



*Maryland's Human Services Agency*

Martin O'Malley  
*Governor*

Anthony Brown  
*Lt. Governor*

Brenda Donald  
*Secretary*

# **2006 Annual Report to the Governor**

## **Maryland Caregivers Support Coordinating Council (MCSCC)**

### **December 2006**



MARYLAND  
CAREGIVERS  
SUPPORT  
COORDINATING  
COUNCIL



Maryland's Human Services Agency

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Governor

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April 10, 2007

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Community Services  
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The Honorable Martin O'Malley  
The State House  
Annapolis, Maryland 21401

Dear Governor O'Malley:

The Maryland Caregivers Support Coordinating Council is pleased to present the attached report of its activities and recommendations for Calendar 2006, the Council's fifth year of operation. We submit this report with the hope that it will help to inform your administration about the role and importance of informal and family caregiving in Maryland.

This Council provides a formal voice for informal caregivers in our state. Throughout 2006, members have continued to work together to fulfill the Council's purpose – *To coordinate statewide planning, development, and implementation of family caregiver support services.* This work has taken on increasing importance as the state strains to meet the growing needs of the disabled and aging populations, and their caregivers.

As you will see in the report, the Council has spent the year talking with caregivers and care providing agencies, while reviewing specific program approaches and implementation strategies. We hope that our recommendations are useful in setting your agenda and framework for the support of the family caregiver. It is our intent that Maryland emerges as a leader in this area.

The Council thanks you, and the General Assembly, for your interest in and support of the informal family caregiver.

Sincerely,

John Kardys, Chair

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## **Council Background**

The Maryland Caregivers Support Coordinating Council (MCSCC) was created during the 2001 Session of the General Assembly. The enabling bill (S.B. 567) passed unanimously in the House of Delegates and with one dissenting vote in the Senate. The bill was signed into law (Chapter 400) in May 2001. The effective date for the legislation was July 1, 2001.

The purpose of the Council is clearly set forth in the law and states that it will "...coordinate statewide planning, development, and implementation of family caregiver support services." Council appointments were made by the Governor's office, members were sworn into office, and the Council held its first meeting in December 2001.

Composed of appointees representative of state agencies, caregivers and other family and advocacy groups, the council is charged to:

- Solicit and gather concerns of caregivers
- Develop and distribute a handbook of current respite and other family caregiver services
- Review successful respite programs of other states
- Develop a model of a family caregiver support program
- Coordinate activities of existing and proposed family caregiver support services among the state and local public agencies
- Research available funding sources and explore possibilities for additional funds
- Identify unmet needs

## **2006 – Activities and Recommendations**

- Solicit and gather concerns of providers and caregivers

During the past year, Council members held two special sessions to meet with family / informal caregivers. On March 18, the Council conducted a Caregiver Speak-Out session at the Alzheimer's Association's Caring Expo. Caregivers were able to walk-in, sit at a table and discuss their issues and their concerns in an informal conversational setting.

During the session, we found that these caregivers struggle with several primary concerns. Younger caregivers felt left out of the social network and support groups. Latino caregivers felt that they had limited access to services and information. These caregivers said that they needed someone to talk with, not just more language appropriate reading materials.

Caregivers struggled with differences of opinion within their family, and wondered how to negotiate these issues. Caregivers wanted to know how to talk to the medical professionals to convince them that they needed social and social service support. All caregivers wanted improvement and help in negotiating both the medical and social service systems. Many caregivers expressed their need for psychological support.

On October 23, the Council held a session at the Maryland Respite Care Coalition's Respite Awareness Day. Many care providing agencies, including respite care agencies, attended. They were anxious to express their views and to hear from caregivers as well.

Agencies had several main concerns. One, a demand for direct services that outstripped the available funding; two, a lack of funds for other caregiver and care recipient needs; and three, a lack of administrative funds for training, recruitment, family assessment, etc.

Other areas of concern included provider recruitment and training, especially for special needs populations, the lack of available skilled in-home care, and support for caregivers of people with mental illness, including those who have been discharged from jails and prisons.

- Develop and distribute a handbook of current respite and other family caregiver services

During the past several years, the Council has struggled with this assignment and has considered several alternatives for development and distribution of this material. Maintaining accurate, up-to-date and accessible information is the goal, of course. This is more than the Council can do on a volunteer basis.

The Council is recommending full support and statewide implementation of the 2-1-1 service referral system. At this time the 2-1-1 system is a pilot project that covers about 70% of the state. It is available only on Verizon land lines.

2-1-1 is an easy to remember telephone number set aside by the FCC as a number to dial nationwide to access community health and human service information. The United Way of Central Maryland has spearheaded the 2-1-1 implementation effort here.

Trained, certified information and referral specialists help callers 24/7 with assessment, clarification, prioritization and specific resource information.

Council members visited the 2-1-1 sites in Baltimore City and on the Lower Eastern Shore. Members found the staff and management sensitive to the issues of caregivers. Agency referral and eligibility information is regularly updated.

Maryland also has pilot Aging and Disability Resource Centers, known as Maryland Access Point (MAP). The Department of Aging will be developing a resource database as part of that initiative.

The Council recommends the implementation of a web based 2-1-1 resource directory that is coordinated with the MAP database.

- Review successful respite programs of other states
- Develop a model of a family caregiver support program

During the past several years, the Council has reviewed respite programs of other states and has conducted community forums for both the family / informal caregiver and for provider agencies. The message was clear. Do not throw out the current system. Do not create additional levels of bureaucracy.

Do promote simplified access, coordination of services, and training and recruitment of providers. Do provide increased funding, and continue to focus on and expand consumer directed, family friendly and flexible services.

The goal of the Caregivers Support Lifespan Respite Model, proposed by the Council is to develop statewide lifespan respite services that are consumer directed, family friendly and flexible for both the caregiver and the provider. This is to be accomplished through the development of a universal application for services, the development of a “no wrong door” access system, and coordination of caregiver and provider training efforts.

In order to implement the model for caregiver support coordination, the Council recommends establishing a staff position - Director of Lifespan Respite. The purpose of this position would be to work with local caregiver and provider networks, including Maryland’s Aging and Disability Resource Centers or MAPs (Maryland Access Point), to develop a universal application for services and related automation and tracking, to streamline lifespan resource information and develop a system of no wrong door access for caregivers. The Director would also assist providers in the coordination of respite care recruitment and training efforts.

- Coordinate activities of existing and proposed family caregiver support services among the state and local public agencies

#### Long-Term and Community-Based Services Advisory Committee

Two Council members, including the Council chair, are serving on the above noted advisory committee managed by the Maryland Health Care Commission. As part of the Long Term Care Planning Act of 2006, the Commission is to study and determine the types of services and programs that the age 65 and older population and individuals with disabilities will need in 2010, 2020, and 2030 and to identify how the State should begin planning for needed services and programs in the areas of transportation, housing, medical and food subsidies and general affordability. The Committee report is due in November, 2007.

#### Mental Health Transformation State Incentive Grant

Several Council members are serving on individual workgroups. Grant activities include a thorough needs assessment of the several State agencies that serve individuals with mental illness and their families; development of a thorough resource inventory of each organization; and, a comprehensive mental health plan to transform the system.

Phase I, the resource inventory and needs assessment, has been completed. Workgroups are beginning the development of the comprehensive State plan.

- Research available funding sources and explore possibilities for additional funds

#### CMS Systems Change Grant - Model Program - Maryland’s Respite for Children

This grant provided funding for three years to complete a feasibility study and recommend a (Medicaid-like) model of respite services for children with serious emotional disabilities. The Council provided oversight and guidance to the University of Maryland Baltimore County

(UMBC) that conducted the study. The grant award was administered by the Mental Hygiene Administration (MHA).

The study found that the objective to develop a model of respite as if it were a Medicaid-like service was a challenge since respite services were not federally allowable under the Medicaid State Plan. The model outlined in the report assumes that a portion of state respite funds will be used as the match for a Medicaid waiver. It should be noted, however, participants in Medicaid waiver programs must meet an institutional level of care.

Care recipients who are certified for institutional care typically need services in addition to respite services in order to remain safely in the community. Most families who receive state funded lifespan respite services do not have a care recipient who meets an institutional level of care.

The main features of the model recommend the pooling of respite funds that provide services to families of children with disabilities; the establishment of an oversight entity to manage the process and ensure equity; provide for seamless services regardless of program portal; prioritize allocation of resources using a specialized family assessment; and, address respite care as an alternative to institutional care.

Unaddressed issues include identification of eligible children and families, funding sustainability, data management, and creation and support of the interagency oversight entity.

The UMBC researchers believe that this model should not be seen as competition for resources for adults who are disabled and the elderly. It is important that available resources are fairly allocated between all families and disability groups.

The Council does not disagree with the study recommendations. However, the Council believes that a lifespan respite model that focuses on the needs of the informal / family caregiver, while providing appropriate services to the care recipient (regardless of age or disability), meets the needs of all disability groups. While funding restrictions (Medicaid waiver) may require the creation and management of a categorical program, this may not always be in the best interest of the informal caregiver or the service community.

The study's executive summary is provided as an attachment to this report. The entire report is available on the Council's website at [www.dhr.state.md.us/oas](http://www.dhr.state.md.us/oas).

### Lifespan Respite Care Act

The Council recommends urging the Maryland delegation to support funding for The Lifespan Respite Care Act (P.L. 109-442). The Act was signed into law by the President in December 2006. The law cannot be implemented unless Congress appropriates funding.

The Lifespan Respite Care Act authorizes competitive grants to Aging and Disability Resource Centers, in collaboration with a public or private non-profit state respite coalition or organization, to make quality respite available and accessible to family caregivers regardless of age or disability.

The Council believes that Maryland has the foundation of services, and the coordination and cooperation of the service delivery network, ready to prepare a federal grant and receive funding. In addition to the Council, Maryland has a well respected Respite Care Coalition, Aging and Disability Resource Centers and caregiver support program managed by the Department of Aging, specialized respite services through the Department of Health and Mental Hygiene, and a well established network of non-profit providers of lifespan respite services through the Department of Human Resources.

- Identify unmet needs

**I.** The respite care program in the Community Services Administration at the Department of Human Resources offers short-term periodic care to individuals with developmental or functional disabilities in order to provide family / informal caregivers with a period of rest and renewal.

Between FY 2002 and FY 2007, the funding appropriation for this Lifespan Respite Care Program has been flat and waiting lists have been established. The Council recommends additional funding.

**II.** The Maryland Department of Aging, Family Caregiver Assistance Program (FCAP) was established during the 2006 Maryland Legislative session, but remains unfunded.

FCAP is a statewide program that offers grants for up to \$500 to caregivers who provide long-term care to an adult dependent. These consumer-directed grants may be used to defray the cost of goods and services required to provide on-going care; including durable medical equipment, medical expenses, medical supplies, prescriptions, home repairs or modifications, and respite care for the family member. The Council recommends providing financial support for this program in the State budget.

**III.** The family caregiver support program developed by the Council provides for the development of a universal application for services as well as improved access. In order to begin implementation, the Council respectfully requests funding of a staff position – Director of Lifespan Respite.

## **2005 – Accomplishments**

- Solicit and gather concerns of providers and caregivers

The Council held four forums to give respite care providers an opportunity to discuss barriers to service and to introduce a model of respite care service coordination and delivery developed by the Council.

At the forums, the Council found a strong and committed group of provider agencies that were anxious to provide high quality services that met family and individual needs. However, inadequate funding to meet rising family need as well as inadequate or non-existent funding for agencies' administrative needs was often mentioned. Agencies want to provide training and transportation to their staff, but found that funders often overlooked these areas.



Few other resources to support the family/informal caregiver seemed to exist in small communities once respite care funding limits were reached. Council members were impressed by the dedication of the provider agencies and their interest in hearing from caregivers themselves. Repeatedly, providers expressed concern for the informal caregiver and the struggles that they must overcome to provide care for a loved one.

Provider agencies suggested that the Council work to enhance the current system, not reinvent it. They were worried about additional layers of bureaucracy and using limited funds to establish a coordinating agency. The Council is working to incorporate the ideas and suggestions from the forums into the model and will propose a revised pilot project.

- Model Program – CMS Systems Change Grant – Maryland’s Respite for Children

Maryland’s Respite for Children grant provided funding for three years to complete a feasibility study which will result in a model of respite services for children with serious emotional disabilities. The grant is administered by the Mental Hygiene Administration (MHA), who has contracted with the University of Maryland Baltimore County (UMBC) to conduct the feasibility study. The Council provided overall monitoring, advice and direction.

During 2005, surveys of respite providers and family caregivers were completed. Twenty child serving respite providers responded to the survey. In a separate survey, one hundred sixteen families provided information.

Five COMAR code areas were reviewed across a number of departments. The general finding from this review was that there is no uniform definition of respite. Licensing requirements, financial eligibility, and funding sources across departments and administrations within departments vary widely. The service model’s challenge will be to try and build consensus on these key components that could be applicable for children across all disability groups.

It was hoped that additional federal funding would be available for a demonstration project to implement the recommendations of the feasibility study. But, it is uncertain at this point. However, it is hoped that the study findings will be widely distributed and useful for future policy and program development in this area.

### **2004 Accomplishments**

- In July 2004 Council members’ three-year terms expired. Several members were reappointed by the Governor. Additional members were nominated for vacancies.
- The Council planned a series of public forums to be conducted in early 2005 to solicit input from providers regarding the implementation of the caregivers support services Lifespan Model at the local level.
- The Council made a decision to use the handbook of respite providers published by the Maryland Respite Care Coalition (MRCC) as a basis for a caregiver resource directory and is exploring use of the web to host the directory.

- CMS Systems Change Grant – Maryland’s Respite for Children grant, provides funding for three years to do a feasibility study to establish parameters for a demonstration project to provide respite services for children with serious emotional disturbances when additional federal funding becomes available,. This grant is administered by the Mental Hygiene Administration (MHA) under the guidance of the Council. The initial study surveys families in order to identify gaps in funding, eligibility and services and to develop a model of respite care services that would be appropriate and useful for this population.

### **2003 Accomplishments**

- Award of Federal Real Choice Systems Change grant: “Respite Care for Children.” The Mental Hygiene Administration applied to the Federal Center for Medicaid and Medicare Services (CMS) for this planning grant on behalf of MCSCC. The grant provides support for laying the foundation in Maryland for the President’s proposed New Freedom demonstration project of respite care for the families of children with disabilities. The Council serves in an advisory capacity.
- Linkage of the Council to the recommendations of the Custody Relinquishment Council for child and adolescent respite care.
- Development of a model for reformed delivery of caregiver support services at the local level.
- Award of \$800,000 for a 3-year Resource Center Grant to a member agency of the Council (Maryland Department of Aging).
- Budget Development for the Council.

### **2002 Accomplishments**

In its initial year of operation, the Council conducted a survey of informal caregivers (individuals who provide unpaid care to family, friends, and others) and organized five regional public forums to hear directly from caregivers about their experiences and needs. More than 750 surveys were returned, 147 persons attended the public forums, and an additional 72 letters were received from persons who could not attend.

Caregivers were found to be individuals with a very strong commitment to their task, but who were often burdened emotionally and financially. Caregiving impacts heavily on every aspect of their lives. While some stated that they were supported in their duties as caregivers through the assistance of a person, program, or agency, many reported that they encountered significant barriers.

These barriers included ineligibility, long waits for service, insufficient resources (e.g., not enough, and at times, poorly trained respite care providers, often not available when really needed), program/agency/staff inadequacies, and legal issues. An extensive report was submitted in October 2002.

**Appendix A**

**A System of Caregiving**

**Core Values and Guiding Principles**

## System of Caregiving

### Core Values

- The system of care should honor the intrinsic merits of family, the expertise of the caregiver, and validate to the fullest extent possible the dignity; self-esteem and capacity for self-determination of the individual care recipient. The needs of families and the individuals cared for will determine the mix of supports or services provided.
- The system of care will be community based, with the focus of supports or services as well as program management resting at the community level. Every effort should be made to integrate formal services and informal support at the family and community level. The system of care should be available through out the lifespan of the family regardless of disability, chronic illness, or special need of the individual care recipient.
- The system of care should be culturally competent, with agencies, programs, services and supports that are responsive to the cultural, racial, and ethnic differences of the populations given care.

## System of Caregiving

### Guiding Principles

- Families and individuals in need of care should have access to a comprehensive array of supports and respite services offered and not imposed, which may use private and volunteer resources, publicly funded services and other flexible dollars that address the disability, chronic illness, or special needs of the individual receiving care.
- Families and individuals in need of care should receive individualized support and respite services, in accordance with their strengths, unique needs, and potentials, guided by their freedom of choice, and an individualized plan which integrates existing supports and services.
- Families, caregivers, and individuals in need of care should receive support and respite services that are available before a crisis within the least restrictive environment which best address safety while meeting the needs of the individual receiving care.
- Families and individuals needing care should receive support and respite services that are integrated, with linkages between all agencies and programs providing services with mechanisms for planning, developing, and coordinating services.
- Families and individuals in need of care should have access to support and respite services provided by care-providers. These are individuals with the necessary skills to meet the needs of the individual in need of care and who convey mutual trust and respect for the family and individual in need of care.
- Families and individuals in need of care should have access to support and respite services, which adhere to ethical standards and assure the highest level of quality care.
- Families and individuals in need of care should have access to support and respite services which are proven as effective in achieving outcomes, which can be demonstrated, and that are delivered in the most economical and efficient manner.
- The rights of families and individuals in need of care should be protected, and effective advocacy efforts should be promoted.
- Families and individuals in need of care should receive support and respite services without regard to race, religion, national origin, gender, sexual orientation, physical disability, or other characteristics, and should be sensitive and responsive to cultural differences and special needs.

**Appendix B**

**Status of Caregiving**

**A Short Review of the Current Data**

## Status of Caregiving in Maryland and the U.S.

### The Family Caregiver

**More than 50 million people provide care for a chronically ill, disabled or aged family member or friend during any given year.**

Source: U.S. Department of Health and Human Services, Informal Caregiving: Compassion in Action. Washington, DC: 1998, and National Family Caregivers Association, Random Sample Survey of Family Caregivers, Summer 2000, Unpublished

**Maryland has 547,647 family caregivers that provide 587 million hours of care per year. The market value for these services would be \$5,819,000.**

Source: National Family Caregivers Association & Family Caregiver Alliance (2006). Prevalence, Hours and Economic Value of Family Caregiving, Updated State-by State Analysis of 2004 National Estimates by Peter S. Arno, PhD. Kensington, MD: NFCA & San Francisco, CA: FCA

**The typical family caregiver is a 46-year-old married, employed woman caring for her widowed mother who does not live with her. Approximately 60% of family caregivers are women.**

Source: National Alliance for Caregiving and AARP, Caregiving in the U.S., 2004.

**1.4 million children ages 8 to 18 provide care for an adult relative; 72% are caring for a parent or grandparent. Fortunately, most are not the sole caregiver.**

Source: National Alliance for Caregiving and the United Hospital Fund, Young Caregivers in the U.S., 2005.

**30% of family caregivers caring for seniors are themselves aged 65 or over; another 15% are between the ages of 45 and 54.**

Source: U.S. Department of Health and Human Services, The Characteristics of Long-term Care Users. Rockville: Agency for Healthcare Research and Quality, 2001.

**15.2% of Maryland's children have special healthcare needs.**

Source: Data Resource Center for Child and Adolescent Health, The National Survey of Children with Special Healthcare Needs 2001.

**17% of family caregivers are providing 40 or more hours of care a week.**

Source: National Alliance for Caregiving and AARP, Caregiving in the U.S., 2004.

**The value of the services family caregivers provide is estimated to be \$306 billion a year. That is almost twice as much as is actually spent on homecare and nursing home services combined (\$158 billion).**

Source: Arno, Peter S., "Economic Value of Informal Caregiving," presented at the Care Coordination and the Caregiving Forum, Dept. of Veterans Affairs, NIH, Bethesda, MD, January 25-27, 2006.

**The need for family caregivers will increase in the years ahead. People over 65 are expected to increase at a 2.3% rate, but the number of family members available to care for them will only increase at a 0.8% rate.**

Source: Mack, Katherine and Thompson, Lee with Robert Friedland. Data Profiles, Family Caregivers of Older Persons: Adult Children. The Center on an Aging Society, Georgetown University, page 2, May 2001.

### **Economics of Caregiving**

**Women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty, and five times more likely to receive Supplemental Security Income (SSI).**

Source: Study conducted by researchers at Rice University and data compiled from the Health and Retirement Study funded by the National Institute of Aging and conducted by the University of Michigan, 1992-2004.

**Caregiving families in which one member has a disability have median incomes that are more than 15% lower than non-caregiving families. In every state, as well as the District of Columbia, the poverty rate is higher among families with a disabled member than among other families.**

Source: Disability and American Families: 2000, Census 2000 Special Reports, July 2005.

**Elderly spousal caregivers with a history of chronic illness themselves who are experiencing caregiving related stress have a 63% higher mortality rate than their non-caregiving peers.**

Source: Schulz, R. and Beach, S. R., Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. Journal of the American Medical Association, Vol. 282, No. 23, December 15, 1999.

**The stress of caring for a loved one with dementia has been shown to impact a person's immune system for up to three years after their caregiving ends, thus increasing their chances of developing a chronic illness themselves.**

Source: Drs. Janice-Kiecolt Glaser and Ronald Glaser, "Chronic stress and age-related increases in the proinflammatory cytokine IL-6." Proceedings of the National Academy of Sciences, June 30, 2003.



**Family caregivers who provide care 36 or more hours a week are more likely to experience symptoms of depression or anxiety than non-caregivers. For spouses the rate is six times higher and for those caring for a parent the rate is twice as high.**

Source: Cannuscio, C.C., C. Jones, I. Kawachi, G.A. Colditz, L. Berkman and E. Rimm, Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study. American Journal of Public Health 92:305-1311, 2002.

**A wife's hospitalization can increase her husband's chances of dying within a month by 35%. A husband's hospitalization can raise his wife's mortality risk by 44%.**

Source: Nicholas D. Christakis, Professor, Health-care Policy, Harvard Medical School, Boston and Suzanne Salamon, M.D., Associate Chief, Geriatric Psychiatry, Beth Israel Deaconess Hospital, Boston, New England Journal of Medicine, Feb. 16, 2006.

**Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as 10 years off a family caregiver's life.**

Source: Elissa S. Epel, Dept of Psychiatry, Univ of Calif, SF, et al, From the Proceedings of the National Academy of Sciences, Dec 7, 2004, Vol 101, No. 49.

**Family caregivers report having a chronic condition at more than twice the rate of non-caregivers.**

Source: Health and Human Services, Informal Caregiving: Compassion in Action. Washington, DC: Department of Health and Human Services. Based on data from the National Survey of Families and Households (NSFH), 1998 and the National Family Caregivers Association, Random Sample Survey of Family Caregivers, Summer 2000, Unpublished and National Alliance for Caregiving and AARP, Caregiving in the U.S., 2004.

## **Caregiving and Work**

**Family caregivers comprise 13% of the workforce.**

Source: Wagner, D. and Neal, M., "Working Caregivers: Issues, Challenges and Opportunities for the Aging Network". National Family Caregivers Support Program, Program Development Issues Briefs, Administration on Aging, DHHS, 2002.

83% of respondents surveyed by the Maryland Disabilities Council reported difficulty finding, obtaining or keeping child care for children with special healthcare needs.

Source: Maryland Disabilities Council, Barriers to Quality Child Care: Families of Children with Disabilities and Special Health Care Needs Speak Up, 2004.

**59% of family caregivers who care for someone over the age of 18 either work or have worked while providing care. 62% have had to make some adjustments to their work life, from reporting late to work to giving up work entirely.**

Source: National Alliance for Caregiving and AARP, Caregiving in the U.S., 2004.

**Women average 14 years out of the paid labor force, primarily due to caregiving responsibilities.**

Source: Maatz, Lisa, President's Commission to Strengthen Social Security. Older Women's League, August 2001.

**American businesses can lose as much as \$34 billion each year due to employees' need to care for loved ones 50 years of age and older.**

Source: MetLife Mature Market Institute and National Alliance for Caregiving, MetLife Caregiving Cost Study: Productivity Losses to U.S. Business, July 2006.

**10% of employed family caregivers go from full-time to part-time jobs because of their caregiving responsibilities.**

Source: National Alliance for Caregiving and AARP, Caregiving in the U.S., 2004.

**Both male and female children of aging parents make changes at work in order to accommodate caregiving responsibilities. Both have modified their schedules (men 54%, women 56%). Both have come in late and/or have left work early (men 78%, women 84%) and both have altered their work-related travel (men 38%, women 27%).**

Source: MetLife Mature Market Institute, Sons at Work: Balancing Employment and Eldercare, June 2003.

**The special healthcare needs of 67,325 children and youth caused family members to cut back or stop working.**

Source: Data Resource Center for Child and Adolescent Health, The National Survey of Children with Special Healthcare Needs, 2001.

### **Caregiving and Healthcare**

**Family caregivers provide the overwhelming majority of long term-care services in the U.S., approximately 80%.**

**Over three-quarters (78%) of adults living in the community and in need of long-term care depend on family and friends as their only source of help; 14% receive a combination of family and purchased assistance, and 8% used paid help only.**

Source: Thompson, L., Long-term care: Support for family caregivers [Issue Brief]. Washington, DC: Georgetown University, 2004 and Long-Term Care Financing Project, Long-term Care Users Range in Age and Most Do Not Live in Nursing Homes. U.S. Agency for Healthcare Research and Quality, November 8, 2000.

## **Appendix C**

### **Executive Summary**

# **Real Choice Systems Change Grant for Community Living: A Feasibility Study to Consider Respite Services for Children with Disabilities in Maryland**

**Real Choice Systems Change Grants  
for Community Living:  
A Feasibility Study to Consider  
Respite Services for  
Children with Disabilities in Maryland**

August 2006

**Prepared by  
the Center for Health Program Development and Management  
for the Centers for Medicare & Medicaid Services  
under CMS Grant # 11-P-92002/3-01 (9/30/2003-12/29/2006) awarded to the  
Maryland Department of Health and Mental Hygiene**



CENTER FOR HEALTH PROGRAM  
DEVELOPMENT AND MANAGEMENT

## Executive Summary

Under a grant awarded by the Centers for Medicare & Medicaid Services (CMS) to the Maryland Department of Health and Mental Hygiene (DHMH) in September 2003, a feasibility study was undertaken to assess respite services for children with disabilities in Maryland. Under the leadership of the Mental Hygiene Administration (MHA), a group consisting of members of the Maryland Caregivers Support Coordinating Council (MCSCC) and staff from the Center for Health Program Development and Management at the University of Maryland, Baltimore County (UMBC) performed the following tasks: analyzed regulations, conducted surveys, and developed a demonstration model.

The project had three major components, as follows:

1. Compiling and analyzing an annotated list of the Code of Maryland Regulations (COMAR) that pertain to respite
2. Conducting two surveys: one of agencies that provide respite services to families of children with disabilities, and the other of the families themselves
3. Developing a demonstration model that would provide “a respite service operated in the manner of a Medicaid service” as prescribed in the CMS request for proposals

### Analysis of Regulations

Respite services are mentioned in five separate titles in COMAR, though the vast majority of these are in Title 07—Department of Human Resources (DHR), the state social service agency; and Title 10—Department of Health and Mental Hygiene, the state public health agency. DHR’s regulations contain eight chapters and its programs primarily address families in crisis and children at risk of abuse or neglect. The DHMH regulations include ten chapters and most of the references to respite services are found in chapters that address Medicaid waiver programs.

The number of regulations pertaining to respite services is an indication of how dispersed they are in Maryland. Each program describes, in more or less detail, the eligibility for and limitations of respite services to distinct groups of people. Some regulations are very prescriptive, defining a specific number of hours, payment rates, provider qualifications, et cetera, while others are very open as to how families can use funds for respite services (e.g., families can hire a neighbor or family member for the best price). It has been expressed that some resourceful families are only able to receive the quantity of respite services that they need by applying to multiple sources.

### Surveys

After the regulations were analyzed, two surveys were conducted: one of agencies that provide respite services to families of children with disabilities, and one of the families themselves.

A survey was sent to agencies around the state to gather their perspectives on and experiences with providing respite services. Throughout the state of Maryland, six jurisdictions have only



one agency providing respite services. For some disabilities, these jurisdictions have no respite services at all. Half of the responding agencies reported being at 100 percent capacity and having a waiting list. Agency concerns included: limited funding and consequent limits to the quantity of service that they could provide, which was described as “hardly meaningful and sufficient”; sustainability; and administrative issues, such as difficulty invoicing and receiving authorization.

Families shared similar issues and were further concerned about lack of parental involvement, limited scheduling flexibility, location of services, and lack of awareness of policies and procedures. About one third of the families that responded were *not* using respite services at the time of the survey. This was because some had already used up their benefit and others were never eligible for the benefit because their incomes/assets were deemed too high, although in reality they could not afford respite services.

### Demonstration Model

The objective to develop a model as if it were a Medicaid service was a challenge because in the past, respite services were not federally allowable under the Medicaid State Plan, and therefore not an eligible Medicaid benefit. Additionally, even though respite may be included as a benefit in Medicaid home- and community-based services (HCBS) waivers, it is unusual for a state to have these waivers solely for a single service. HCBS waiver programs offer services to certain populations in the community as alternatives to institutionalization. Participants in the waiver programs must meet an institutional level of care. Under federal regulations, institutional care in the context of HCBS waivers is defined as care in a hospital, nursing facility, or intermediate care facility for the mentally retarded (ICF-MR). Individuals needing this level of care typically need services beyond the scope of respite services in order to remain safely in the community.

The model outlined in this paper assumes that a portion of state respite funds will be used as the state match for a Medicaid waiver which would provide respite services, up to 300 percent of the Federal Poverty Level (FPL), to families with children who have a disability. Further, a portion of the current state funds would be designated to provide respite services for families *above* 300 percent of the FPL.

The main features of the model are to:

- Pool funds from agencies currently providing respite services to families of children with disabilities (DHR and DHMH, including the Developmental Disabilities Administration and MHA) and from other child-serving agencies, where children’s involvement is the outcome of negative social situations that might be reversed by the provision of respite services
- Establish an interagency oversight entity to manage the process and insure equity among the populations that would now receive respite services through the new system
- Insure seamless use of the service for families regardless of which program portal they use to access respite services (i.e., the family should not have to fill out additional applications or make more contacts if they are deemed eligible at any point of entry)

- Prioritize the allocation of resources using instrumentation that assesses family need, including the severity of the child’s disability, family burden, and stress, in a manner that is accurate, equitable, and fair
- Address respite care as an alternative to institutional care

In addition to the model described above, the feasibility study acknowledges a new opportunity presented by the Deficit Reduction Act (DRA) of 2005, which allows states to amend their state plans to offer home- and community-based services, such as respite, as a state plan optional benefit. Although this option only covers individuals with incomes at or below 150 percent of the FPL, it does permit states to provide services to individuals who do not meet the institutional level of care provided in a hospital, nursing home, or ICF-MR. The requirements outlined under the DRA for the content of the state plan are complex and the service cannot be limited to children.

If the model outlined in this report were to be implemented, it would need to be further developed and the state would need to address funding and sustainability, data management, and system-level issues. While funding the model is partially enabled by the use of existing state dollars, new funds or the reallocation of existing resources will be required to support the initial activities of creating the interagency oversight entity and other administrative activities.

Sustainability opportunities lie largely in the hopes that the model will be incorporated into the lifespan model now being developed by the MCSCC. The children’s respite demonstration model would benefit from the visibility of the MCSCC lifespan respite model in both the political and social sense, and by not being seen as competition for resources focused on older adults, age 50 plus, and young individuals, age 18-64, with disabilities.

In order to evaluate and improve program performance and administration, it will be necessary to develop data management approaches that capture information that is salient, accurate, and validated by the various involved parties. Currently, it is difficult to understand who is receiving respite services, in what amount, and at what cost. It is clear that there is unmet need, but this need has not been quantified.

On the system level, it will be important to establish processes that fairly allocate resources among all disability groups. Agency staff will need to understand the needs of populations whom they do not usually serve. At the same time, it will be no small effort to move funds from established programs and budgets, requiring interventions such as regulatory changes or executive orders.

The goal of the model is to create a statewide program for respite services with a single point of entry for all eligible children with a disability. The proposed model faces significant administrative, fiscal, regulatory, and perhaps even statutory challenges. However, given the need for respite services, it is important to address these challenges.