

**Report of the
Committee to Study Intermediate Care Facilities
for the Mentally Retarded (ICFs-MR)**

December 2009

EXECUTIVE SUMMARY

In fall 2009, the Secretary of the Department of Health Services established a Committee to study Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) in Wisconsin, as directed in 2009 Wisconsin Act 28, the 2009-11 biennial budget bill. The committee was charged with studying the need for existing ICFs-MR in maintaining an effective, high-quality, planned system of services for persons with developmental disabilities.

As of November 2009, fifteen ICFs-MR operate in Wisconsin providing long-term care services to individuals with developmental disabilities. Of the fifteen, two are state-run centers, and thirteen are private or county-administered ICFs-MR. As of December 2008, a total of 884 individuals resided on a long-term basis in ICFs-MR in Wisconsin.

In Wisconsin and nationally, the number of ICFs-MR and the number of individuals with developmental disabilities residing in an ICF-MR have declined significantly over the last decade. The declines in the number of institutions and of institutional residents have been accompanied by an increased use of home- and community-based services for individuals with developmental disabilities. In Wisconsin, the number of individuals with developmental disabilities served in community settings almost doubled from 8,590 in 1999 to 15,655 in 2008, while the number of individuals with developmental disabilities served in institutional settings decreased by approximately two-thirds from 2,974 in 1999 to 945 in 2008. As a result, the proportion of individuals with developmental disabilities receiving publicly-funded long-term care services who were served in a community setting grew from 74% in 1999 to 94% in 2008. More individuals with developmental disabilities at each care level are served in the community than in an institution.

Wisconsin is in the lowest third of states in terms of the proportion of individuals with developmental disabilities residing in a long-term care institution; specifically, Wisconsin is one of 16 states where 10% or fewer individuals with developmental disabilities resided in an institution as of June 2007. States that have been most successful in transitioning to decreased use of ICFs-MR have developed community capacity in a planful manner either before or as relocations occurred. Wisconsin is committed to addressing the needs of each person with a developmental disability, whether in a community or institutional setting, using an individualized, person-centered approach.

The level of Medicaid reimbursement for non-state-administered ICFs-MR is set in the biennial budget bill. Similar to many other Medicaid provider groups, the full cost incurred by these institutions is not covered by the Medicaid reimbursement level. In contrast, Medicaid reimbursement for the State Centers fully funds the cost of operation. The state uses this approach to maximize the use of federal Medicaid matching funds to support the State Centers, thereby conserving the need for state funding.

Under Wisconsin law, an individual may be placed for long-term care in an ICF-MR only if a court finds the individual incompetent, appoints a guardian, and issues a protective placement order for an ICF-MR based on the finding that the facility is the most integrated setting appropriate to the individual's needs. The protective placement must be reviewed annually by the court.

The Committee's key findings are:

- Wisconsin has a strong long-term care system for serving people with developmental disabilities, with quality services both in institutional and in community-based settings.
- The state needs a range of service capacities for people with developmental disabilities to meet both the range of needs of individuals and the varying needs a single individual may have over his or her lifetime.
- To support people with developmental disabilities safely and successfully in the community, Wisconsin needs strong systems for specialized services that are accessible statewide, particularly in the areas of medical, psychiatric, dental, crisis intervention, and respite services.
- Given the increasing number and proportion of individuals with developmental disabilities who are choosing to live in community-based settings, Wisconsin needs to maintain a robust and adequately-funded community-based system.

RECOMMENDATIONS

A majority of Committee Members supported the following recommendations:

- 1) Ensure that institutional and community settings meet the safety, medical, personal, social, and spiritual needs of an individual in an environment that fosters a sense of belonging, meaningful interaction and continued growth.
- 2) Expand specialized services, including short-term medical and behavioral services, dental services, crisis services, and respite services, to ensure these services are accessible statewide for individuals with developmental disabilities living in the community. A possible approach is developing capacity on a regional basis.
- 3) Leverage existing ICF-MR staff expertise to expand expertise and capacity in the community; for example, by training providers in the community.
- 4) Use staff and specialized services at the ICFs-MR, such as dental services, to serve individuals with developmental disabilities living in the community.

- 5) Ensure a capacity within the state for specialized long-term care for a period of time for people with developmental disabilities with complex medical acuity and behavioral and psychiatric needs.
- 6) Consider modernization of state DD Centers by building new, smaller, state-of-the-art buildings that are suitable for medically complex, frail individuals and that reflect best practices and contemporary standards that are community-oriented.
- 7) Ensure that information about short-term ICF-MR programs is known as an option for people on waitlists.
- 8) Provide short-term support for individuals and families on waitlists.
- 9) Develop strategies for improving retention of community-based caregivers.
- 10) Establish a parent forum, composed of parents of individuals living in both institutional and community-based settings, as a way of sharing information about the service array available for people with developmental disabilities.
- 11) Undertake a rigorous study of mortality rates in Wisconsin for people with developmental disabilities in both institutional and community settings to understand the relative mortality and safety risks in both settings.
- 12) Increase the Medicaid reimbursement rate at non-state ICFs-MR (for example, by reallocating funding that had previously been used for residents who die to increase the Medicaid ICF-MR reimbursement rate).
- 13) Ensure that institutional funds that are reallocated to the community remain sufficient to support fully individuals' needs.
- 14) Refine the ICF-MR reimbursement method to more accurately reflect the level of acuity of individuals with developmental disabilities.
- 15) Explore the possibility of using the same Medicaid reimbursement formula for state and non-state ICFs-MR.
- 16) Instruct DHS to conduct an internal review of its current oversight methods designed to ensure that people with developmental disabilities are living in the "most integrated settings," as required by state and federal law.
- 17) Instruct DHS to create a task force composed of state center staff, ICF-MR staff, and other knowledgeable people as appropriate to develop a plan to adapt programs and environments within state centers and ICFs-MR to best meet the needs of an aging population.

Report of the Committee to Study Intermediate Care Facilities for the Mentally Retarded (ICFs-MR)

INTRODUCTION

In fall 2009, the Secretary of the Department of Health Services established a Committee to study Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) in Wisconsin, as directed in Section 9122(7i) of 2009 Wisconsin Act 28, the 2009-11 biennial budget bill. This provision was initiated by the Legislature. As specified in statute, the committee was charged with “studying the need for existing intermediate care facilities for the mentally retarded in maintaining an effective, high-quality, planned system of services for persons with developmental disabilities.” The committee was composed of a broad range of stakeholders with interest and expertise in ICFs-MR. The full committee membership is provided in Appendix A.

The ICF-MR Committee met three times between October 6 and November 19, 2009. The Committee reviewed data and information from state and national sources and heard presentations from state and national experts in areas that the Committee determined were important to examine. The Committee expresses its appreciation to these resource experts for participating in this project. The Committee also recognizes and expresses its appreciation to Michael Pancook for his valuable contribution as staff to the Committee and for researching and compiling data reviewed by the Committee. The background section summarizes the material reviewed by the Committee.

BACKGROUND

Institutions for Individuals with Developmental Disabilities

Under Wisconsin statutes and regulations, an Intermediate Care Facility for the Mentally Retarded (ICF-MR) is a residential facility with the capacity to serve 4 or more individuals, which provides nursing care to any resident, and which primarily serves residents who are developmentally disabled and who require and receive active treatment. As of November 2009, fifteen ICFs-MR operate in Wisconsin providing long-term care services to individuals with developmental disabilities (see Appendix B). Of the fifteen, two are state-run centers and thirteen are private or county-administered ICFs-MR. The state operates a third ICF-MR, Northern Wisconsin Center, which as of September 2006 serves exclusively short-term intensive treatment program (ITP) clients. Two of the non-state facilities, Racine Residential Care and St. Coletta’s of Wisconsin, Inc., are in the process of downsizing and intend to close in late 2009 or early 2010. Two other ICFs-MR, Southern Wisconsin Center and Bethesda Lutheran Communities, are restructuring by strengthening opportunities for voluntary relocations.

As of December 2008 (the most recent period for which detailed data is available), a total of 884 individuals resided on a long-term basis in ICFs-MR in

Wisconsin. Of this total, approximately half, or 447, resided in the two state Centers and the remaining half, or 437, resided in the county and private ICFs-MR (see Appendix C). The population of the private and county ICFs-MR ranged from 9 to 114, which was considerably smaller than the two State Centers, which served 184 and 257 long-term residents at Southern and Central Wisconsin Center, respectively (see Appendix B).

The number of ICFs-MR and the number of individuals with developmental disabilities residing in an ICF-MR have declined dramatically over the last decade (see Appendix C). Between 1999 and 2008, the number of non-state-owned institutions declined from 36 to 15 (representing a decrease of 58%); and the number of state-owned institutions serving long-term care residents decreased from 3 to 2 (representing a drop of 33%). Over that time, the total number of residents in ICFs-MR declined from 2,818 to 884, representing a decline of 69%. The decline in residents was sharper in non-state owned institutions, where the number of residents decreased from 1,920 in 1999 to 437 in 2008 (a decline of 77%). During the same period, the number of long-term care residents in state-owned institutions decreased from 898 to 447 (a decline of 50%). As a result of these population changes, as of 2008, state-run ICFs-MR began serving more individuals with developmental disabilities than non-state-owned ICFs-MR.

Long-term ICF-MR residents tend to be middle-aged, with an average age of 53 as of December 2008 (see Appendix D). The age of residents ranged from 9 to 97. Five residents of a non-state ICF-MR were under the age of 18 and three residents of a state center were under the age of 18.

In recent years, the number of long-term care admissions to ICFs-MR has declined (see Appendix E). Between 2005 and 2008, the number of admissions to a non-state ICF-MR decreased from 40 to 21 per year (a decline of 47.5%), and the state centers admitted no new long-term care residents. New admissions tended to be middle-aged, with an average age ranging from 42 to 48 in the 2005-2008 period. In each of these years, the number of deaths at the ICFs-MR exceeded the number of new long-term care admissions. Thus, the difference in the relative annual entry and death rates produces a decrease in the ICF-MR resident population. Any resident relocations that occur, due to downsizings, closures or other factors, contribute further to the decrease of the ICF-MR population.

Wisconsin Utilization of ICFs-MR Compared to Other States

The use of ICF-MR institutions varies widely among states (see Appendix F). In June 2007 (the most recent year for which comparative state data is available), Wisconsin operated 17 institutions. The average number of institutions per state was 126; and the median was 27. Maryland and Minnesota – states with comparable population sizes to Wisconsin – operated 4 and 291 institutions, respectively.

The size of institutions also varies considerably among states. As of June 2007, 4 of Wisconsin's institutions were between 7 and 15 beds; and 13 were 16 beds or larger. Maryland's 4 institutions were all 16 beds or larger. In Minnesota, the majority of

institutions (157) had 6 or fewer beds; 97 institutions had between 7 and 15 beds; and 37 institutions had 16 or more beds.¹ Nationally, 41.4% of individuals in an ICF-MR institution resided in a facility with 15 or fewer beds, whereas in Wisconsin, only 4.1% of ICF-MR residents live in a smaller facility.²

Relative Use of Community versus Institutional Settings for Individuals with Developmental Disabilities

The declines in the number of institutions and of institutional residents have been accompanied by an increased use of home- and community-based services for individuals with developmental disabilities (see Appendix G). Wisconsin provides home- and community-based services through the Community Integration Programs (CIP 1A, CIP 1B), the self-directed supports waiver known as IRIS (Include, Respect, I Self-Direct), and the Family Care and Family Care Partnership managed long-term care programs.

The total number of individuals with developmental disabilities served in the publicly-funded long-term care system increased from 11,564 in 1999 to 16,600 in 2008 (an increase of 44%). During this period, the number of individuals with developmental disabilities served in community-settings almost doubled from 8,590 in 1999 to 15,655 in 2008, while the number of individuals with developmental disabilities served in institutional settings decreased by approximately two-thirds from 2,974 to 945. As a result, the proportion of individuals with developmental disabilities receiving publicly-funded long-term care services who were served in a community setting grew from 74% in 1999 to 94% in 2008.

Wisconsin's experience mirrors the national trend (see Appendix H). Since 1995, both Wisconsin and the nation transitioned from serving the majority of individuals with developmental disabilities in institutional settings to serving the majority in community settings. Throughout this time, Wisconsin has consistently served a lower percentage of individuals in institutional settings than the national average. In 2007, 20% of individuals with developmental disabilities nationally who receive publicly-funded long-term care resided in an institution compared to 7% in Wisconsin.

Wisconsin's use of institutions to serve individuals with developmental disabilities ranks among the lowest when compared to other states and Washington, DC (see Appendix I). Wisconsin is in the lowest third of states in terms of the proportion of individuals with developmental disabilities residing in a long-term care institution; specifically, Wisconsin is one of 16 states where 10% or fewer individuals with developmental disabilities resided in an institution as of June 2007. Ten states served a lower percentage of individuals with developmental disabilities in ICFs-MR than Wisconsin.

¹ *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007*; College of Education and Human Development, University of Minnesota; August 2008; p. 60

² *Ibid*, p. 62

It is important to note that Wisconsin is committed to addressing the needs of each person with a developmental disability, whether in a community or institutional setting, using an individualized, person-centered approach.

Acuity of Individuals in Community and Institutional Settings

The following level of care categories are applied to individuals with developmental disabilities:

- *DD 1A*: individuals with fragile, unstable, or relatively unstable health status.
- *DD 1B*: individuals who require considerable guidance and supervision and who persistently or frequently exhibit behaviors directed toward self or others which may be dangerous to health and welfare.
- *DD 2*: individuals who exhibit appropriate social responses at most times, but may occasionally exhibit inappropriate behaviors. These individuals possess varying levels of functional abilities and their health statuses are usually relatively stable to stable.
- *DD 3*: individuals who exhibit appropriate social responses with rare incidents of inappropriate or maladaptive behaviors. These individuals' health statuses are stable.

The average acuity level within an ICF-MR institution is higher than the average acuity level of community-based individuals with developmental disabilities. In 2008, the majority of institutional residents were either DD 1A or 1B, with 85% of long-term care residents of state centers and 76% of residents at a non-state ICFs-MR at these levels (see Appendix J). As the population in ICFs-MR decreases, the average acuity level rises as the most medically complex, frail residents generally remain in the ICF-MR.

In contrast, 24% of members of community-based individuals with developmental disabilities in Family Care or Partnership in December 2008 were at the DD 1A or 1B levels, and the majority were at the DD 2 level of care. This indicates that in general, lower need individuals with developmental disabilities either never entered an institution or relocated from an institution to a community setting.

Although a greater proportion of individuals in institutions exhibit higher medical needs, more individuals at each care level currently reside in the community settings than in institutional settings. The difference between the size of the institutional and community populations at each level of care is even greater than shown in the data used for this analysis, as it does not include CIP 1A and 1B clients, who live in community settings.

Legal Framework

ICFs-MR are eligible for federal Medicaid reimbursement. Under federal Medicaid law, states are not required to cover ICF-MR services in a state Medicaid program; however, in practice, all states do. Some states do not provide ICF-MR services in-state, but fund ICF-MR services for their residents, if needed, in other states. A state Medicaid plan that covers ICF-MR services must do the following:

- require a written plan of care and regular independent professional review of each resident’s need for ICF-MR services;
- provide for a utilization review program that screens each admission to an ICF-MR under criteria established by professionals not responsible for care of the resident and without financial interest in the facility;
- make these services available with reasonable promptness and provide methods relating to payment “sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population;”³
- certify participating ICFs-MR as meeting federal requirements, including that each resident receive a continuous active treatment program.

States may provide services to individuals with an ICF-MR level of care outside of an institution and receive federal matching MA funds through home- and community-based waivers. Unlike funding for ICFs-MR, federal matching funds for the waiver programs do not cover room and board. If a state operates a home- and community-based waiver program, it must provide ICF-MR services as well and allow individuals and their guardians the right to choose between waiver and ICF-MR services. Wisconsin currently operates the following home- and community-based waiver programs for individuals with developmental disabilities at the ICF-MR level of care: the Community Integration Programs 1A and 1B, the IRIS self-directed supports program, the Family Care program, and the Partnership program.

The Americans with Disabilities Act (ADA) and state placement laws create a legal framework to protect the rights of individuals with developmental disabilities. ADA requires that a public entity shall administer services in the most integrated setting appropriate to the needs of qualified individuals with disabilities. The United States Supreme Court’s *Olmstead* decision found that unnecessary institutionalization of individuals with disabilities could constitute discrimination under this provision of ADA. The *Olmstead* decision also recognized that the ADA does not require or condone terminating institutional settings for persons unable to handle or benefit from community settings.

Wisconsin placement laws establish further guidance on the appropriate use of institutions for providing services to individuals with developmental disabilities. An individual may be placed for long-term care in an ICF-MR only if a court finds the individual incompetent, appoints a guardian, and issues a protective placement order. These protective placements must be reviewed annually. The annual review process, known as a “Watts review,” includes a county Adult Protective Services agency evaluation of the physical, mental, and social conditions of the individual. The initial or continued protective placement in an ICF-MR may occur only if the court finds that the facility is the most integrated setting appropriate to the individual’s needs or that the county of residence “would not reasonably be able to provide” care under a community-based care plan “within the limits of available state and federal funds and county funds required to be appropriated to match state funds, taking into account information

³ SSA §1902(a)(30)(A)/42 USC §1396a(a)(30)(A)

presented by all affected parties.”⁴ Under a court case known as the “Judy K.” case, the court found that a county must make a good faith effort to find and fund a community placement. State law defines the most integrated setting as one that enables the individual to interact with persons without developmental disabilities to the fullest extent possible. To ensure that an individual is in the most integrated setting, state law requires that the county of residence develop a community-based care plan that must be considered by the court as part of the annual Watts review process.

Rates and Funding

Medicaid reimbursement for ICFs-MR is specified in the Medicaid State Plan and is based on four cost centers: (1) direct care, which includes direct care staff costs (nurses, nurse assistants, etc.) and direct care supplies and services; (2) support services, which includes dietary staff, housekeeping, laundry, administration, and utilities; (3) property taxes/municipal fees; and (4) property costs, which includes mortgage interest and depreciation. The nursing home reimbursement formula also includes incentive payments for certain outcomes. Medicaid payments to ICFs-MR are composed of approximately 60% federal Medicaid funds and 40% state general purpose revenue (GPR).

The level of Medicaid reimbursement for non-state-administered ICFs-MR is set in the biennial budget bill. Similar to many other Medicaid provider groups, the full cost incurred by these institutions is not covered by the Medicaid reimbursement level (see Appendix K). The estimated average Medicaid deficit for a non-state ICF-MR in state fiscal year 2008-09 was \$104.58 per patient day, which represents 32% of the total average cost per day. ICFs-MR must offset through surpluses in other lines of business or other funding sources, such as Foundation funding.

In contrast, Medicaid reimbursement for the State Centers is cost-based and the Medicaid reimbursement fully funds the cost of operation. The state uses this approach to maximize the use of federal Medicaid matching funds to support the State Centers, thereby conserving the need for state GPR funding. Any portion of the cost of the State Centers that is not reimbursed through Medicaid would need to be paid 100% with state GPR funding. The Department has submitted and received approval for a federal cost allocation plan, which allows a portion of indirect costs incurred at the Department to be allocated to the State Centers and included in the Center Medicaid reimbursement rate. This approach enables the state to claim all allowable federal Medicaid funding, and thereby minimizes the use of scarce state funding resources.

The state Medicaid reimbursement level also does not fully cover the cost of services in the CIP 1A and 1B waiver community-based programs for individuals with developmental disabilities. For these programs, counties provide the balance of funding needed to cover the cost of services (see Appendix L). With respect to the CIP 1A program, counties contributed \$7.27 million in 2006, \$7.18 million in 2007, and \$5.43 million in 2008. Over these years, the county contribution accounted for 7-8% of funding

⁴ Wis. Stat. § 46.279(2)

for CIP 1A participants. The CIP 1B program uses a combination of state-funded and county-funded slots. Based on December 31st caseloads for 2006, 2007, and 2008 and the October 30th caseload in 2009, over two-thirds of participants in this program are supported through county-funded slots. The county funding for these slots plus the supplementary county funding used to cover the full cost of state-funded slots totaled \$88.9 million in 2006, \$91.9 million in 2007, and \$78.6 million in 2008. Over these years, county funds comprised 31-35% of funding for this program. For both of the CIP programs, counties contributed \$96.2 million in 2006, \$99.0 million in 2007, and \$84.0 million in 2008, which represented 26-28% of the funding for the programs. Under the ICF-MR Restructuring Initiative, begun in January 2005, the state fully funds the community-based costs of individuals who relocate from ICFs-MR, thereby averting the need for county funding to help support these individuals.

The costs of serving individuals with developmental disabilities in institutions and in community settings differ (see Appendix M). In 2008, the estimated average cost of an individual in a state center, including Medicaid card services such as personal care, therapies, and medical equipment, was \$666 per patient day. The estimated average cost in a non-state ICF-MR was \$341 per patient day. Based on DHS's *SFY 2008 Report on Relocations and Diversions from Institutions*, individuals relocating from a non-state ICF-MR to a community setting incurred \$260 per day in Medicaid waiver and card service costs, on average. Prior to relocation, the average Medicaid expenditure for these individuals while in the ICF-MR was \$203 per day. The average Medicaid expenditure for these individuals while in an ICF-MR, \$203/day, differs from the average cost of these services, \$341/day, because as noted above, Medicaid payments for ICF-MR care do not fully cover the cost of the services.

Services for Individuals Residing in the Community

A range of residential and other services support individuals with developmental disabilities who live in the community. Community-based residential capacity in Wisconsin for individuals with developmental disabilities has grown significantly over the last decade (see Appendix N). Individuals with developmental disabilities may reside in Community Based Residential Facilities (CBRFs), Adult Family Homes (AFHs), a family member's home, or their own home or apartment. Between 2001 and September 2009, capacity of Community Based Residential Facilities (CBRFs) serving individuals with developmental disabilities, which serve five or more persons, increased from 4,542 to 4,907, which represents an increase of 8%. During that time, capacity of Adult Family Homes (AFHs) serving three or four persons with developmental disabilities doubled from 2,219 to 4,404. Data was not available to the Workgroup on the capacity and growth trends of smaller Adult Family Homes serving one or two persons.

Individuals with developmental disabilities may utilize specialized crisis or behavioral services periodically. The three State Centers operate short term intensive treatment programs (ITPs) that provide these types of services for individuals with long-term community-based living arrangements. The majority of individuals participating in these short-term services are at the DD 1B level of care and require treatment for

behavioral challenges (see Appendix O). The Centers operate the following short-term programs:

- Northern Wisconsin Center's EXCEL is a short-term, comprehensive evaluation and treatment program with 30 beds which serves children and adults with dual diagnoses of a developmental disability and mental illness. Between February 2003 and November 2009, the program had 184 admissions.
- Southern Wisconsin Center's 17-bed ITP provides short-term, intensive treatment for people with challenging behaviors, medical and/or nursing conditions, or other conditions in order to return individuals to a community setting as soon as possible. Between January 1992 and November 2009, the program had 174 admissions.
- Central Wisconsin Center operates two programs. The Short Term Assessment Program (STAP) is designed to meet the unique needs of children and adolescents with mild to profound developmental disabilities combined with significant behavioral challenges and/or psychiatric needs. Adults may receive program services as well. The Medical Short Term Care Unit (MSTCU) provides evaluation, consultation, and treatment for children and adults residing in the community. Between January 2003 and November 2009, the two programs had 189 admissions.

The average length of stay varies among the programs at the different Centers. The median length of stay for participants in Central Wisconsin Center's programs was 28 days in each of the last five years. Northern Wisconsin Center short-term service clients experienced median lengths of stays in the range of 3 to 4 months between 2005 and October 2009. The median lengths of stays at Southern Wisconsin Center varied significantly – between 87 days in 2008 and 306 days in 2006 – and tended to be longer than the other Centers. The statistics for Southern Wisconsin Center may be strongly influenced by outliers as the program served fewer patients in most years than did the other Centers' programs.

Another important specialized service for people with developmental disabilities is dental services. Due to their disabilities, individuals living in the community may pose unique challenges to community-based dental providers, which can affect access to these services. Data from state long-term managed care programs indicates that individuals with developmental disabilities experience dental access challenges, but that these challenges are similar to those faced by Medicaid clients generally. Of Family Care members with a developmental disability active on December 31, 2008, 47.8% had used a dental service in 2008. Of 2008 PACE/Partnership members with a developmental disability, 28.6% used a dental service during the year. In comparison, a slightly lower percentage, 25.8%, of other Medicaid and BadgerCare recipients received dental services in 2007. State experts in the area of dental services note that the biggest barriers to increased access are: (a) limited number of dental clinics with the physical capacity and design to accommodate people with developmental disabilities and (b) limited competency of dentists in serving people with developmental disabilities.

Use of Institutions in Long-Term Managed Care Programs

Family Care, Family Care Partnership, and PACE, the state long-term managed care programs, cover services provided both in institutions and in the community. These programs use institutional services to a very limited extent for their members (see Appendix P). Of the 6,347 individuals with a developmental disability enrolled in Family Care on December 31, 2008, only 27 had stayed in either a State Center or non-state ICF-MR in the prior year while enrolled in the program. On December 31, 2008, eleven individuals, representing 0.2% of all members with a developmental disability, resided in an institution. Of the 325 individuals with a developmental disability enrolled in Family Care Partnership or PACE, none had stayed in a State Center or non-state ICF-MR in the prior year while enrolled in the program. However, the data on Family Care Partnership and PACE members may be artificially low as 2008 was the first year these programs began enrolling individuals with developmental disabilities.

Experiences in Other States

As noted above, there has been a decreased reliance nationally on ICFs-MR to serve individuals with developmental disabilities. Charles Mosely, a national expert with the National Association of State Directors of Developmental Disabilities, briefed the Workgroup on experiences in other states. In a recent survey, 24, or approximately half of all states, indicated that they have plans to close and/or downsize public ICFs-MR in the state. Strategies that states use to reduce ICF-MR capacity include: (a) freezing admissions; (b) reducing the number of state-run centers through consolidation; (c) changing the roles of state-run centers to deliver medical and/or dental services to community-based individuals with developmental disabilities; (d) using state ICF-MR staff to train community-based providers as a means of expanding community capacity; and (e) developing community-based service capacity.

Most states have relied on group homes, such as adult family homes, rather than small ICFs-MR, to serve individuals relocating from large ICFs-MR due to the greater regulatory flexibility accorded group homes. A number of states have maintained ICFs-MR to serve individuals with dual mental health/developmental disability diagnoses. One of the community-based service capacities that is critical is emergency response crisis capacity.

A successful model used in some states is the establishment of regional centers for psychiatric and/or crisis intervention services for individuals with developmental disabilities. States that have been most successful in downsizing ICFs-MR have developed community capacity in a planful manner either before or as relocations occurred. States that can be considered possible models are: Vermont, Pennsylvania, Arizona, Ohio, Washington, and New Mexico. A useful guiding principle for states is that the quality of services for an individual who relocates to a community setting should be at least as good as the quality of services the individual received in his/her institutional setting.

FINDINGS

Based on its review of the information in the areas noted above, the Committee identified the following key findings:

- Wisconsin has a strong long-term care system for serving people with developmental disabilities, with quality services both in institutional and in community-based settings.
- The state needs a range of service capacities for people with developmental disabilities to meet both the range of needs of individuals and the varying needs a single individual may have over his or her lifetime.
- To support people with developmental disabilities safely and successfully in the community, Wisconsin needs strong systems for specialized services that are accessible statewide, particularly in the areas of medical, psychiatric, dental, crisis intervention, and respite services.
- Given the increasing number and proportion of individuals with developmental disabilities who are choosing to live in community-based settings, Wisconsin needs to maintain a robust and adequately-funded community-based system.

RECOMMENDATIONS

The following recommendations received the support of a majority of the Committee Members, that is, at least 8 votes in support of the recommendation. A summary of the voting and all comments related to the voting is provided in Appendix Q.

- 1) Ensure that institutional and community settings meet the safety, medical, personal, social, and spiritual needs of an individual in an environment that fosters a sense of belonging, meaningful interaction and continued growth.
- 2) Expand specialized services, including short-term medical and behavioral services, dental services, crisis services, and respite services, to ensure these services are accessible statewide for individuals with developmental disabilities living in the community. A possible approach is developing capacity on a regional basis.
- 3) Leverage existing ICF-MR staff expertise to expand expertise and capacity in the community; for example, by training providers in the community.
- 4) Use staff and specialized services at the ICFs-MR, such as dental services, to serve individuals with developmental disabilities living in the community.

- 5) Ensure a capacity within the state for specialized long-term care for a period of time for people with developmental disabilities with complex medical acuity and behavioral and psychiatric needs.
- 6) Consider modernization of state DD Centers by building new, smaller, state-of-the-art buildings that are suitable for medically complex, frail individuals and that reflect best practices and contemporary standards that are community-oriented.
- 7) Ensure that information about short-term ICF-MR programs is known as an option for people on waitlists.
- 8) Provide short-term support for individuals and families on waitlists.
- 9) Develop strategies for improving retention of community-based caregivers.
- 10) Establish a parent forum, composed of parents of individuals living in both institutional and community-based settings, as a way of sharing information about the service array available for people with developmental disabilities.
- 11) Undertake a rigorous study of mortality rates in Wisconsin for people with developmental disabilities in both institutional and community settings to understand the relative mortality and safety risks in both settings.
- 12) Increase the Medicaid reimbursement rate at non-state ICFs-MR (for example, by reallocating funding that had previously been used for residents who die to increase the Medicaid ICF-MR reimbursement rate).
- 13) Ensure that institutional funds that are reallocated to the community remain sufficient to support fully individuals' needs.
- 14) Refine the ICF-MR reimbursement method to more accurately reflect the level of acuity of individuals with developmental disabilities.
- 15) Explore the possibility of using the same Medicaid reimbursement formula for state and non-state ICFs-MR.
- 16) Instruct DHS to conduct an internal review of its current oversight methods designed to ensure that people with developmental disabilities are living in the "most integrated settings," as required by state and federal law.
- 17) Instruct DHS to create a task force composed of state center staff, ICF-MR staff, and other knowledgeable people as appropriate to develop a plan to adapt programs and environments within state centers and ICFs-MR to best meet the needs of an aging population.

PROPOSALS NOT SUPPORTED BY MAJORITY OF THE WORKGROUP

The following proposals were considered, but were not supported by a majority, i.e., at least 8 members, of the Workgroup.

- 1) Expand community opportunities for residents at state DD Centers on weekends and holidays. (7 Ayes, 4 Nays, and 4 Abstain)
- 2) Place a moratorium on ICF-MR restructuring. (7 Ayes, 5 Nays, 3 Abstain)
- 3) Advocate for federal changes to allow self-directed waiver funds be used for ICFs-MR. (3 Ayes, 8 Nays, 4 Abstain)
- 4) Establish a Legislative Council Study committee to review the recommendations of this workgroup and investigate whether the long-term care system for individuals with developmental disabilities is adequate to meet the spectrum of needs. (5 Ayes, 6 Nays, 4 Abstain)

CONCLUSION

The ICF-MR Committee has identified a package of recommendations to strengthen the long-term care system for individuals with developmental disabilities. Some of the recommendations require further legislative action because they involve a commitment of funds above the level of funding currently provided in the 09-11 biennial budget; specifically, recommendations 6, 12, and 15. Other recommendations could be implemented through a mix of legislative and administrative measures; specifically, recommendations 2, 5, 8, 9, and 13. The remaining recommendations do not require further legislative action for implementation. The Committee urges the Department of Health Services and the Legislature to give consideration to the Committee's recommendations in order to enhance the quality, access and choice of services in the long-term care system in Wisconsin for individuals with developmental disabilities.

