA state plan services to individuals who are elderly, physically disabled and developmentally disabled through managed care organizations (MCOs), also operates under four federal waivers. The Family Care program replaces many of the services provided under several of the other waiver programs in counties choosing to participate in the program. Finally, the state has obtained a federal waiver to offer a new self-directed care program, Include, Respect, I Self-Direct (IRIS), which covers waiver services and operates in Family Care counties as an alternative to managed care.

State Relocation Initiatives

DHS operates four separate MA waiver programs that offer community-based services to individuals who previously received services in institutions. Two of these programs, the community integration program 1A (CIP 1A) and the intermediate care facility for the mentally retarded (ICF-MR) restructuring initiative; specifically serve individuals with developmental disabilities. The ICF-MR restructuring initiative is operated under the same authority as the CIP 1B waiver program. These program distinctions are all established at the state level. Federally, all of these waivers for people with developmental disabilities are operated under a single federal waiver.

Community Integration Programs (CIP IA and CIP IB). CIP IA and CIP IB operate under one federal Waiver and provide MA-funded, community-based services to individuals with developmental disabilities. CIP IA supports services for persons who are relocated from the state centers for people with developmental disabilities, while CIP IB supports services for other qualified persons. However, CIP IA and CIP IB are administered under a single federal waiver of MA rules. Further, CIP IA and CIP IB participants are eligible to receive the same array of community-based support services, such as supported employment services and pre-vocational services, which are not available to other MA recipients.

Community placements using CIP funding can be initiated by county staff, parents or guardians, the courts, or, if a client lives at one of the centers, by staff at the center. Placements can also be initiated as part of facility closing plans for private ICFs-MR. Once a person is identified for community placement, county officials work with the person's parents or guardian to plan for the individual's community-based services. Courts are often involved in ordering placements so the individual can live in the most integrated and least restrictive setting available.

County and center staff complete a comprehensive assessment of each individual's needs, preferences and desired outcomes to determine the services and supports the individual requires for a successful community placement. An individualized service plan (ISP) is also developed for each applicant. This plan details the supports and services that will be made available to the applicant, how and when they will be delivered, the cost of these services, and how the services will be funded.

Staff in the DHS Bureau of Long-Term Support determine whether the individual's needs can be effectively met under the proposed ISP and are charged with the responsibility of reviewing and approving all initial plans. Future plans are subject to state approval but are not always reviewed by state staff. The review process determines whether the individual's needs can be effectively met with the services and supports proposed in the plan and whether the costs are appropriate and all the necessary community resources are in place. The state and counties are jointly responsible for assuring that clients receive all necessary services identified in the ISP. Since not all of the costs of community living identified in a person's plan are eligible for MA reimbursement, counties may have to cover certain costs, such as room and board services, with funding from other sources. These costs are frequently supported by funding made available to counties under the state-funded Community Options and community aids programs.

DHS reimburses counties based on the total actual costs of eligible services. Some of these costs are fully reimbursed by state Medicaid funds while others require the county to allocate other local funding sources including local taxes levied by the county. For 2007-08, under CIP IA, state and federal MA funds available to reimburse expenses for covered services are equal to a maximum average per day of \$125 for each person relocated from the centers before July 1, 1995, \$153 for relocations that occurred between July 1, 1995, and June 30, 1997, \$225 for persons placed between July

1, 2002, and June 30, 2003, and \$325 for persons placed on or after July 1, 2003. For CIP IA clients whose service costs exceed the fully funded rate, counties can be reimbursed with federal matching funds for approximately 59% of the excess costs. This additional funding is available as a result of the county, rather than the state, providing match for federal MA dollars.

Under CIP IB, services provided to eligible individuals are funded by state/federal MA at various reimbursement levels. The basic per day amount a county receives for a state-funded CIP 1B slot is \$49.67 per day. This amount is often lower than the actual costs, requiring counties to allocate other funds to cover the entire cost of the services provided. In addition, enhanced rates are available to cover the entire cost of services provided to individuals who are placed in the community from facilities that close or have approved plans for significant downsizing. The enhanced rate is determined by the person's costs as estimated in the person's initial service plan. Total funding allocated to the department is based on a formula that is related to the facility's MA reimbursement rate. Similar to CIP IA, additional federal funds are available to support approximately 59% of the costs that exceed the applicable CIP IB rate (if below the federal maximum). In calendar year 2007, counties and tribes contributed \$91.9 million as the local match for federal MA funds under CIP IB and \$7.2 million as the local match for federal MA funds under CIP IA.

The CIP reimbursement rates represent an average amount that may be reimbursed by the state for services provided to all participants within a county. Consequently, the state permits more funds to be spent on behalf of one individual and less on another as long as the average per diem expenditure for participants does not exceed the overall allowable per diems. If expenditures exceed the allowable per diems, counties use their own funds (combined with available federal matching funds) to support the excess costs. This mechanism provides counties flexibility in managing resources

to maximize program participation. State funding allocations are based on the reimbursement rate, number of allocated slots and total number of days in the contract year. In addition, counties are not able to transfer funds between waiver programs.

As of December 31, 2007, there were 1,325 active CIP IA cases and 11,377 CIP IB cases. The CIP IB slots can be either state-supported (the state pays the 41% match under MA) or locally-supported from county COP or community aids funds or county property taxes.

ICF-MR Restructuring Initiative. 2003 Wisconsin Act 33 (the 2003-05 biennial budget act) included statutory changes that were intended to reduce the number of individuals with developmental disabilities admitted to, and living in, ICFs-MR. The act transferred from the state to counties the responsibility for the non-federal costs of care for individuals with developmental disabilities who were receiving services at a developmental disability level of care in ICFs-MR and nursing homes, other than the state centers for people with developmental disabilities. The change was intended to increase access to community-based, long-term care services for individuals with developmental disabilities by allowing counties access to funding which had been previously designated solely for institutional care, as long as total program costs for institutional and community services could be managed within the same allowable funding limit established in the state budget. Act 33 also provided funding for DHS to pay ICFs-MR that agreed to reduce the number of their licensed beds.

Under the initiative, DHS establishes a global budget to provide services, both to individuals in institutions and in community-based programs. Institutions continue to receive payment for care they provide from the state's MA program. County-prepared plans for persons relocated under the initiative are funded through the CIP 1B waiver program.

As of January 1, 2005, the start date of the state relocation initiative, 1,413 individuals at a developmental disability level of care resided in Wisconsin ICFs-MR and nursing homes, other than the state centers. As of June 30, 2008, 616 of these individuals had been successfully relocated from institutions to alternative community-based residential settings.

Other MA-Supported Programs for Individuals with Disabilities

Brain Injury Waiver (BIW). Individuals who have a brain injury and receive or are eligible for post acute rehabilitation institutional care may receive community-based support services under this waiver program, which began on January 1, 1995. Before the waiver was implemented, individuals who had a brain injury were most frequently institutionalized, since: (a) the other MA waiver programs for which these individuals are eligible do not provide sufficient funding to meet the needs of this group; and (b) people who suffer a brain injury after they are 21 years old are not considered developmentally disabled and thus are not eligible for the CIP IA or CIP IB programs. The annual amount budgeted to provide these waiver services is determined by the number of approved slots, which are allocated to counties based on the number of eligible individuals residing in each respective county, and the applicable reimbursement rate.

For 2007-08, the budgeted reimbursement rate was \$180 per day, and the total number of approved waiver slots was 217. Counties have the option of funding additional slots, with county funds serving as the match for federal MA funds. In 2007-08 the total amount budgeted to provide BIW services was approximately \$18.9 million, including \$3.8 million the state received as federal matching funds based on county contributions. In calendar year 2007, counties contributed \$2.3 million to provide BIW services. As of June 30, 2008, 265 individuals were receiving services under the program.

The Katie Beckett Provision. Before 1982, federal MA income and resource guidelines presented eligibility barriers for disabled children who could be provided needed care in their homes. If a child under the age of 21 was living at home, the income and resources of the child's parents were automatically considered available for medical expenses for the child. However, if a child was institutionalized for longer than a month, the child was no longer considered to be a member of the parent's household and only the child's own financial resources were considered available for medical expenses. The child was then able to qualify for MA. As a result, some children would remain institutionalized even though their medical care could be provided at home.

In 1982, federal MA law was modified to incorporate the "Katie Beckett provision," named after Katie Beckett, a child who was dependent upon a ventilator and was unable to return to her home, not for medical reasons but because she would have lost her MA coverage. This provision permits states to extend MA coverage to disabled children under the age of 18 who: (1) would be eligible for MA if they were in a hospital, nursing facility or ICF-MR; (2) require a level of care typically provided in a hospital, skilled nursing facility, or ICF-MR; (3) are determined to be appropriate to receive care outside of a facility; and (4) have an estimated cost of care outside of an institution that is no more than the estimated cost of institutional care. Unlike certain other MA recipients, the families of the children eligible under the Katie Beckett provision are not subject to co-payment or deductible requirements.

As of July, 2008, 5,501 children in Wisconsin qualified for MA under the Katie Beckett provision. In the 2007-08 fiscal year, MA expenditures for these children totaled approximately \$39.6 million (all funds).

Children's Long-Term Support (CLTS) Waiver. 2003 Wisconsin Act 33 provided funding to support a new MA waiver program, operating

under three MA home- and community-based waivers, that provides children with long-term care needs a single entry point for eligibility determinations in each county. These waivers include: (a) the children's developmental disability waiver for children who meet the ICF-MR level of care; (b) the children's mental health waiver for children who meet the psychiatric hospital or severe emotional disturbance level of care; and (c) the children with physical disabilities waiver for children with hospital, intensive skilled nursing, skilled nursing, and intermediate care facility levels of care. The CLTS program seeks to improve access to services, choice, coordination of care, quality, and financing of long-term care services for children with physical, sensory, and developmental disabilities, and severe emotional disturbance.

DHS allocates waiver slots and funding to counties throughout the state based on each county's estimated expenses for eligible waiver services. The daily rate paid to counties to provide services (excluding intensive in-home treatment services for children with autism) under the CLTS waivers is \$30.60. For children in crisis the daily rate was \$48.33 in 2008. Total funding for the state-supported slots was \$7.2 million (all funds) in 2007-08. Counties may also create additional waiver slots by supplying the local match to obtain the federal financial participation on these services. In calendar year 2007, counties contributed an additional \$2.6 million in local funds to provide CLTS waiver services. Once funding has been allocated, counties then have the authority to serve as many individuals as available funds will allow. As of July 1, 2008, there were 2,174 children served by state-funded slots and 933 children by locally-matched CLTS slots.

Similar to other MA waiver programs, counties may establish waiting lists for services when the funding provided is not sufficient to provide services to all eligible individuals. As of June 30, 2008, 3,919 children were on the CLTS waiting list, including 392 waiting for intensive in-home treat-

ment services. Children may continue receiving services under the waiver until they reach the age of 22 (as long they continue to be eligible for MA), after which they would need to receive some services under an adult waiver program. This could result in some individuals being placed on waiting lists for MA services once they reach 22 years of age, although counties can prevent a disruption in services by placing children already receiving services under CLTS on waiting lists for adult waiver slots.

In order to be eligible to participate in the CLTS waiver, children must meet functional and financial eligibility criteria that are similar to the family support program and the Katie Beckett eligibility criteria. The functional criteria require a child to have a severe physical, emotional or mental impairment which is diagnosed medically, behaviorally or psychologically and which is characterized by the need for individually planned and coordinated care, treatment, vocational rehabilitation or other services and which has resulted, or is likely to result in, a substantial functional limitation in at least two of the five following functions of daily living: (a) learning; (b) mobility; (c) receptive and expressive language skills; (d) self-direction; and (e) self-care.

The financial eligibility criteria require that, in 2008, the child's income may not exceed \$1,911 per month and countable assets may not exceed \$2,000. Children who have income and/or assets that exceed these limits may become eligible for MA by "spending down" to the CLTS income and asset criteria. The income threshold, which is indexed to three times the federal payment rate for SSI, is also adjusted annually to reflect inflation.

Although the income of the parents of the child is not considered for determining eligibility for MA Waivers, families may be required to contribute to the cost of services based on annual income and family size. Fees are assessed for families with income equal to or greater than 330% of the federal poverty level (FPL), beginning at one percent of the

service plan costs and increasing up to a maximum of 41% of service costs for families with incomes over 1580% of the FPL. County support and service coordination and administrative costs are excluded for purposes of calculating the fee. Families may request a fee recalculation if they experience a dramatic change in income, and may either deduct a disability allowance of either the standard \$3,300 from their adjusted gross income or their actual allowable medical deduction reported on their income taxes from the previous calendar year, whichever is greater.

The services provided under the CLTS waiver are similar to those available under other MA home- and community-based waivers. However, some of the services that are necessary for adults, such as home-delivered meals, housing counseling, adult day care, and services provided by adult family homes, residential care apartment complexes, and community-based residential facilities, are not available to children under the waivers. The CLTS waiver also supports services that are not available under other waivers, including specialized medical and therapeutic supplies. In addition to receiving waiver services, CLTS participants have access to all MA-covered card services.

Intensive In-Home Treatment Services. 2003 Wisconsin Act 33 created the intensive in-home treatment services benefit operating under two of the three children's long-term care waivers (the children's developmental disability waiver and the children's mental health waiver). Intensive, in-home treatment services are defined as one-on-one behavioral modification therapy services for children with autism disorder, Asperger's disorder, or pervasive developmental disorder. These services are intended to teach children with autism the skills that children would typically learn by imitating others around them, such as social interaction and language skills.

Until January 1, 2004, intensive in-home treatment services were provided as a fee-for-service benefit under the early and periodic screening, di-

agnosis, and treatment (EPSDT) benefit. However, in June, 2000, the U.S. Department of Health and Human Services (HHS) notified the state that in-home autism services offered under the EPSDT benefit would no longer be eligible for federal MA matching funds. HHS later indicated that the appropriate method for claiming federal financial participation for intensive in-home autism services is through a section 1915 (c) home- and community-based waiver. As a result, the administration developed a proposal to recreate the benefit as a service available under the CLTS waivers.

The state began providing intensive in-home treatment services under the CLTS waivers on January 1, 2004. When the intensive in-home treatment benefit became available under the waivers, responsibility for administering the in-home autism benefit was transferred from the state to counties. As a result, counties began conducting assessments, establishing individual service plans (ISPs), and performing quality assurance activities for each participant.

In order to qualify for intensive in-home treatment services a child must have a verified diagnosis of autism, Asperger Disorder or Pervasive Developmental Disorder, not otherwise specified (PDD-NOS). The vast majority of children eligible to receive intensive in-home treatment services are eligible for MA under the Katie Beckett provision, while a small number of eligible individuals qualify for MA as supplemental security income (SSI) recipients.

Some children receive 20 to 35 hours per week of intensive in-home treatment services plus one hour per week of case management services (the intensive level of service), while other children receive ongoing services, which are limited by the services identified in the ISP and the funding that is available. An ISP is developed for each participant to identify the type of care and number of hours of service that each individual requires. A child is eligible for intensive in-home treatment services at the intensive level for up to three years

as long as the child begins receiving services by the time he or she is eight years old. As of July 1, 2008, 640 children were receiving intensive in-home treatment services, while 1,190 children were receiving ongoing autism services.

Funding is provided to counties to support intensive in-home treatment services based on an established weekly rate and the number of hours specified in each participant's individual service plan. In addition, counties receive funding to support approximately one hour per week of case management services per recipient and are permitted to claim up to 7% of direct service and case management costs to support administrative expenses. At the ongoing level, counties receive \$30.60 per enrollee per day to support all benefit and administrative costs.

Community Options Program. Under the community options program (COP), individuals who are at risk of entering a nursing home are screened to determine if they could continue to remain in the community if adequate support services are provided. COP includes services that are entirely funded from state general purpose revenues (COP-regular) and services that are funded with state and federal MA funds for services provided under an MA waiver (COP-waiver). Although the COP-waiver program only serves persons over the age of 65 and persons who are physically disabled, the state-funded COP program serves the following groups: (a) persons with developmental disabilities; (b) elderly persons; (c) persons with chronic mental illness; (d) persons with physical disabilities; and (e) persons with Alzheimer's disease. The state-only COP funds (within the limits of the portion of COP state funds allocated specifically for this purpose) are used to provide the cost of an individualized assessment and care plan for any person who is seeking admission to or is diverted from admission to a nursing home, the service funds are used to support COP eligible individuals who are likely to become medically indigent within six months by spending excess income or assets for medical or remedial

care. In addition COP regular funds may be used to provide the non federal portion of MA-eligible waiver services to serve more waiver eligible people, for the non federal match portion of MA-eligible services when costs exceed the state reimbursement rate for a waiver program, and to support "wrap around" services for individuals that are not covered under MA, such as room and board costs. In calendar year 2007, 49% of the individuals receiving services under the GPR-funded COP program were persons with developmental disabilities.

Funding for the state-only and COP-waiver program is provided to counties as a calendar year allocation that counties may then use to serve as many or as few participants as the funding allows. However, counties are subject to a state waiver requirement that the average cost of care statewide under the COP-waiver program may not exceed the average cost of care in nursing homes. Currently, DHS limits the average expenditure per COP-waiver participant to \$41.86 per day. The COP allowable average is calculated annually. Under current statute, the average per person reimbursement for COP regular may not exceed the state share of the average per person payment rate the department expects under for nursing home reimbursement. Approximately \$132 million was expended for state-only and COP-waiver services in calendar year 2007.

Family Care. The Family Care program 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 to be a cost-effective system for delivering long-term care services.

The Family Care program consists of two major components. First, aging and disability resource centers (ADRCs) provide information, assessments, eligibility determinations and other preliminary services. Second, managed care organizations (MCOs) manage and provide the Family Care

benefit for every person enrolled in the program under a capitated, risk-based payment system. The Family Care benefit provides a comprehensive and flexible range of long-term care services, including the types of services currently available under COP, the MA community-based waiver programs, and the MA fee-for-service program. Acute care services, such as hospital care or physician care, are supported outside of the monthly capitation rate on a fee-for-services basis.

While MCOs provide comprehensive case management services, Family Care enrollees may also choose to participate in the "self-directed supports" option, which is available through each of the MCOs. Under the self-directed supports option, participants have greater control over how most services are received and who provides such services. For instance, participants work with an interdisciplinary team to determine when and where work will be performed and are permitted to employ family members and friends to provide services. When an individual chooses to self-direct certain services, the associated funding is carved out of the capitation rate and managed by either a "fiscal intermediary" or "co-employment agency."

As of December, 2008, twenty-two counties were independently operating resource centers, while sixteen counties operated six additional ADRCs collaboratively. At the same time, MCOs operated in twenty-six counties. Appendix I illustrates each of these ADRCs and MCOs by county. All of the MCOs, with the exception of Milwaukee County, provide services to individuals who are elderly, developmentally disabled, and physically disabled. The Milwaukee County CMO currently serves only the elderly population. As part of the effort to expand Family Care statewide, additional counties are also engaged in the planning process and anticipate operating ADRCs and/or MCOs beginning in either late 2008 or early 2009. As of November 1, 2008, 4,998 of the 17,655 persons (28.3%) enrolled in Family Care were developmentally disabled.

In order to be eligible for the Family Care benefit, 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 something other than mental illness or substance abuse. An individual meets the functional eligibility criteria if one of the following applies: (a) the person's functional capacity is at the nursing home level; (b) the person's functional capacity is at the non-nursing home level and that person has a condition that is expected to last at least 90 days or result in death within 12 months after application; or (c) 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 the person was a resident in a nursing home or was receiving long-term care services when the Family Care benefit became available in the person's county of residence. Financial eligibility criteria are met if an individual qualifies for MA.

In 2007-08, approximately \$324.5 million (all funds) was expended on the Family Care program for capitated payments to MCOs. Funding provided to support ADRCs is budgeted by calendar year, and is expected to total approximately \$29.6 million (all funds).

IRIS (Include, Respect, I Self-Direct). As a condition for federal authority to expand the Family Care managed care program statewide, the Centers for Medicare and Medicaid Services (CMS) required the state to offer a fee-for-service alternative to managed care in order to provide individuals with sufficient choice in obtaining long-term care services. The IRIS Program is a self-directed support waiver under the MA home and community-based services waiver authority where individuals are given the ability to fully self-direct their own care and manage an individual designated budget amount. Under the self-directed supports option, participants have greater control over how services are received and who provides these services. IRIS is only available in counties where Family Care services are also available.

The IRIS program consists of two major components. First, an independent consulting agency (ICA) is responsible for assisting individuals in selecting a consultant that will work with the individual to develop a support 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. The ICA also maintains a 24-hour call center that provides immediate access to IRIS participants who may need assistance in resolving any unanticipated and urgent issues. DHS has contracted with The Management Group to provide these services.

Second, a financial services agency (FSA) assures that all services are paid according to an individual's plan and assists enrollees in managing all fiscal requirements such as payment to providers and assuring that employment and tax regulations are met. The FSA also provides training and support to help individuals with financial accountability and processes all payments to service providers. DHS has contracted with Milwaukee Center for Independence (MCFI) to serve as the fiscal agent for all individuals enrolled in IRIS throughout the state.

To be eligible for IRIS services, an individual must reside in a Family Care county and meet the same financial and non-financial eligibility required of Family Care participants. This includes meeting a nursing home level of care as determined by the long-term care functional screen.

The services available under the IRIS program are the same as the services allowed by the other MA home and community-based services waiver programs in Wisconsin. In addition, IRIS also allows enrollees to receive customized goods and services, which are services, support or goods that enhance the individual's opportunity to achieve outcomes related to living arrangements, relationships, community inclusion, work and functional or medical status.

Individuals participating in the IRIS program are given an annual budget based upon their functional needs and a comparison to people with comparable needs within the managed care programs. The individual then develops an individual support plan. Once the plan is reviewed and approved by the ICA, the person may use funds from his/her individual budget to obtain the services they need on a fee-for-service basis.

Individuals receiving IRIS services may reside on a short-term basis in any living arrangement (CBRF, adult family home, RCAC, etc.) as long as it is not a nursing home or other institutional facility. Individuals are not permitted to use any of their individual budget amount to pay for room and board. Further, IRIS enrollees may use their individual budget to pay caregivers, including family members, friends and members of their community, to provide services. Enrollees work with an ICA consultant to develop an appropriate care plan that fits their individual budget. The budget amount determined by DHS is based on results from the individual's long-term care functional screen.

The estimated costs for the services included in the plan are based on the average Family Care capitation rates (discussed in detail in the next section). Once the care plan and budget have been determined, the FSA then assists enrollees in managing the payments for services received. Annually, excess funds not used by an individual revert back into the program and are reallocated to other enrollees as needed.

MA Purchase Plan. 1999 Act 9 created an option provided under federal MA law to extend MA coverage to certain working, persons with disabilities. The goal of this program, the "MA purchase plan" (MAPP), is to remove financial disincentives for individuals with disabilities to work. For instance, a disabled person may want to work, but choose not to do so because the additional income the individual would receive may make him or her ineligible for health care coverage under MA or

Medicare. The MA purchase plan provides the opportunity for an individual to earn more without losing his or her health care coverage. This plan also allows an individual to accumulate savings from earned income in an "independence account" to increase the rewards from working.

An individual is eligible to participate in the MA purchase plan if: (a) the individual's family income, excluding income that is excluded under federal SSI rules, is less than 250% of the FPL (\$2,166.67 per month for an individual and \$2,916.67 per month for a two-person family in 2008); (b) the individual's countable assets do not exceed \$15,000; (c) the individual is determined to have a disability under SSI standards (disregarding one's ability to work); (d) the individual is engaged in gainful employment or is participating in a training program that is certified by DHS; and (e) the individual is at least 18 years old. As of July 1, 2008, 12,759 individuals were enrolled in MA under MAPP.

Individuals enrolled in MAPP pay a monthly premium if their gross monthly income, before deductions or exclusions, exceeds 150% of the FPL (\$1,300 for an individual in 2008).

Non-MA Funding for Programs that Support Individuals with Developmental Disabilities

While the MA program is the primary source of public funding counties use to provide services to individuals with developmental disabilities, counties receive funding under other programs to partially support MA-eligible services and services that are not eligible for funding under the state's MA program.

Community Aids. Under the state's community aids program, DHS distributes state and federal funds to counties for community-based social, mental health, developmental disabilities, 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, which are funds earmarked for specific services and programs.

Additional information on the community aids program can be found in the Legislative Fiscal Bureau Informational Paper entitled "Community and Children and Family Aids."

Basic County Allocation. DHS is directed to distribute up to \$176,068,400 (all funds) annually under the community aids BCA. Counties use the BCA, in combination with funding from other sources (such as other state and federal programs and revenue from the county levy) to support their human services programs, including the services they provide for individuals with developmental disabilities. While counties annually report to DHS the total amount they expend on services they provide to individuals with developmental disabilities, they do not report this information by funding source. Consequently, it is not known how much of the community aids BCA counties expend to support services to persons with developmental disabilities.

Family Support Program. Family support program funding is a categorical allocation within the community aids appropriation. DHS will distribute \$4,909,300 to counties in CY 2009 to pay for services that help children who have severe disabilities remain in their homes. Counties may expend up to 10% of the funds they receive to pay for staff and other administrative costs. Local advisory committees determine who receives funding and how much funding is spent. Table 1 identifies expenditures for the family support program for specific service categories in calendar year 2008. County administrative costs account for the difference between the total amount allocated for the family support program and the expenditure for the services listed in Table 1.

To qualify for program services, a child must be

Table 1: Family Support Program Expenditures, by Service Category -- Calendar Year 2008

	Amount	Percent of Total
Architectural modifications of home	\$274,700	6.4%
Child care	168,100	3.9
Counseling and therapeutic resources	307,800	7.2
Dental and medical care	121,900	2.8
Diagnosis and evaluation	11,400	0.3
Diet, nutrition, and clothing	156,800	3.7
Equipment and supplies	1,270,900	29.7
Homemaker services	31,500	0.7
In-home nursing services--attendant care	46,300	1.1
Home training/parent courses	64,300	1.5
Recreation/alternative activities	473,400	11.1
Respite care	1,083,000	25.3
Transportation	78,200	1.8
Utility costs	32,500	0.8
Vehicle modification	70,800	1.6
Other	<u>89,000</u>	<u>2.1</u>
Total	\$4,280,600	100.0%

diagnosed with a severe physical, emotional, or mental impairment which requires individually planned and coordinated care, treatment, vocational rehabilitation or other services. This condition must also have resulted in or be likely to result in a substantial limitation in at least three of the following seven functions of daily living:

- Self-care;
- Receptive and expressive language;
- Learning;
- Mobility;
- Self-direction;
- Capacity for independent living; and
- Economic self-sufficiency.

Although family income is not a basis for eligibility, some families are required to share in the cost of program services, based on a sliding fee scale. Families with income under 330% of the federal poverty level (FPL) do not have any cost sharing requirement. (In 2008, 330% of the FPL was \$58,080 for a family of three.) For families with income at or above 330% of the FPL, the family's contribution begins at 1% of service costs, and increases to 41% of service costs for families at 1,580% of the FPL or above. These cost sharing requirements, which also apply to several other

programs administered by DHS including the children's long-term care support waiver, are set forth in administrative rule (HFS 1.065).

Under the family support program, families receive an assessment to determine services they need to enable their child with a disability to continue to live at home. Counties must ensure that the family participates in the assessment and that the assessment process involves people knowledgeable about the child's condition. The assessment also includes a review of available services and sources of funding, such as the family's health insurance coverage or medical assistance eligibility. A written service plan is then developed, with family support program funds used to provide services for which other funding sources are not available.

In calendar year 2007, 2,434 children received services under the program. Most of these children had developmental disabilities, although the program also provides services to children with physical disabilities and children with severe emotional disturbances. The program provides up to \$3,000 in services and goods annually to eligible families, along with additional amounts that may be provided with the Department's approval. In 2007, the average per child allocation was \$1,543. In that year, 374 of the participating families were considered "underserved," and 2,773 children were on a waiting list for services. The number of children waiting for services has remained relatively stable over the past five years.

Table 2 provides information on the age of family support program participants and the reason the participant received program services.

Early Intervention Services for Infants and Toddlers with Disabilities (Birth-to-Three). The early intervention program for infants and toddlers up to three years of age with developmental delays (the "birth-to-three program") is a federal program authorized under Part C of the Individuals with Disabilities Education Act (IDEA). Under the pro-

Table 2: Family Support Program, Participant Age and Reason for Care

	Percent
Age of Participant	
6 years or younger	16%
7 to 12 years	37
13 to 20 years	45
21 years or older	<u>2</u>
Total	100%
Reason for Care*	
Unable to help with personal care	35%
Needs assistance with personal care	59
Cannot walk	26
Requires assistance to walk	13
Severe developmental delay	35
Moderate or mild developmental delay	56

*Some participants may exhibit several of these needs.

gram, Wisconsin supplements federal grant funds with state funds to develop and implement a statewide, comprehensive program of early intervention services for infants and toddlers with disabilities, and their families. Counties also provide a significant amount of funding for the program.

Federal legislation establishes the following goals of the birth-to-three program: (a) enhance the development of infants and toddlers with developmental delays or disabilities and minimize the potential for further developmental delay; (b) reduce educational costs by minimizing the need for special education and related services; (c) minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for independent living in society; (d) enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and (e) enhance the capacity of state and local agencies and providers to identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low-income, inner-city, and rural populations.

Counties are responsible for administering the program based on state and federal guidelines.

Their specific responsibilities include:

- Establishing a comprehensive system to identify, locate, and evaluate children who may be eligible for the birth-to-three program;
- Designating a service coordinator for every child referred to the program for evaluation;
- Ensuring that families receive core services at no cost, such as evaluation, service coordination, and the development of an individual family service plan (IFSP); and
- Determining parental liability for services received in accordance with the IFSP.

An early intervention team evaluates children referred to the program to determine their eligibility for services. These early intervention teams are comprised of a service coordinator and at least two professionals from different disciplines of suspected areas of need. A child is eligible if he or she is under three years of age and has a significant developmental delay or has a physician-diagnosed and documented physical or mental condition with a high probability of resulting in a developmental delay. Children can receive services until they reach the age of three. Table 3 provides the number and percent of children, by age of referral, for program participants for October, 2007.

Table 3: Birth-to-Three Program: Age at Referral for Participants Active in October, 2007

Age	Number	Percent
Up to 6 months	179	3.2%
6 to 12 months	494	8.7
12 to 18 months	759	13.4
18 to 24 months	997	17.6
24 to 30 months	1,557	27.5
30 to 36 months	<u>1,677</u>	<u>29.6</u>
Total	5,663	100.0%

Once eligibility is determined, the early intervention team conducts an assessment to further identify the unique needs of the child and his or her 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 individual family service plan (IFSP). The IFSP must include a statement of the outcomes expected to be achieved for the child and family, how those outcomes will be achieved, a timeline for the provision of services, the manner in which services will be provided, and how the services will be paid.

The most frequently used services by participants in the birth-to-three program (other than service coordination, a mandatory service for all participants) include communication services, special instruction, occupational therapy, physical therapy, and family education. In addition to these services, the following services may also be provided:

- assistive technology services and devices;
- audiology services;
- certain health care services;
- medical services provided only for diagnostic or evaluation purposes;
- nursing services;
- nutrition services;
- psychological services;
- social work services;
- transportation; and
- vision services.

Appendix II identifies the county-by-county allocation of state, federal, and local birth-to-three funds for calendar year 2007. Table 4 identifies revenues received by counties in calendar year 2007 for the birth-to-three program from all sources.

Epilepsy Service Grants. DHS allocates \$150,000 general purpose revenue annually to private, nonprofit organizations or county agencies that provide direct or indirect services to or on be-

Table 4: Calendar Year 2007 Total Revenue for Birth-to-three Program

Revenue Type	Amount
Community Aids and County Funds	\$13,944,400
State and Federal Funds	13,010,200
Medicaid	2,043,700
Parental Cost Share	421,600
Private Insurance	311,500
Other	<u>297,900</u>
Total	\$30,029,300

half of persons with epilepsy. "Direct services" include services provided to a person with epilepsy or a member of the family of a person with epilepsy, including counseling, referral to other services, case management, daily living skills training, provision of information, parent helper services, employment services, and support group services. "Indirect services" include services provided to a person working with or on behalf of a person with epilepsy and including service provider training, community education, prevention programs and advocacy.

DHS issued grants to four regional affiliates of the Epilepsy Foundation (Southern Wisconsin, Central and Northeast Wisconsin, Southeast Wisconsin, and Western Wisconsin).

Total County Expenditures. Appendix III shows county expenditures for programs that serve persons with developmental disabilities for calendar years 2000 through 2007. This appendix includes expenditures from all sources described in this paper besides Family Care.

Institutional Services

The DHS Division of Long Term Care (DLTC) currently operates three residential facilities for the care of persons with developmental disabilities: Northern Center (NWC) in Chippewa Falls; Cen-

tral Center (CWC) in Madison; and Southern Center (SWC) in Union Grove (Racine County). These facilities are certified as Intermediate Care Facilities for the Mentally Retarded (ICF-MR) by CMS.

As counties' 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 Centers. In 1995, Central Center and Southern Center entered into an agreement with the United States Department of Justice under the Civil Rights of Institutionalized Persons Act (CRIPA). Under the agreement, CWC and SWC may not accept permanent placements unless services outside of the centers are not adequate to meet the needs of the individual, in which case an admission may only be made on a temporary basis. All requests for temporary, longer-term admissions must be approved by the appropriate court.

A short-term admission is typically made to provide evaluation, assessment, crisis intervention, 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 Centers and the Medial Short Term Care Program at CWC. These types of admissions require the approval of the local community board or appropriate Managed Care Organization, the director of the 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 and may be extended to 180 days with mutual agreement of the referring entity and the Center Director. Short term admissions are typically voluntary admissions.

In recent years there have been no admissions for long-term care to the State Centers. However, if there were, it is required that within 30 days after a person is admitted for long-term care, DHS and the county or appropriate Managed Care Organization must identify the support services that would be necessary for an individual to successfully live in

the community. In addition, a person over the age of 18 may only be admitted to a Center for long-term 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 the Watts review for all long-term admissions to the Centers.

The State Centers provide residents with services that may not otherwise be available to them and assist them in returning to the community. Counties are responsible for the care and treatment of persons with developmental disabilities and, thus, play a significant role in determining where an individual will receive services.

The State Centers provide the following services: (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 centers may offer dental, mental health, therapy, psychiatric, psychological, general medical, pharmacy, and orthotics services.

The Centers are certified as ICFs-MR by the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS). An ICF-MR provides care and active treatment to residents with mental retardation (intellectual disability) and who need medical, nursing and/or psychiatric supports to acquire skills for personal independence.. This certification makes the centers eligible for federal cost sharing under the state's MA program. Unlike MA payments to other ICFs-MR, MA payments to the centers are based on the actual eligible costs of operating each center, as limited by the amount budgeted by the Legislature for this purpose.

Currently, two of the three state-operated facilities, Central and Southern Center, serve individuals with developmental disabilities on a long-term basis. These individuals have lived at the Centers many years and neither Center is currently admitting new individuals for long-term care. The 2003-05 biennial budget (2003 Wisconsin Act 33) required DHS to relocate Northern Center's residents to either a community-based setting or to another ICF-MR, but authorized the facility to continue to provide short-term ITP services and certain alternative services.

Table 5 shows the respective population and reimbursement rates as of June 30, 2008, for each of the state centers. The population at the centers has declined significantly over the years. For example, in 1970, nearly 3,700 persons resided in the centers, compared to 486 as of June 30, 2008. This decrease is largely due to the state-initiated movement to relocate center residents into the community which 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 as a result of implementation of the community integration program (CIP IA) in 1983 and the recent phase-out of long-term care services at Northern Center.

Table 5: State Centers Resident Population and Daily Inpatient Rates as of June 30, 2008

	Rates	Population
Northern Center	\$1,281	15
Central Center	723	270
Southern Center	668	<u>201</u>
Total		<u>486</u>

Table 6 illustrates the number of residents that have been relocated from the state centers into a community-based setting as a result of the CIP IA program from 2005-06 through 2007-08.

Table 7 identifies the total budget and the number of full-time equivalent (FTE) staff positions for each center for the 2007-08 fiscal year.

Table 6: CIP IA Relocations

	<u>2005-06</u>	<u>2006-07</u>	<u>2007-08</u>
CWC	7	20	7
NWC	17	2	0
SWC	<u>8</u>	<u>11</u>	<u>6</u>
Total	32	33	13

Other facilities offer institutional care for Wisconsin residents with developmental disabilities. Like the state centers, these ICFs-MR are certified by the U.S. Department of Health and Human Services, CMS and must meet federal MA care and treatment standards. Over time, the number of these facilities has continued to decline, as an increasing number of individuals receive services in a community-based setting. For example, excluding the three state centers, as of June 30, 2008, there were 14 facilities serving individuals with developmental disabilities operating in Wisconsin with 537 licensed beds. At the end of calendar year 2005, there were 26 facilities with 990 total licensed beds. Current facilities range in size from 5 to 131 staffed beds. Counties operated 8 of the 14 ICFs-MR (57%), which accounted for 45% of the licensed ICF-MR beds (244 of 537). Nearly all ICF-MR residents in the state are supported by MA.

As noted above, DHS encourages counties to provide care to persons with developmental disabilities in the community rather than institutions. These changes included: (a) requiring counties to provide services to persons with developmental disabilities in the community unless it is determined that a community-based placement would not be the most integrated setting appropriate to the needs of the individual, taking into account information presented by all affected parties; (b) transferring responsibility for the non-federal share of ICF-MR costs for persons with developmental disabilities from the state to counties; and (c) providing funding to ICFs-MR entering into phase-down agreements and to counties to encourage community-based placements through additional CIP IB slots and one-time funding allotments.

**Table 7: State Centers for the Developmentally Disabled -- Budget and Authorized Positions
State Fiscal Year 2007-08**

	Central Central Center	Northern Center	Southern Center	Total
I. Program Revenues - MA				
State Operations	\$62,205,000	\$0	\$40,330,500	\$102,535,500
Utilities and Fuel	1,890,100	925,200	\$1,668,600	4,483,900
Repair and Maintenance	<u>258,300</u>	<u>0</u>	<u>350,400</u>	<u>608,700</u>
Subtotal	\$64,353,400	\$925,200	\$42,349,500	\$107,628,100
II. Program Revenues - Other				
Alternative Services	\$200,900	\$9,153,900	\$24,100	\$9,378,900
Farm Operations	0	0	30,000	30,000
Activity Therapy	21,000	5,300	5,000	31,300
Gifts and Grants	35,000	70,000	30,000	135,000
Interagency and Intra-Agency Programs	253,000	1,135,600	249,800	1,638,400
State Owned Housing Maintenance	<u>107,900</u>	<u>0</u>	<u>0</u>	<u>107,900</u>
Subtotal	\$617,800	\$10,364,800	\$338,900	\$11,321,500
III. GPR Funding				
General Program Operations	\$3,000	\$20,000	\$0	\$23,000
Total Funding (All Sources)	\$64,974,200	\$11,310,000	\$42,688,400	\$118,972,600
Total Authorized Positions (All Sources)	848.46	127.00	568.00	1,543.46

These provisions are described in greater detail under the prior section on MA waiver programs, under the "*Relocation Initiative*" heading.

Table 8 provides information on the various types of institutional settings for persons with developmental disabilities in Wisconsin at the end of 2004, 2005, 2006, and 2007. As shown in this table, the number of developmentally disabled persons in institutions decreased by 995 (48.1%) over this three-year period, from 2,069 on December 31, 2004, to 1,074 on December 31, 2007.

Table 8: People with Developmental Disabilities in Institutions as of December 31

Institution Type	2004	2005	2006	2007
State Centers	671	583	540	498
Other ICFs-MR	1,276	926	603	511
Nursing Homes	<u>122</u>	<u>107</u>	<u>76</u>	<u>65</u>
Total	2,069	1,616	1,219	1,074

**Board for People with
Developmental Disabilities**

The Board for People with Developmental Disabilities ("the Board") is a state agency charged with advocacy, capacity building, and systems change to benefit individuals with developmental disabilities. Formerly known as the Wisconsin Council on Developmental Disabilities in the Department of Health Services (DHS), 2007 Wisconsin Act 20 recreated the Council as an independent state agency. While the Board is fully responsible for its own rule-making and policy positions, the Department of Administration performs human resource, payroll, contracting, purchasing, and budgeting functions.

The Board'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, be independent and productive, and be integrated

and included in all facets of community life. The main responsibilities of the Board include:

- reviewing and analyzing services and supports available to people with developmental disabilities;
- developing, implementing, and evaluating a state plan for advocacy and systems change;
- advising DHS and providing counsel to the governor and the legislature;
- contracting with agencies to administer programs funded with council resources;
- advocating for persons with developmental disabilities;
- strengthening a statewide self-advocacy organization led by individuals with developmental disability; and
- supporting opportunities for people with developmental disabilities to participate in coalitions and develop leadership skills.

The Board is comprised of a combination of persons with developmental disabilities (or their representatives) and representatives of relevant state agencies or departments. Currently, the Board has 25 members, appointed by the Governor to a four-year term. At least sixty percent of the Board must consist of persons with developmental disabilities, their parents or guardians, or of immediate relatives or guardians of persons with developmental disabilities who cannot advocate for themselves. The remainder of the Board must be made of representatives from the following agen-

cies or organizations:

- A representative from the agency that administers Vocational Rehabilitation services in the Department of Workforce Development (DWD);
- A representative from the agency that administers Medical Assistance (DHS);
- A representative from the agency that administers the Older Americans Act (DHS);
- A representative from the agency that administers the Maternal and Child Health program (DHS)
- A representative from the Department of Public Instruction (DPI);
- A representative from the University Center of Excellence (Waisman Center);
- A representative from the state's Protection and Advocacy agency (Wisconsin Coalition for Advocacy);
- A public (County) provider;
- A private, not for profit developmental disability service provider; and
- A representative from a "non-governmental agency" that does advocacy.

In 2008-09, the Board is budgeted \$1,283,200 to support its operations (\$724,600 FED and \$15,000 GPR) and grants it distributes (\$543,600 FED). The Board receives these federal funds from the U.S. Department of Health and Human Services, Administration on Developmental Disabilities.

APPENDIX I

Family Care Participation by County December, 2008

County	ADRC	CMO
Barron	x	
Brown	x	
Calumet*	x	
Chippewa	x	x
Columbia	x	x
Dodge	x	x
Dunn	x	x
Eau Claire	x	x
Fond du Lac	x	x
Forest	x	
Green*	x	
Green Lake*	x	x
Jackson*	x	x
Jefferson	x	x
Juneau*	x	
Kenosha	x	x
La Crosse*	x	x
Manitowoc	x	
Marathon*	x	x
Marquette*	x	x
Milwaukee	x	x
Monroe*	x	
Outagamie*	x	
Ozaukee	x	x
Pierce	x	x
Portage	x	x
Racine	x	x
Richland*	x	x
Sauk*	x	x
Sheboygan	x	x
St. Croix	x	x
Trempealeau	x	
Vernon*	x	x
Washington	x	x
Waukesha	x	x
Waupaca*	x	
Waushara*	x	x
Wood*	x	

*Counties operate ADRC jointly with other counties.

APPENDIX II

Birth-to Three Allocations and County Expenditures Calendar Year 2007

County	County Expenditure	State/Federal Allocation	Total
Adams	\$104,238	\$33,423	\$137,661
Ashland	40,892	34,984	75,876
Barron	124,645	105,858	230,503
Bayfield	39,294	40,647	79,941
Brown	756,570	705,420	1,461,990
Buffalo	17,111	30,187	47,298
Burnett	50,392	35,854	86,246
Calumet	191,111	127,436	318,547
Chippewa	233,121	111,226	344,347
Clark	108,886	69,163	178,049
Columbia	122,573	123,459	246,032
Crawford	56,353	30,610	86,963
Dane	1,343,091	795,013	2,138,104
Dodge	222,540	170,091	392,631
Door	147,210	88,613	235,823
Douglas	67,668	99,946	167,614
Dunn	208,121	145,775	353,896
Eau Claire	190,411	232,782	423,193
Florence	3,895	15,858	19,753
Fond Du Lac	288,487	235,630	524,117
Forest/Oneida/Vilas	200,443	161,595	362,038
Grant/Iowa	130,150	134,517	264,667
Green	23,238	60,262	83,500
Green Lake	45,677	39,490	85,167
Iron	643	18,806	19,449
Jackson	78,902	39,673	118,575
Jefferson	455,052	187,112	642,164
Juneau	87,989	50,723	138,712
Kenosha	127,995	336,115	464,110
Kewaunee	68,544	47,829	116,373
La Crosse	167,310	205,509	372,819
Lafayette	15,356	28,936	44,292
Langlade	150,854	75,195	226,049
Lincoln	80,929	72,175	153,104
Manitowoc	294,180	214,393	508,573
Marathon	419,038	361,434	780,472
Marinette	89,690	82,100	171,790
Marquette	47,669	31,299	78,968
Menominee	43,065	20,856	63,921
Milwaukee	2,222,125	3,034,838	5,256,963

APPENDIX II (continued)

**Birth-to-three Allocations and County Expenditures
Calendar Year 2007**

County	County Expenditure	State/Federal Allocation	Total
Monroe	\$191,152	\$73,768	\$264,920
Oconto	272,123	58,785	330,908
Outagamie	478,748	368,664	847,412
Ozaukee	269,951	217,378	487,329
Pepin	25,431	44,720	70,151
Pierce	43,296	70,540	113,836
Polk	103,707	96,768	200,475
Portage	180,085	175,257	355,342
Price	5,548	23,361	28,909
Racine	299,898	472,827	772,725
Richland	104,224	53,194	157,418
Rock	467,262	370,870	838,132
Rusk	32,412	36,280	68,692
St. Croix	194,337	137,928	332,265
Sauk	320,612	137,854	458,466
Sawyer	19,682	38,207	57,889
Shawano	55,204	75,110	130,314
Sheboygan	232,518	288,213	520,731
Taylor	24,950	36,306	61,256
Trempealeau	63,498	54,179	117,677
Vernon	124,614	51,591	176,205
Walworth	260,165	165,652	425,817
Washburn	48,490	37,340	85,830
Washington	161,469	205,459	366,928
Waukesha	277,602	619,189	896,791
Waupaca	249,039	155,158	404,197
Waushara	59,045	39,478	98,523
Winnebago	273,903	340,019	613,922
Wood	<u>39,951</u>	<u>131,295</u>	<u>171,246</u>
Total	\$13,944,374	\$13,010,222	\$26,954,596

APPENDIX III

**County Expenditures for Services Provided to
Individuals with Developmental Disabilities
Calendar Years 2000 through 2007
(All Funds Collected and Spent at the County Level)***

<u>County</u>	<u>2000</u>	<u>2001</u>	<u>2002</u>	<u>2003</u>	<u>2004</u>	<u>2005</u>	<u>2006</u>	<u>2007</u>
Adams	\$1,321,739	\$1,406,691	\$1,454,933	\$1,741,573	\$1,279,316	\$1,385,761	\$1,538,971	\$1,973,785
Ashland	1,653,649	1,662,598	1,738,002	1,582,476	1,831,811	1,836,958	2,142,815	2,076,148
Barron	3,166,731	4,256,699	4,378,010	4,837,792	6,050,830	5,587,788	4,999,725	5,176,560
Bayfield	1,054,734	1,146,734	1,391,663	1,685,218	1,976,167	2,095,892	2,140,297	2,014,224
Brown	15,351,723	16,131,859	17,536,434	19,495,666	22,529,768	26,958,707	32,498,956	36,002,133
Buffalo	1,039,154	1,158,905	1,179,937	1,186,988	1,735,508	1,860,067	2,423,887	2,201,337
Burnett	753,427	943,963	1,004,809	1,068,291	1,202,728	1,253,313	1,602,039	1,896,717
Calumet	3,174,497	3,320,083	3,529,611	3,573,803	4,036,424	4,482,321	4,681,869	5,267,270
Chippewa	3,551,046	3,862,943	4,509,403	5,315,763	6,243,110	7,282,954	9,132,282	10,355,084
Clark	5,174,187	5,500,367	5,789,295	6,018,698	6,684,994	6,807,819	6,901,356	7,114,980
Columbia	4,772,250	5,766,874	6,144,957	6,066,232	7,677,351	8,567,147	9,385,151	9,957,657
Crawford	2,624,403	2,693,187	2,908,469	2,923,674	2,959,756	2,962,825	3,234,339	3,312,938
Dane	62,384,761	67,672,417	67,837,046	73,857,484	76,775,600	78,889,136	80,989,610	80,930,404
Dodge	4,260,157	4,656,868	5,472,518	5,846,551	7,039,286	7,655,241	8,903,195	9,444,040
Door	2,641,991	2,975,385	2,965,481	2,880,386	3,828,683	3,512,613	4,481,317	4,860,290
Douglas	4,307,397	5,471,372	5,763,738	5,933,962	6,232,779	6,703,822	6,546,397	6,747,704
Dunn	4,147,813	4,052,359	4,030,124	4,560,812	4,932,619	5,409,055	6,182,229	6,984,458
Eau Claire	8,706,715	9,423,672	10,088,521	11,609,232	11,643,687	12,872,099	13,925,266	14,552,945
Florence	231,654	201,767	247,423	232,521	321,346	349,685	406,046	381,298
Forest-Oneida-Vilas	7,016,695	7,562,228	7,221,298	8,294,983	8,648,130	10,226,039	11,596,284	11,556,512
Fond du Lac	8,639,120	10,133,008	2,230,797	2,816,914	3,112,249	3,103,202	2,858,176	3,054,442
Grant-Iowa	4,592,000	4,829,187	5,075,912	5,423,031	5,796,635	6,484,135	6,594,559	6,648,995
Green	2,213,256	2,380,176	2,506,100	2,648,058	2,963,761	3,007,606	2,788,219	3,035,761
Green Lake	817,239	1,830,734	2,014,278	2,514,732	3,048,756	3,360,345	3,490,884	3,613,179
Iron	376,987	435,147	564,474	545,624	616,364	796,712	923,910	875,742
Jackson	2,978,313	3,143,513	3,230,707	2,982,752	3,330,843	3,379,455	3,707,839	4,108,035
Jefferson	5,598,914	6,355,836	8,101,116	10,155,065	11,534,827	13,899,921	14,476,593	17,262,039
Juneau	1,393,423	1,446,999	1,487,927	1,767,506	1,838,490	2,242,811	2,607,522	2,899,390
Kenosha	9,334,373	9,378,863	9,742,801	10,585,680	13,710,855	14,578,861	15,357,821	11,395,539
Kewaunee	2,009,052	2,338,931	2,535,457	2,762,766	3,258,572	3,350,892	3,437,525	3,437,525
La Crosse	7,300,807	9,129,428	1,182,811	1,422,880	1,983,444	2,119,770	2,132,016	2,505,136
Lafayette	1,304,855	1,430,382	1,619,155	1,804,476	1,807,743	2,031,981	2,348,876	2,139,189
Langlade-Marathon	12,867,416	14,347,952	16,940,767	18,282,353	18,083,380	21,125,067	23,474,132	24,414,508
Lincoln	2,451,053	2,743,370	2,734,871	3,291,545	3,314,211	4,188,217	4,497,385	4,524,040
Manitowoc	3,449,090	3,997,838	5,492,645	6,529,961	7,235,350	9,889,545	12,384,703	14,139,212
Marinette	2,632,439	2,690,360	2,837,232	3,437,723	3,404,661	3,193,998	3,607,221	3,891,529
Marquette	1,155,982	1,268,025	1,508,018	1,416,252	1,553,423	1,555,752	1,482,720	1,412,435
Menominee	280,007	324,792	416,667	462,388	525,180	382,545	463,895	489,591
Milwaukee	52,940,547	57,072,953	73,693,315	80,873,012	91,994,620	90,070,410	83,691,641	87,323,875
Monroe	3,388,112	3,739,973	4,125,772	4,620,193	4,581,912	5,068,056	5,544,127	6,040,049

APPENDIX III (continued)

**County Expenditures for Services Provided to
Individuals with Developmental Disabilities
Calendar Years 2000 through 2007
(All Funds Collected and Spent at the County Level)***

County	2000	2001	2002	2003	2004	2005	2006	2007
Oconto	\$3,569,367	\$3,998,171	\$5,684,525	\$6,327,049	\$7,061,238	\$7,830,253	\$7,871,525	\$8,207,649
Outagamie	13,726,766	13,987,011	13,584,541	14,109,517	14,839,323	16,395,219	18,942,458	20,525,504
Ozaukee	5,213,489	5,792,129	6,726,458	7,528,623	8,201,025	9,012,186	8,989,087	10,243,581
Pepin	1,066,028	1,192,583	1,191,984	1,206,402	1,423,660	1,799,986	1,865,382	1,874,952
Pierce	3,423,013	3,865,913	4,031,580	4,155,662	4,820,016	4,734,038	4,410,740	4,436,298
Polk	1,769,269	2,290,314	2,393,339	2,602,525	3,053,106	3,407,889	3,265,349	3,615,375
Portage	4,133,608	5,889,191	1,057,247	1,021,584	1,311,301	1,301,070	1,301,562	1,218,870
Price	1,669,705	1,683,408	1,611,557	1,818,553	1,935,395	2,280,547	2,815,150	2,960,079
Racine	10,747,099	11,817,936	12,723,189	13,031,676	13,012,005	11,982,693	10,985,143	5,019,013
Richland	2,330,171	2,040,676	251,322	394,402	477,662	279,134	301,513	364,507
Rock	15,481,778	16,533,781	18,078,964	19,332,143	19,352,457	20,787,800	24,127,433	24,961,084
Rusk	1,263,343	1,153,889	941,543	1,351,703	2,197,358	2,627,032	2,971,349	2,963,381
St. Croix	8,504,566	9,145,184	10,133,649	11,244,630	12,837,269	2,532,199	7,343,190	7,746,633
Sauk	4,835,489	4,973,670	4,725,616	5,119,074	5,840,299	6,401,226	2,244,162	2,519,693
Sawyer	1,378,679	1,418,423	1,439,864	1,776,696	2,050,619	2,188,340	4,928,395	5,218,421
Shawano	2,795,106	2,716,076	2,820,675	3,075,112	3,719,861	4,414,040	14,349,614	18,605,875
Sheboygan	8,024,905	8,833,314	9,852,905	9,573,674	10,954,761	11,407,513	2,377,199	2,646,396
Taylor	2,285,424	2,432,612	2,569,228	2,688,470	2,755,712	3,074,434	3,262,112	3,172,103
Trempealeau	35,004	2,655,438	2,671,570	2,683,987	3,019,574	3,479,514	3,699,622	3,811,033
Vernon	2,136,650	2,492,548	2,658,188	2,759,554	3,071,204	3,146,918	3,190,461	3,963,278
Walworth	4,150,339	4,430,899	4,719,653	5,060,691	6,537,015	6,676,988	6,800,798	6,909,952
Washburn	1,549,880	1,049,456	1,280,250	1,591,721	2,114,002	2,438,532	2,573,529	2,669,587
Washington	8,321,767	9,972,911	10,775,188	11,271,767	11,716,010	13,550,552	14,303,386	14,958,023
Waukesha	16,486,881	16,437,222	16,639,906	19,260,527	24,043,241	25,298,511	27,086,075	30,965,719
Waupaca	4,453,232	4,758,630	5,453,369	5,654,831	7,046,465	7,859,958	9,026,085	10,388,623
Waushara	1,778,263	2,072,166	2,391,638	2,012,619	1,886,467	2,042,870	2,221,559	2,310,583
Winnebago	13,178,397	15,996,435	16,115,676	16,892,311	21,094,819	21,869,243	22,847,728	24,291,294
Wood	<u>5,720,422</u>	<u>5,353,225</u>	<u>7,482,172</u>	<u>7,697,897</u>	<u>8,212,142</u>	<u>9,226,744</u>	<u>11,316,616</u>	<u>12,323,930</u>
Total	\$413,086,348	\$453,867,649	\$473,238,290	\$514,298,416	\$571,909,175	\$598,573,952	\$634,999,017	\$664,908,131

*Does not include Family Care program expenditures.