



Maryland's Human Services Agency

Robert L. Ehrlich, Jr.
Governor

Michael S. Steele
Lt. Governor

Christopher J. McCabe
Secretary

2005 Annual Report to the Governor

Maryland Caregivers Support Coordinating Council (MCSCC)

December 2005

Robert L. Ehrlich, Jr.
Governor

Michael S. Steele
Lt. Governor

Christopher J. McCabe
Secretary

March 31, 2006

John Kardys, Chair
Community Services
Administration, DHR

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

Flora Baquol
Community Member

Sabrina Cooley
Lorien Health Systems

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Susan J. Vaeth
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Thelma Savage
Council Staff
Social Services Administration,
DHR

April Seitz
Council Staff
Community Services
Administration, DHR

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

Dear Governor Ehrlich:

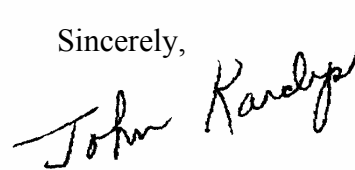
The Maryland Caregivers Support Coordinating Council is pleased to present the attached report of its activities for Calendar 2005, the Council's fourth year of operation. We submit this report with the hope that it will continue to help to inform your administration about the role and importance of family caregivers and family caregiving in Maryland.

This Council provides a formal voice for informal caregivers in our state. Throughout 2005, 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 2005 accomplishments, there have been substantive activities and achievements in the development of a model program and a framework of support for family caregivers. It is our intent to continue this effort so that Maryland emerges as a leader in this area.

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

Sincerely,



John Kardys, Chair

Membership Roster of the Maryland Caregiver Support Coordinating Council 2005



John Kardys, Chair	Community Services Administration, DHR
Paul D. Brylske, Co-Chair	Kennedy Krieger Institute Family Center
Flora Marshall Baquol	Community Member
Sabrina Cooley	Lorien Health Systems
Janet B. Flora	Carroll County Area Agency on Aging
Mary Anne Kane-Breschi	Office for Genetics & Children with Special Health Care Needs, DHMH
Alidz T. Khachaturian	Maryland Respite Care Coalition
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Susan J. Vaeth	Maryland Department of Aging
Thelma Savage	Council Staff Social Services Administration, DHR
April Seitz	Council Staff Community Services Administration, DHR

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Status of Caregiving in Maryland and the U.S.

ADULTS

- In a 2004 survey, the National Alliance for Caregiving and AARP found that 21% of the adult population over the age of 18 provides caregiving for someone 18 years of age or older.
- In Maryland, that would mean that over 828,044 adults are caregivers for other adults. (2000 Census)
- Caregiving of adults involves providing one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) for the care recipient. ADLs include personal care, grooming, dressing, and assistance with transferring from bed, chair or toilet. IADLs include shopping, housework, cooking, transportation and help managing finances.
- About 20% of the care recipients are 18 – 49 years old. Over 80% of the care recipients are age 50 or older.
- According to the survey, 69% of adult caregivers provide help to just one person. One in five caregivers provide more than 40 hours of care per week. Over 83% care for relatives.
- A typical caregiver is a 46 year old woman with some college who provides more than twenty hours of care each week to her mother.
- Four in ten caregivers are men. Male caregivers are more likely to be working full or part time than female caregivers (66% v 55%).

CHILDREN

- The National Survey of Children with Special Health Care Needs conducted by the Data Resource Center for Child & Adolescent Health in 2001 found that 15.2% of Maryland's children had special health care needs.
- In Maryland, that would mean that over 205,720 children have special health care needs. (2000 Census)
- The survey found that 18% of the children and youth with special health care needs had conditions that consistently and often affected their daily activities. In Maryland that would be over 37,040 children.
- The special health care needs of over 30% of these children and youth caused family members to cut back or stop paid employment.
- Over 15% of the families reported they could not get the level of services they needed, including respite care.

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

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. This extensive report was submitted in October 2002.

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.
- The 2003 annual report can be viewed on the Council’s webpage at www.dhr.state.md.us/oas/mcsccl.htm.

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.

2005 – Activities

- Solicit and gather concerns of providers and caregivers

During 2005 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.

The forums were held at Spring Grove Hospital Center in Catonsville, at the Eastern Shore Hospital Center in Cambridge, at the Accokeek Library in Prince George's County, and at the University of Maryland Cooperative Extension Service in Boonsboro. Each forum was held from 10:00 AM to Noon. Over seventy individuals attended. Council members guided the discussion.

The first half of the forums allowed the participants to discuss barriers and obstacles for serving caregivers and providing respite care to families, how the providers deal with these challenges, and suggestions for changes to improve service delivery. The second half of the forums was used to introduce the Council's model of respite care and collect feedback from the providers to be used to further develop the model.

Providers expressed concern for the informal caregiver and the struggles they must overcome to provide care for a loved one. 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.

Agency personnel wanted to provide training and transportation to their staff, but found that funding agencies often overlooked these areas. Few other resources 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.

The provider agencies tended to endorse the Council's model respite care program, with some reservations. They supported the proposal to have a respite care coordinator as well as a coordinated or consolidated application for services. This single point of entry, even a virtual one, would be an improvement for providers, caregivers and families.

Provider agencies suggested that the Council work to enhance the system, not reinvent it. They were worried about additional layers of bureaucracy and using limited funds to establish a coordinating agency. A complete list of comments from the forums is attached in Appendix A.

The Council is working to incorporate the ideas and suggestions from the forums into the model and will propose a pilot project within the next year.

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

Maryland’s Respite for Children grant provides 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 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. This has been the second year of the grant project.

Council members serve on a workgroup to develop the specific components of the proposed model for respite expansion. It is expected that the feasibility study will be completed by the summer of 2006.

There have been several work tasks that have been completed over the last year. The surveys of respite providers and family caregivers have been received and compiled. Information from both of these sets of stakeholders is essential so that the model of respite care will be designed to meet the needs of both providers and recipients. 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.

The final step in completing the feasibility study will be to create a Child Respite Model. The Council workgroup that is working on this model is looking at a program design that considers several key components. These include administrative oversight and implementation, eligibility criteria, combination or coordination of the disparate funding streams, workforce training and development, specific programmatic variables and requirements, and how to develop measure and evaluate outcomes.

Funding continues to be a challenge to this process. 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, the findings will be widely distributed and useful for future policy and program development in this area.

- Council Strategic Planning Retreat

In September, the Council held a planning retreat. The Council members discussed our specific charges and developed three specific goals. Each of the three goals is being managed by a

workgroup that meets to complete the action items and report back to the full Council for feedback and guidance.

The goals and action items are specified in the 2005 – 2007 Action Plan section of this report below.

2005 - 2007 Action Plan

Council Role: To focus our efforts on improving services to caregivers statewide by targeting policy development in support of caregiver services and by developing and supporting effective service coordination models.

Council Strategic Goals: By September 2007

1. All legislators, government and related department heads are aware of issues of caregivers and what caregivers need to continue as caregivers.
2. A model for caregiver services delivery will be developed and will be piloted in one jurisdiction.
3. A web based (print available) resource directory will be completed and available statewide.

2005-2006 Action Plans for Goals:

Goal 1: All legislators, government and related department heads are aware of issues of caregivers and what caregivers need to continue as caregivers.

Action Items 2005-2006:

1. List and prioritize caregiver needs based on the data
2. Define the message-cost/benefit
3. Identify target audience to once we have a data and message refined, 2006-2007
4. Identify potential partners
5. Identify solutions to those needs based on best practices
6. Develop informational packet for distribution

Measures/Desired Outcomes:

- We have had meetings with targeted policy makers and have letters of support from department heads
- We have a written proposal with partners
- Legislation/action is in place by 2007 to respond to some of the identified needs of caregivers.

Goal 2: A model for caregiver services delivery will be developed and will be piloted in one jurisdiction.

Action Items 2005-2006:

1. Refine the model based on feedback from forums
2. Identify existing resources available to support this; keep looking for partners; develop funding.
3. Bring in expert consultant to help us refine model, which may involve developing an RFP.

Action Items 2006-2007

1. Identify partners for implementing the model. Who is going to make this happen? Which jurisdictions?
2. Develop and implement a marketing plan for sharing the model with potential partners.
3. Finish product and insure funding

Goal 3: A web based (print available) resource directory will be completed and available state wide

Action Items 2005-2006

1. Research 211 and the Department of Aging's Adult and Disability Resource Center – Maryland Access Point (MAP) resource directories/resource process
2. Promote a lifespan focus with regard to caregiver issues, especially by MAP
2. Complete resource directory by the end of October 2005
3. Develop an outreach plan to advise caregivers that a print version of the directory is available

Action Items 2006-2007

1. Develop Web based directory
2. Outreach to let caregivers know the web based directory is available

Appendix A

Press Release for Provider Forums



**MARYLAND
CAREGIVERS
SUPPORT
COORDINATING
COUNCIL**

Press Release

COUNCIL TO HOLD FOUR PUBLIC FORUMS FOR RESPITE AND PERSONAL CARE SERVICE PROVIDERS

Providers get a chance to give their perspective on barriers to care

Baltimore, MD (March 14, 2005) – The Maryland Caregivers Support Coordinating Council will hold four forums to give providers an opportunity to discuss barriers to services and to introduce a model of respite care developed by the Council.

The Council is working on the forums in cooperation with the Administration of Governor Robert L. Ehrlich, Jr., through the Maryland Department of Aging, the Maryland Department of Health and Mental Hygiene, the Maryland Department of Disabilities and the Maryland Department of Human Resources.

The Council invites providers of services to consumers and families (including the elderly, adults and children with disabilities) to attend. As time permits, providers who sign up will have the opportunity to address the following issues:

- Barriers and obstacles for serving consumers and providing respite care to families
- How providers deal with these challenges
- Suggestions for change to improve service delivery
- The positive aspects of service delivery, i.e., what is working?

One hour will be allotted to address the above four issues. We strongly encourage providers to bring written testimony summarizing responses to those questions.

During the second part of the forum, the Council will introduce a model of respite care that attempts to coordinate services among providers while honoring the diverse types of services and funding streams. We would like to have feedback from providers so that we can further develop the model.

All forums will be held in the morning. The dates are:

- March 17 -- Spring Grove Hospital Center, Rice Auditorium, 55 Wade Avenue, Catonsville 10:00 a.m. to Noon
- March 29 -- Eastern Shore Hospital Center, English Hall, 5262 Woods Road in Cambridge, 10:00 to Noon
- April 12 -- Accokeek Library Meeting Room, 17773 Livingston Road, Prince George's County, 10:30 a.m. to 12:30 p.m.
- April 21 -- University of Maryland Cooperative Extension Service, 7303 Sharpsburg Pike, Boonsboro, 10 a.m. to Noon

The Council also encourages written responses, regardless of whether providers attend the forums. The Council values your input. If you cannot attend, please send your comments to:

Sue Vaeth
Maryland Department of Aging
301 W. Preston Street, Room 1007
Baltimore, MD 21201

For additional information or for directions to the forums, please call Connie Urquhart at 410-767-5624. Or visit the Web site www.dhr.state.md.us/oas.

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Appendix B

Provider Forums Participant Comments

2005 PROVIDER FORUMS

PARTICIPANT COMMENTS AND ISSUES

Agencies and providers that attended the provider forums were provided an opportunity to comment on the current system of respite care, barriers to services and the needs of caregivers who used their agencies. Their comments have been summarized into the following nine areas.

- **Respite**

Caregivers need an emotional break - Adult care is largely crisis oriented.
Specialized training is needed for those providing care for children with behavioral problems. Special training is needed in languages and cultural issues.
Specialized training is needed in dementia care issues.
Expand and promote use of independent providers.

Respite is important as a planned resource.
Respite promotes family stability.
Respite provides the opportunity for expanded and ongoing community support, options and outlets for needy families.
Respite nurtures the entire family.
Promote caregiver choice and support throughout the lifespan.

- **Funding / Costs**

Funding pays only for direct services.
Assessments may not be covered by available funding.
Agencies have other infrastructure costs related to running programs.
Demand exceeds funding and limits availability of services.
There is limited or no funding for provider training.

Income eligibility guidelines restrict services.

- **Information and Referral**

There are few alternate resources in small communities once respite funding limits are reached. Waiting lists are established throughout the state.

- **Administrative Burdens**

Bureaucratic delays in other programs (especially Medicaid waivers) put additional burdens on existing respite programs.
Local contracts or requirements can limit program flexibility.

- **Operational Issues**

Families may need to select from a pool of shared providers, because of limited provider resources. This can make it difficult for the disabled or fragile individual to receive care.

It is difficult to develop overnight respite care services.

Ongoing monitoring to assure quality safe and responsive care.

Other services (foster care) may take precedence over respite care.
Focus on respite care for caregivers as an alternative to foster care (for children).
Families live in unsafe neighborhoods or unsafe housing.

- **Transportation**

Transportation costs or ability to get providers to the families restricts program flexibility.

- **Special Resources**

Licensed foster parents.
Trained providers who team up with other providers.
Church members.
Colleges who offer studies in nursing, education, etc.
Retirees.
Adult education courses are available for home care providers.

- **Caregiver Issues**

Some caregivers are reluctant to use respite services because they feel it reflects poorly on their ability to care for their family member.

Families have other barriers to using the service – housing, personal needs items (like bed pads), mental health issues (no respite available for this population).

Some caregiver families need skills training themselves.

- **Suggestions**

Increase the respite rate for especially needy populations.
Provide for provider training.

MODEL PROGRAM

After a short presentation of the Council's proposed respite service delivery model, those present had a chance to comment on the model and make suggestions for further development and change.

- Participants agreed that it would be helpful to the families and useful for the provider agencies to simplify and centralize the service referral process. The details of which need much further development and discussion.
- Enhance the system, do not reinvent it.
- Minimize any new regulations or policies. They create barriers.
- Collaboration, new partners, new relationships are a good idea for the model.
- Provide a state coordinator and / or local coordinating agency.
- Have a single application / database for families in order to avoid duplication.
- Develop a partnership with the State's 211 initiative.
- There are some areas of the State that have local coalitions or councils that currently work to provide and coordinate services. Use these coalitions and promote further local coalition building.
- Carefully pick the coordinating agency or the state coordinator and thoroughly describe their duties.
- Concerned about funds for coordinating agency. They must be adequate. Do not add to existing duties.
- There is a need for a registry of providers including who they work with, their preferences for specialized populations, their ability to travel, etc. in order to make good match of provider with consumer / caregiver.
- Coordinating entity / agency needs high level of knowledge. There was concern about how to refer to other resources.
- Positive aspect – one location for resources.
- There are services and information available, but families and providers are not able to access it.
- Keep for profit agencies in the loop. They are often blended into the local service community.
- Importance of volunteers – need to gather information about where volunteers are – faith-based, etc.
- Provide for other family services – in addition to respite.
- Coordinate services for the family, not just the individual.
- Provide for further development of case management services and support for needy families.