

2004 Annual Report to the Governor

Maryland Caregivers Support
Coordinating Council
(MCSCC)

December 2004

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February 10, 2005

The Honorable Robert L. Ehrlich, Jr.
The State House
Annapolis, Maryland 21401

Dear Governor Ehrlich:

The Maryland Caregivers Support Coordinating Council is pleased to present the attached report of its activities for Calendar 2004, the Council's third year of operation. We submit this report with the hope that it will help to inform your administration about the role and importance of family caregivers and family caregiving in Maryland.

This Council provides a formal voice for informal caregivers in our state. Throughout 2004, 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 funding challenges for services to disabled children and adults, and their caregivers.

As you will see in the report's descriptions of the Council's key 2004 accomplishments, there have been substantive achievements in initiating development of a framework of support for family caregivers. It is our intent to continue this effort so that Maryland emerges as a model in this area.

The Council thanks you, and the General Assembly, for your interest in and support of our work.

Sincerely,

John Kardys, Chair
Maryland Caregivers Support
Coordinating Council



Membership July 2001 - June 2004

Stacey Beall
Community Member

Gisele Murphy Booker
Community Member

Mary Anne Kane-Breschi
Office for Genetics & Children with Special
Health Care Needs
DHMH

Vicki Brown
Community Member

Paul D. Brylske, Co-Chair
Kennedy Krieger Institute Family Center

Sheue-yann Cheng
Community Member

Janet B. Flora
Carroll County Area Agency on Aging

Shelley Northern Jennings
Alzheimer's Association

Alidz T. Khachaturian
Maryland Respite Care Coalition

Connie Marth
Delmarva Community Services

Tom Merrick
Mental Hygiene Administration
DHMH

Rosemarie D. Satyshur, Ph.D.
Social Services Administration
DHR

Elizabeth Skates
Community Member

Constance L. Urquhart
Developmental Disabilities Administration
DHMH

Bobette Watts
Governor's Office for Individuals with
Disabilities

Susan J. Vaeth
Maryland Department of Aging

Elizabeth D. Seale, Chair
Deputy Secretary
DHR

Jeanne Anastasi
Advisory Staff to Council
Community Services Administration
Office of Adult Services
DHR

Gloria Valentine
Advisory to Staff
Social Services Administration
DHR





Membership July 2004 - June 2007

Flora Marshall Baquol
Community Member

Paul D. Brylske
Kennedy Krieger Institute/Family Center

Sabrina Cooley
Lorien Health Systems

Janet B. Flora
Carroll County Area Agency on Aging

Mary Anne Kane-Breschi
Office for Genetics
DHMH

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Community Services Administration
DHR

Alidz T. Khachaturian
Maryland Respite Care Coalition

Connie Marth
Delmarva Community Services

Tom Merrick
Maryland Department of Disabilities

Rosemarie D. Satyshur, Ph.D.
Social Services Administration
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Joan Smith
Mental Hygiene Administration
DHMH

Constance L. Urquhart
Developmental Disabilities Administration
DHMH

Susan J. Vaeth
Maryland Department on Aging

Jeanne Anastasi
Advisory Staff to Council
Community Services Administration
DHR

Gloria Valentine
Advisory Staff to Council
Social Services Administration
DHR



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

2002 Activities

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. This extensive report was submitted in October 2002.

2003 Activities

- Award of Federal Real Choice Systems Change grant: “Respite Care for Children.” The Mental Hygiene Administration applied to the Federal Centers 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.
- The 2003 annual report can be viewed on the Council’s webpage at www.dhr.state.md.us/oas/mcsccl.htm.

2004 – Key Accomplishments

In July 2004 Council members’ three-year terms expired. Many agency representatives were re-appointed, however new appointments caused some interruption in the Council’s forward momentum. It has been difficult to recruit family caregivers and consumers of respite. In addition, the Council had significant change in its leadership.

- Solicit and gather concerns of Providers

The Council has 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 model at the local level.

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

After careful review and consideration of existing resource materials, the Council recommends, using the handbook of respite providers published by the Maryland Respite Care Coalition (MRCC).

Because published handbooks of this nature become out of date almost as soon as they are released, the Council is exploring the most appropriate web site for publication and distribution. However, the Council does not have staff dedicated to it. Updating is more work than can be done on a volunteer basis by the Council members.

The Council is also monitoring the pilot project to implement a 2-1-1 hotline for human services, (Maryland Health and Human Services Referral Board (MHHSRB)) and The Maryland Department of Aging's Maryland Access Point (MAP) project. The MAP pilot project will create aging and disability resource centers in two counties (Worcester and Howard), and seeks to coordinate all information and assistance for services for adults with disabilities. The Coordinating Council will monitor the progress of both of these projects.

- Develop a model family caregiver support program

After an exhaustive two-year review of other states' programs, the Lifespan Model program was developed. Activities this year have centered on planning provider forums. These forums will be used to present the model to providers and to gather their feedback. In this way, we hope to refine the model. Once the model has been reviewed and finalized, the Council will plan for its implementation.

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

Maryland's Respite for Children grant provides funding for three years to do a feasibility study, which will hopefully result in a demonstration project to expand respite services for children with 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 receives updates at their monthly meetings and monitors the overall project design and implementation of the grant. The grant reinforces the work of the Council in the recognition of respite as an essential service component needed to reduce caregiver burden.

The first year of the grant ended in October 2004. There have been some delays in implementation due to a later than expected start up date. Key components of the feasibility study have included identification of the target population (initially children with serious emotional disturbance – if a demonstration project is approved there will be a built in capacity to phase in youth with other disabilities).

A provider survey has been sent out and UMBC has developed the capacity to compile the results through a computer database. A family survey, including a satisfaction component, is almost completed and should be mailed out early in 2005. The surveys will provide data to help define the parameters of the current respite system, and help identify gaps in funding and eligibility criteria. The caregiver perspective is vital to developing a model that will be responsive to the needs of youth and families.

The feasibility study will result in a model of respite that includes a review of the current literature, Best Practices, recommended service levels, funding options, and an evaluation component that would include caregiver input.

2005 - Action Plan

The Caregivers Coordinating Council will work on the following activities in the upcoming year.

- Complete recommendations for appointment of new Council members.
- Conduct five provider forums to solicit needs of providers, and to introduce the Lifespan Model program and gather feedback
- Bring together managers of state and local public programs to provide cross training, and to develop strategies to work together more collaboratively, given the disparate funding streams, policies, and regulations.
- Develop specific recommendations for the coordination of caregiver support services among State and local public agencies.
- Develop a public relations campaign to focus attention on the needs of informal caregivers, and the contributions of those caregivers.
- Research and recommend possible grant opportunities to assist the Council in its work.
- Monitor the implementation of the 2-1-1 hotline for human services by the Maryland Health and Human Services Referral Board (MHHSRB), and see if the database that will be used by the agencies can be made available to the public. This would replace the need for a handbook.
- Begin discussions about planning for caregivers following natural disasters.