2001-2002 Report to the Governor from the Maryland Caregivers Support Coordinating Council

October 2002

MARYLAND
CAREGIVERS
SUPPORT
COORDINATING
COUNCIL

"One of my colleagues has said there are only four kinds of people in the world: Those who have been caregivers; and those who currently are caregivers; those who will be caregivers; and those who will need caregivers."

Rosalynn Carter
Testimony before the Senate Special Committee on Aging, September 10, 1998

MARYLAND CAREGIVERS SUPPORT COORDINATING COUNCIL

Stacey Beall
Community Member

Gisele Murphy Booker
Community Member

Vicki Brown
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MD Respite Care Coalition, Inc.

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September 30, 2002

The Honorable Parris N. Glendening
State House
Annapolis, Maryland 21401

Dear Governor Glendening:

The Maryland Caregivers Support Coordinating Council is pleased to present the attached report of its inaugural year. This report is submitted with the hope that it will serve as a foundation for further action on behalf of Maryland caregivers.

Throughout the last ten months the appointed members of the Council have worked together, traveled around the State, and deliberated on the best approach to fulfill the Council's legislated mandate to consider the broad range of issues that affect caregivers. Through this process we have gained an even greater appreciation for the courage and strength caregivers exhibit each and every day, often against circumstances that could leave them and those that they care for devastated.

We cannot overstate the importance of supporting caregivers so that they are able to continue the great work that they do. They are an even more valuable resource than is indicated by the estimated $196 billion of care that they provide annually, on a national basis.

This Council is the formal voice for caregivers in Maryland. Through our efforts, we will ensure that Maryland becomes a model state where caregivers and those that they care for can have an optimal quality-of-life. While there is much more work to do, much has been learned about caregivers' needs, and we have begun to consider the best approach to ensure a quality, sustainable infrastructure for their support.

The Council thanks you and the Maryland General Assembly for having the interest and foresight to consider this important group.

Sincerely,

Denese F. Maker, Chair
Maryland Caregivers Support Coordinating Council

Maryland Department of Human Resources •Saratoga Street Center•311 West Saratoga Street, Room 279•Baltimore, MD 21201-3521• http://www.dhr.state.md.us/oas/mcscc.htm

Dedication

The Maryland Caregivers Support Coordinating Council wants to thank the more than a thousand caregivers who participated in the public forums, sent written testimony, or completed the *Survey of Maryland Caregivers 2002.* The work that you do on a daily basis, assisting others, is courageous. Your willingness to share your personal experiences with the Council enriched our ability to carry on the work we have been called to perform. It is our sincerest hope that the efforts of this Council will help you, others like you, and ultimately, those for whom you provide care.

Foreword

In compliance with mandates established under legislation (Senate Bill 567, enacted into law on July l, 2001), the Maryland Caregivers Support Coordinating Council is submitting this written report to the Governor and the Maryland General Assembly as a record of its activities conducted during 2001 and 2002. It is prepared for use in serving and better planning support for informal caregivers. This report presents the findings of the Council as it seeks to:

- Understand the needs of Maryland caregivers from the perspective of the caregiver
- Assemble from local, state, and national sources the best approaches to assist caregivers
- Make recommendations for, and coordinate statewide planning and implementation of, family caregiver support services
- Reduce and avoid difficulties presently encountered by Maryland caregivers

Membership Roster of the
Maryland Caregiver Support Coordinating Council 2001-2002

Denese F. Maker, **Chair**	*Community Services Administration DHR*
Paul D. Brylske, **Co-Chair**	*Kennedy Krieger Institute*
Stacey Beall	*Community Member*
Gisele Murphy Booker	*Community Member*
Vickie L. Brown	*Community Member*
Sheue-yann Cheng	*Community Member*
Janet B. Flora	*Carroll County Area Agency on Aging*
Shelley Northern Jennings	*Alzheimer's Association*
Alidz T. Khachaturian	*MD Respite Care Coalition, Inc.*
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Dorinda A. Adams, Council Staff	*Office of Adult Services, DHR*
John Kardys, Advisory Staff to Council	*Office of Adult Services, DHR Community Services Administration*
James Reinsel, Advisory Staff to Council	*Community Services Administration DHR*

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Executive Summary

"We save the government money, even if it kills us, taking excellent care of our disabled loved ones at home … Please let this [report] reveal that we caregivers are suffering inhumanely and we are being ignored."

Words of a Maryland Caregiver, 2002

The Maryland Caregivers Support Coordinating Council (MCSCC or Council) was established by the Maryland General Assembly and the Governor in May 2001. Composed of appointees representative of state agencies, caregivers and care recipients, and advocacy groups, the Council is charged to:

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

Process

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 conducted 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.

The Caregiver

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 due to the assistance of a person, program, or agency, many reported that they encountered significant barriers. These barriers included ineligibility, long waits, 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.

Next Steps

The Council plans to move into year two and three of its tenure armed with information gathered through its research on national and local models, through the survey and public forums, and through deliberations on the best approach to develop a quality, comprehensive, and sensible system to support Maryland caregivers.

Based on the findings from its first year of activities, the Council will specifically do the following:

1. Develop and implement an operating budget to allow the Council to work effectively and accomplish its mandated function.

   An operating budget would allow the Council to acquire staff, support the implementation of a "best practices" model of caregiving, increase awareness efforts, conduct annual public forums, complete a more rigorous study of caregiver needs that will serve as a baseline for evaluation, and provide technical and/or financial assistance to caregiving activities/groups.

2. Continue model development and ensure that it is "consumer driven."

   Through the comments and testimonies of caregivers from around the state, the Council learned that caregivers often suffered because of the inflexibility of mandated approaches to resource access. That is, if the consumer (caregiver) could determine how funds allocated for their use in caregiving would be spent, or experienced fewer restrictions on who they could retain to provide care, then they could more effectively relieve caregiving burdens.

3. Build respite provider capacity (quantity, qualifications, and training).

   Repeatedly, caregivers informed the Council that respite providers were inadequately trained, particularly in the specific needs across the lifespan, such as the unique needs of children with mental health problems, and the special needs of the elderly. Capacity building includes identification of potential providers, training/certification, and verification of the background of potential providers.

4. Improve respite services funding and flexibility.

   In addition to building capacity, respite services need to be more affordable and flexible so that services can be accessed on a "when needed" basis by caregivers. Caregivers report that respite services are often too little and too late; often needs cannot be anticipated.

5. Reduce system barriers and complexities.

   The Council plans to address the personal loss, difficult circumstances, and grave barriers that caregivers face on a daily basis as a result of the burden imposed by systemic inefficiencies. System challenges include the requirements of Medicaid Waivers, Department of Social Services, courts (and other legal entities), and

schools. Also, many caregivers expressed that the staff of many of the agencies/programs designed to help seemed overworked, inadequately trained, unfamiliar with rules/regulations/laws, ineffective, and, at times, even rude.

I. Introduction and Brief History of the Council

The Maryland Caregivers Support Coordinating Council was established by the Maryland General Assembly during the 2001 legislative session and signed by the Governor May 15, 2001. Under the leadership of Delegate Marilyn Goldwater, co-sponsored by Delegates Kopp, Bronrott, and James in the House, sponsored by Senator Frosh, and co-sponsored by Senators Hollinger, Pinsky, and Ruben in the Senate, the bill outlined the purpose, membership, and mandated activities of the Council (Appendix 1).

Members of the Council were selected by the Governor to insure representation from constituent communities, including caregivers of individuals with Alzheimer's Disease and related disorders, developmental disabilities, physical disabilities, chronic illness, mental or emotional conditions that require supervision, and those who are vulnerable to abuse or neglect (including children and adults). The 17-member council consists of 2 representatives from the Maryland Department of Human Resources, 3 from the Maryland Department of Health and Mental Hygiene, 1 from the Department of Aging, 1 from the Governor's Office for Individuals with Disabilities, 1 from the Maryland Respite Care Coalition, 2 consumers of respite services, 3 family caregivers, and 3 representatives of organizations that provide or have an interest or expertise in respite services. (See page iii for a listing of the Council's members.)

> *"My biggest fear is [that] I die before my son John and then what will happen to him … he will always need some sort of supervision."*
>
> *Words of a Maryland Caregiver, 2002*

The Council held its first meeting on December 4, 2001, when it established an Executive Committee and three working committees, and appointed co-chairs. The Executive Committee consists of all chairs and co-chairs. The three committees formed are the Needs Assessment Committee, the Program Committee, and the Fiscal and Regulatory Policy Committee. Each committee established a work plan to address their defined roles in accordance with the mandates of the Council.

The Needs Assessment Committee was charged to solicit and gather concerns of caregivers by conducting surveys, holding public hearings, and establishing other means for public access, such as a hotline. The purpose of these activities was to identify informal caregivers' unmet needs and to establish priorities for additional funding.

The Program Committee has reviewed respite programs in Maryland and other states, and from this information, is developing a model family caregiver support program that incorporates best practices from the researched models. Additionally, this committee is to develop and distribute a handbook of current respite and other family caregiver services available in the state.

The Fiscal and Regulatory Policy Committee researched available funding sources and explored possibilities for additional funds. Work will continue to develop means to coordinate activities of existing and proposed family caregiver support services among state and local public agencies.

II. 2001-2002 Progress Report

At its first meeting in December 2001, the Council established a three-committee structure and addressed the various components of the legislative mandate, which are:

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

The tasks selected to be addressed during the initial year of the Council were to solicit information on concerns, review successful respite programs in other states, begin modeling a caregiver support program for Maryland, and identify unmet needs. The requirement for developing the handbook had already been substantially completed by the Maryland Respite Care Coalition in the interim period between passage of the law and the appointment and activation of the Council. It was therefore decided that the task concerning the handbook would not occupy a significant place on the Council's agenda during the first year.

Initiatives and Federal Funding

The Council decided that research on funding opportunities should follow in year two as its development would depend on the caregiving model identified by the Council, which, in turn, would be based on the needs of Maryland caregivers. Simultaneously, the Council will be closely monitoring the progress of the federal Lifespan Respite Care Act of 2002, which was introduced in the Senate in May (S2489) by Senators Mikulski, Clinton, Snowe, and Breaux. This legislation would authorize funds for:

- Development of state and local lifespan respite programs
- Evaluation of programs
- Planned or emergency respite care services

- Training and recruitment of respite care workers and volunteers
- Caregiver Training

The House version of S2489 is H. R. 5241 and has 40 co-sponsors, which include Maryland Representatives Cummings and Morella. This bill is the first to address the needs of the caregiver by providing new federal dollars for respite services across the lifespan. The establishment of the Maryland Caregivers Support Coordinating Council provides a sound state and local infrastructure to respond to this federal initiative. In addition, the *Survey of Maryland Caregivers 2002* (see Section IV) will serve as valuable documentation of caregivers' needs across the lifespan. Maryland will be well positioned to qualify for these funds should they become available.

MCSCC Core Values and Guiding Principles

The makeup of the Council is representative of many perspectives of caregiving and diverse caregivers and care recipients. A glossary for the Council's internal use and a statement of Core Values and Guiding Principles were established (Table 1). The Core Values and Guiding Principles provide a framework from which the Council can determine its priorities and define a caregiving model for Maryland. The core values express the intrinsic value of the family/caregiver and care recipient, and the need for services and policies to be community-based and culturally relevant. The guiding principles highlight the rights of individuals and families receiving assistance.

Concerns of Caregivers

In assessing the needs of informal caregivers, it was necessary for the Council to lay a strong foundation for the work that was to be undertaken over the three-year term. Two projects were undertaken to establish this foundation: a survey of informal caregivers (caregivers who are unpaid for assistance they provide to family, friends, and others) and regional public forums supplementing the findings of the survey to give Council members direct access to the concerns of Maryland caregivers. The outcomes of the public forums and the survey are presented in Sections III and IV, respectively.

Unmet Needs

Through a review of the databases of Maryland agencies represented by Council membership (DHMH, MDOA, and DHR), information about waiting lists for services was gathered. Notably, the 2000 Census shows that there are 854,345

Marylanders with disabilities. In addition, 50,974 grandparents are the primary caregivers for their grandchildren. As many as 14,170 are waiting for services from various publicly funded programs, including children's, aging, and non-aging programs. Many of these individuals are served by both formal and informal caregivers.

An older and thus more conservative statistic from the ARCH National Resource Center (fact sheet 11 - May, 1992) estimated that 10 to 15 percent of children within the United States have a chronic health condition, with about 1 million of these children having costly and disabling conditions (General Accounting Office, 1989). In addition, it is estimated that approximately 17,000 to 100,000 children are technology-dependent (Office of Technology Assessment, 1987). Because of concerns for high hospital costs on a continued basis for long-term care in institutional settings and the interest for returning children to the nurturing environment of their families, these children are now living at home in communities all across the country. In 1980, respite care was the most requested service of families caring for children with disabilities at home (Cohen & Warren, 1985).

> *"A caregiver's needs are usually invisible. No one notices."*
> *Words of a Maryland Caregiver, 2002*

The Needs Assessment Committee compiled a matrix of caregiver issues identified through personal experiences and through the review of literature on national surveys (Table 2). Issues can be categorized into four domains: eligibility, services and service availability, paid caregivers/providers, and general caregiver issues. Many of these issues are reflected in the testimonies presented at the public forums and in the *Survey of Maryland Caregivers 2002*.

Table 1: System of Caregiving Core Values and Guiding Principles

Core Values

1. 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.
2. 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 throughout the lifespan of the family regardless of disability, chronic illness, or special need of the individual care recipient.
3. 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.

Guiding Principles

1. 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.
2. Families and individuals in need of care should receive individualized support and respite services. This should be done in accordance with their strengths, unique needs, and potentials, guided by their freedom of choice, and an individualized plan that integrates existing supports and services.
3. 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.
4. 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.
5. Families and care recipients should have access to support and respite services provided by care providers with the necessary skills to meet the needs of the care recipient and who convey mutual trust and respect for the family and care recipient.
6. Families and individuals in need of care should be able to exercise choice and control over how they receive services based on each individual situation.
7. Families and individuals in need of care should have access to support and respite services, which adhere to ethical standards and assure quality care.
8. Families and individuals in need of care should have access to support and respite services, which are proven effective in achieving outcomes, can be demonstrated, and are delivered in the most economical and efficient manner.
9. The rights of families and individuals in need of care should be protected, and effective advocacy efforts should be promoted.
10. 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.

Table 2: Matrix of Caregivers' Issues Identified Through Council Members' Review of the Literature

Eligibility	Services/Service Availability	Paid Caregivers/Providers	General Caregiver Issues
• Low and middle income people sometimes do not meet income eligibility guidelines, but need help	• Passing people from one organization to another with no coordination or assistance • Caregivers do not know what programs exist or how to access them • Caregivers need a support system • Should be choice for informal or formal providers • Should be consumer driven • Should be outcome based • Conflict of publicizing services when resources are inadequate to serve all who are in need • Misinformation or misunderstanding about legal issues, (e.g., POA, guardianship, advanced directives) • Needs exceed service availability, especially for transportation, medications, and home care • Choice of in-home or out-of-home care	• Trouble finding providers, especially in rural areas • Trouble retaining aides because of low pay/status • Plans of care and actual needs often exceed resources (e.g., insurance payments) • How to get new providers into the system • Transportation issues regarding helping providers get to work, especially in rural areas • Raising wages will impact how much families can buy • Aides are not adequately trained, educated, monitored, or supported • Aides not given enough or adequate information about the home situation • Aides should be involved in care planning	• Relationship of caregiving and abuse should be explored • How much money do caregivers save government programs by providing care? • Caregiver health, stress • Economic losses because of caregiving – for businesses and individuals • Frustration because caregivers' expectations of services do not reflect reality • Caregivers not always familiar with the role and availability of respite services • Continual need to train new aides, not enough respite time given • Cannot afford respite that is available • Poor discharge planning • Doctors do not have information to tell caregivers • Doctors not knowing enough/have enough training to care for older people/people with disabilities • Caregivers need information about hiring, training, and what to expect

Models of Caregiving

The Program Committee reviewed a voluminous amount of material and conducted a telephone survey of informal providers in Maryland. Models both inside and outside of Maryland were considered. Extensive searches on national models and policy analyses related to caregiver support were conducted by the Enoch Pratt Library System's State Library Resource Center and Government Reference Service for the Council. In studying materials from around the country on respite care and other supports specific to defined target populations or individual program levels, the Program Committee recommended to the Council that the research focus be on state level, system approaches. Specifically, there would be a focus on lifespan caregiver support approaches.

A key source document for the Program Committee's work was the National Respite Coalition's *State Lifespan Respite Laws, Bills, and Programs: A Side by Side Comparison*. This document outlines the provisions of six states' (including Maryland's) caregiver support programs. The other five states, located primarily in the western or mid-western region, include Oregon, Wisconsin, Nebraska, Oklahoma, and Montana. In varying degrees, the committee researched materials from these states and the effectiveness of and barriers encountered by their models.

One example of a nationwide approach is the National Family Caregiver Support Program (established by the Older Americans Act of 2000), which targets non-professional individuals serving as family caregivers for individuals aged 60 and over, as well as grandparents aged 60 and over caring for grandchildren under age 18. This program provides a model for a caregiver support program and has elements that are consistent with the committee's findings. Components of this national program include information and referral, training and education, financial assistance with both in-home and out-of-home respite care, and supplemental care services. These may include supplies, transportation, and equipment. The program is intended to be flexible and responsive to the individual caregiver's needs. Much is being learned from the early stages of this program, which may provide guidance for a model that would serve all caregivers and not duplicate what is now in place through the Older Americans Act.

Types of Support

The ARCH National Resource Center's *Local Program Survey Report 2000* was also reviewed. The report's topics include types of respite and additional family support services provided, hours of operation, types of settings for care provision, service population characteristics across the lifespan (children and adults), eligibility criteria, administrative and service strategies, and funding sources and rates around the country. This survey provides an in-depth source on national trends within the field of respite provision.

Another key source document for the Program Committee was the Executive Summary of the Family Caregiver Alliance's *Survey of Fifteen States' Caregiver Support Programs* (1999). This survey collected information from a total of 33 programs within the 15 states, and set forth 5 programs as best practice models. These models include:

1. California's Caregiver Resource Centers, administered by the California Department of Mental Health
2. New Jersey's Statewide Respite Program, administered by New Jersey's Department of Health and Senior Services
3. New York's Consumer and Family Support Service program, administered by the Office of Mental Retardation and Developmental Disability
4. Oregon's Lifespan Respite Care Program, administered by the Oregon Department of Human Services
5. Pennsylvania's Family Caregiver Support Program, administered by the Pennsylvania Department of Aging

A critical policy dimension related to model development was identified by this study. This issue concerns whether the model of caregiver support should be established as an integrated part of the community service system for the identified people in need of care, or, conversely, whether it should be established as a distinct support system for caregivers that is separate but linked to the various service systems for those in need of care. All of the model and best practice programs identified at this stage of research require further investigation to determine the pros and cons relative to Maryland.

Survey of Maryland Grassroots Models

Models of caregiving include the large and the small, public and private, complex and simple. Grassroots approaches in Maryland were targeted for research of Maryland best practices since information from the public programs and formal groups was readily available and could be reviewed later. A matrix of Maryland health and human service agency programs is included in Appendix 2. Small, local, and somewhat informal groups were difficult to locate and were identified through word-of-mouth and colleague referrals.

"Grassroots" programs are defined for this purpose as not publicly supported and not affiliated with formal groups such as the Alzheimer's Association. Based on referrals received, ten grassroots respite/caregiver programs were contacted. Of the ten selected, seven programs completed the survey through telephone interviews.

Many of the contacts were support groups through area agencies on aging, governmental agencies, hospitals, or associations. One of the groups surveyed was a parish nurse program that most closely represented the "grassroots information" being sought.

Hospital-based programs targeted their patients and caregiver support issues primarily through discharge planning. Referrals to community resources were provided. Support groups held by hospitals were open to the community, and the hospitals took calls from community residents seeking information about resources. The level of service ranged from hospital social workers working through discharge planning and facilitating support groups to a faith-based hospital that has a Caregiver Resource Center with a paid staff. Hospitals also hold seminars open to the public on topics relevant to caregiver needs and based on input from caregivers.

One respite care program provides respite care to families for children up to 18 years of age. This program is grant funded, and one of its grants is restricted to recipients who have Medicaid/Mental Hygiene Administration eligibility. A local Respite Coordinating Council has grown out of this program, the purpose of which is to gain provider input and to spread the word among potential recipients.

The parish nurse program is faith-based and focuses on one congregation and the surrounding community. The staff person is full-time and paid by the church. Her role is to identify care needs, recruit volunteers, and coordinate service provision. The program works well due to its faith-based nature. The services include advocacy, referrals, education, and problem identification. The parish nurse does not provide hands-on care but rather recruits and trains those who do. The “trust” found in the faith-based approach affects the recruitment of volunteers, eligibility and “enrollment” process, and provision of care by focusing on a defined population of providers and recipients.

The findings were surprising in that a higher number of programs with elements similar to the parish nurse program were not identified. This seems to confirm the complex nature of providing direct services. The majority of programs identified were of the resource and referral nature, which directs individuals to care sources rather than coordinates the effort for them. Everyone interviewed spoke of the uniqueness of each caregiving situation both in the requirements for care and the family resources.

From this brief, convenience sample survey, it appears that these caregivers are seeking support that addresses their specific needs. In addition, among the highest request areas are establishing a central place to find multiple resources, training to assist caregivers in selecting care providers, communicating with health professionals, and understanding what is needed upon hospital discharge.

With the exception of the parish nurse program, there appears to be a distinction between programs that provide info/referrals and no direct services and programs/agencies that provide direct services but may not be caregiver oriented.

III. Regional Public Forums

As mandated by the statute, the Council, with the assistance of the Center for Health Program Development and Management (Center), initiated a process for the public to provide the Council with information about their particular experiences and issues as informal caregivers in Maryland. In a very short timeframe (from June 27, 2002, to July 24, 2002), the Council held five regional public forums, at which 147 individuals attended. These public forums were held at locations around Maryland to allow as many individuals as possible to have this opportunity. An additional 72 people contacted the Council by phone, mail, fax, or e-mail to share their concerns.

Notice of the public forums was disseminated via a flyer that was posted on the DHR website; mailed to local and statewide community-based organizations, advocacy organizations, and consumers; and e-mailed to the extensive listings of the health and human services agencies involved in the Council. The information was also distributed through the Maryland General Assembly weekly calendar (reaches 1,500 people a week), and faxed to state legislators.

Those who gave testimony were often emotionally moved when relating their personal situations, as were those in attendance. The record of each public forum can be found in Appendix 3.

Caregivers' Public Forum Summary

Five major concerns were mentioned consistently throughout the regional public forums and correspondence received from those who could not attend: respite care issues, caregiver burden, administrative burden, information and referral, and funding of services.

- Respite Care Issues

  Participants felt that more funding is needed for respite care services and that the system should be consumer driven. Better-qualified and trained respite providers who can offer appropriate care based on the age and diagnosis of the care recipient are needed. The system should be able to react to emergency needs, be affordable, and be available in appropriate locations.

- Caregiver Burden

  Caregivers related the following issues: the 24/7 syndrome (providing care 24 hours a day, 7 days a week), fatigue, stress, employment concerns, job loss, bankruptcy, marital problems, and the need for extended time away from their caregiving responsibilities. In some cases the caregiver was part of the "sandwich generation" (caring for multiple generations). They expressed concern that the burden was so time consuming that they were neglecting themselves and significant others.

- Administrative Burden

  Significant administrative barriers were identified, such as long delays in receiving a response, inadequate resources, legal issues, eligibility issues, fragmentation of programs, language barriers, lack of objective grievance procedure, and, at times, rude staff. Participants said that the system is fragmented and lacking a lead agency to be responsible for respite care. They want consumers, the faith community, and other partnerships to be involved in deciding on changes to the system.

- Information and Referral

  Both caregivers and providers expressed frustration about the lack of information on services. The information is not timely or readily available/coordinated and is often inconsistent and confusing. They want a system that will be user friendly, current, accurate, and readily available. They want to have someone to talk with if they need advice or information on financial management, medication management, home technology, behavioral management, school enrollment, and how to help someone at the end of life.

- Funding of Services

  Participants expressed the need to have more funding available for respite services. The care recipient is determined to be eligible, but there is no funding available to provide the service. They suggested that a sliding fee scale be established. Caregivers thought it was unfair that their income is taken into consideration when eligibility is established.

Following are themes as presented in the testimonies of specific regions.

Easton

Transportation	• Need accessible vehicles and availability to families and providers when needed • Need transportation to assist caregivers to transport care recipients as needed and to allow care recipients to be independent (e.g., go to work)
Respite Issues	• Inadequately trained providers, pay too low to attract better candidates • Need providers who are willing to interact w/ care recipient, not just custodial
Caregiver Burden	• Fatigue/depression • marital and family strain and/or dissolution • Behavior management issues (especially as children mature and change) • Employment concerns (needing to work to pay for caring help, trapped in jobs for insurance coverage)
Administrative Issues	• Too much “red tape” (lengthy eligibility determinations, level of care for services too high--lower levels of care should be allowed, like tube feeding)
Information and Referral	• Need centralized source of information/clearinghouse (kudos to Arc newsletter)
Funding of Services/Care and Other Needs	• Need more money for the schools for equipment and other needs • Need money for a centralized support system

Baltimore City

Respite Issues	• Need funds for more respite care • Respite providers need more training
Caregiver Burden	• Need support groups for caregivers • Issues for non-custodial caregivers (access to services and assistance) • Caregiver fatigue/burn-out/isolation • "Caregivers are partners, not pets"
Administrative Issues	• Streamline programs • Management and delivery systems need change (too complex, involve consumers) • Faith community and other partnerships • Language/translation issues • Same standards/service levels across jurisdictions • Inclusionary rather than exclusionary approaches • Focus of services too narrow • Need objective grievance procedure (non-departmental/third party)
Information and Referral	• Information is hard to get • Training for school personnel
Funding of Services/Care and Other Needs	• Sliding fee for some services • More funding for home-based care (better quality and less expensive than institutional care)

Columbia

Respite Issues	• More services and funding • Provider sensitivity training • Ability to schedule short-term/when needed/or emergency • Provider training for management of children with mental health issues/autism
Caregiver Burden	• Grandparents Special/non-custodial Issues (getting financial assistance/acknowledgement/legal help) • Job loss/bankruptcy • Emotional support • How to help care recipient at end of life
Administrative Issues	• Broaden eligibility to include higher income, insured and actual cost of care • Medicaid Waivers/DSS/Court/School (negotiating the system and bureaucratic barriers) • Long waits for services • Legal barriers--caregiver need access to information about care recipient when care recipient is an adult
Information and Referral	• Medication management/multiple medications • 24-hour availability-hotline/advocate • Need more and more timely information (e.g., about school enrollment and from doctors' offices) • Home technology to assist caregiving • Financial management • Behavioral management

Funding of Services/Care and Other Needs	• Increased involvement of faith community • More appropriate school placements (class size, teacher training, etc.) • Care recipient support/mentoring (e.g., Big Brothers) • Nursing care (funds and training)

Clinton

Respite Issues	• Affordability, availability and quality of respite providers • Sometimes must travel long distances • Sometimes funds are available, though providers are not. Funds and/or providers are not available when needed. • Sometimes eligible, but funds not available; providers are sometimes unwilling or unable to provide care needed • Pleas for in-home respite, especially for people with special behavioral issues
Caregiver Burden	• Caregiver burden leading to marital problems and neglect of other children in family • Expression of need for extended time (a vacation of a week or two) without caregiving responsibilities to renew energy and ability to provide care • Caregiver and other family illness/debility along with care recipient needs
Administrative Issues	• Caregiver income an impediment to getting help care recipient needs • Requirement to get training before assistance (time away from work)
Funding of Services/Care and Other Needs	• A “joke” among caregivers: Agency states: “You make too much money.” Caregiver response: “Oh, can you provide financial advice because I don’t know where all that money is…” • “(Care recipient) is eligible, but there are no funds.”

Hagerstown

Respite Issues	• Funding for grassroots efforts • Less red tape and fewer ”strings” attached to receive services • Families not informed
Caregiver Burden	• “Sandwich” experience-grandchildren and elderly mother • Simultaneous and sequential caregiving responsibilities • Emotional devastation; stress • 24/7 responsibilities and no financial resources for relief/socialization
Administrative Issues	• Grandparent custody issues • Legal issues of relative caregivers (not supported, acknowledged) • Case decisions without court oversight; not enough transparency • System lacks trust of family caregivers; bias against families • Some services are during the school year only
Funding of Services/Care and Other Needs	• Custody without financial support • Some financial assistance reduced if help received from other source
Information and Referral	• Fragmented system without lead agency for respite • Information not timely or readily available/coordinated; often inconsistent and confusing • Different information from each source…need coordination of information

IV. Survey of Maryland Caregivers 2002

At the request of the Council, a convenience sample survey of informal caregivers in Maryland was conducted from June 26 to July 26, 2002, by the Center for Health Program Development and Management (Center) at the University of Maryland, Baltimore County.

A. Introduction and Summary

An analysis of survey responses establishes the following in relation to informal caregivers:

Caregiver Profile

- The majority of caregivers (57 percent) are pre-retirement age (41-60), and 32 percent are over age 60
- The highest percentage of caregivers have completed high school, though substantial numbers above age 60 have not (20 percent)
- Income tends to decrease as caregivers age; more than 30 percent of caregivers 60 and older earn $20,000 or less, compared to about 12 percent of younger caregivers

Caregiver Care Recipient Relationship

- Younger caregivers are caring most for children and mothers, while older caregivers are caring primarily for their mothers or spouses

Care Recipient Characteristics

- The highest percentage of younger caregivers are caring for care recipients with developmental disabilities/mental retardation; older caregivers mostly care for care recipients with Alzheimer's/Dementia or mobility issues
- More than half of care recipients fall into the nearly completely disabled or the completely disabled categories
- The majority of caregivers (87 percent) have provided care for more than a year
- Forty-five percent of caregivers report providing "constant care" to the care recipient

Impact of Caregiving on Caregivers

- Twenty-two percent of caregivers care for two or more care recipients
- Emotional strain, not enough time, physical health strain, and family conflict are the top caregiver difficulties
- The top caregiver needs are for respite, financial support and a central information source

Family Conflict

- "A lot" of family conflict is associated with care recipients in the 81+ age group, full-time employment of the caregiver, others not doing their fair share, and providing constant care to the care recipient

Caregiver Employment

- Ninety-two percent of full-time caregivers report having to go to work late, leave early, or take time off
- Thirty-eight percent of caregivers who work part-time and 29 percent of those who work full-time have had to take leaves of absence; eight percent have retired early
- Thirty percent report difficulty with their employer

Financial Hardship

- Fifty percent of caregivers report that they have financial hardship of 3 or more on a scale of 1 (no hardship) to 5 (a great deal of hardship)

B. Methodology

Study Population. The objective of this study was to survey informal caregivers in Maryland about their experiences with providing care to another individual. For the purposes of this study, an informal caregiver is defined as an individual who assists an adult or special needs child with any number of a broad range of services (personal needs, household chores, personal finances, or coordination of outside services) without payment.

Due to the lack of a centralized database of informal caregivers in Maryland and the difficulty of identifying these individuals, a convenience sample of informal caregivers was surveyed. Survey participants were solicited similarly to the ways in which public forum attendants were. This sampling method is commonly used in exploratory research and provides useful information and insight into the issue at hand. As a non-probability sample, the findings from this survey may or may not be generalized to all Maryland informal caregivers.

Survey Instrument. The research instrument used in this study was adapted from the 1997 National Family Caregiver Survey conducted by the National Alliance for Caregiving and the American Association for Retired Persons. The survey instrument was modified by the Center's project team with input from MCSCC. The subject areas addressed in the survey instrument are:

- Caregiver/care recipient relationship
- Level of care recipient illness or disability
- Caregiver knowledge and support
- Impact on caregiver

The survey instrument was pre-tested among a sample of 15 informal caregivers in Maryland. Modifications to the survey instrument were made based on suggestions and comments received from pre-test participants.

Data Collection. The study was conducted over a six-week period between June 2002 and July 2002. The surveys were distributed:

- By mail to informal caregivers identified by local agencies and MCSCC
- At public forums convened in regional locations across Maryland
- Via website (DHR/MCSCC's)
- At local businesses
- Through personal contacts

The surveys were returned to the Center via mail, fax, or at one of the five regional public forums. These efforts yielded a total of 629 returned surveys.

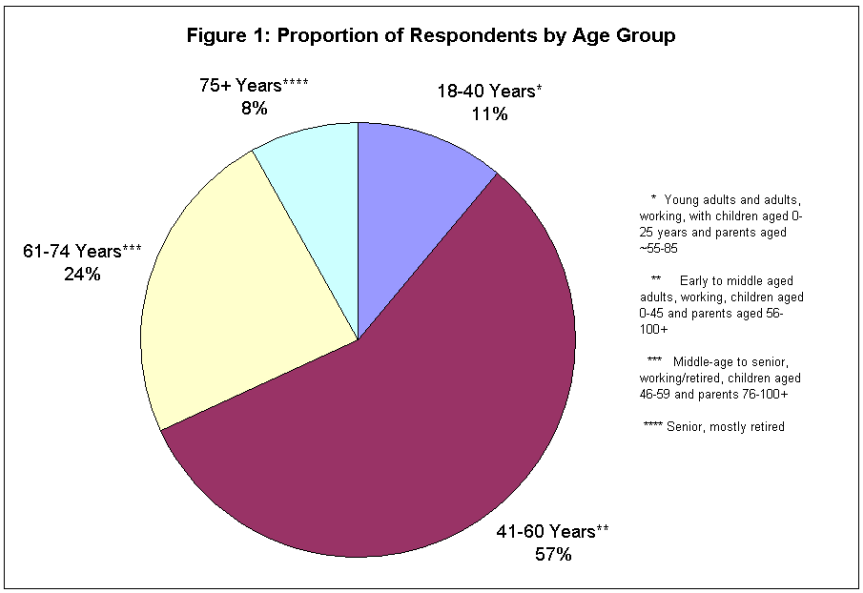
> *"My sister has lived with me since my parents died 18½ years ago … I am now 64 years old. Seek[ing] help … is like a road block … As a caregiver I never asked for any help until [recently], only to face a lot of red tape and rejection."*
> *Words of a Maryland Caregiver, 2002*

Analytical Framework. Survey responses were entered into a Microsoft ACCESS database specifically constructed for this study, and analyzed using the SAS statistical software package. Survey results are examined using descriptive analyses, including frequency distribution of survey responses and cross-tabulations between variables of interest. Findings are presented in narrative, graphic, and tabular form. Percentages presented in this report may not total 100 percent due to rounding. Analyses of survey results using probability-based statistical tests are inappropriate due to the use of a convenience sample.

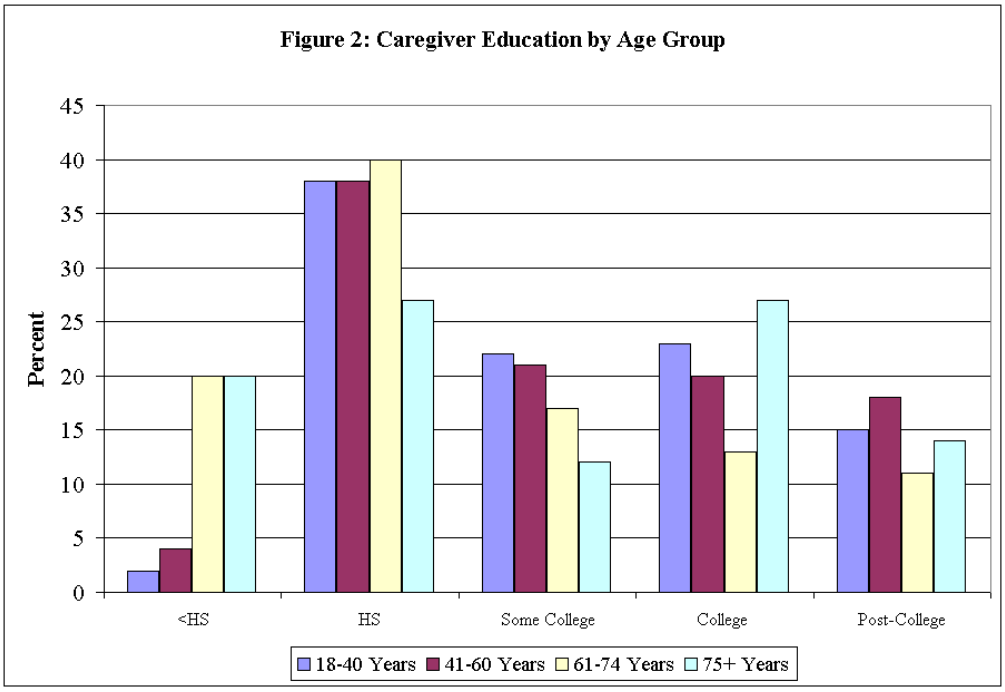
C. Detailed Results

Caregiver Profile

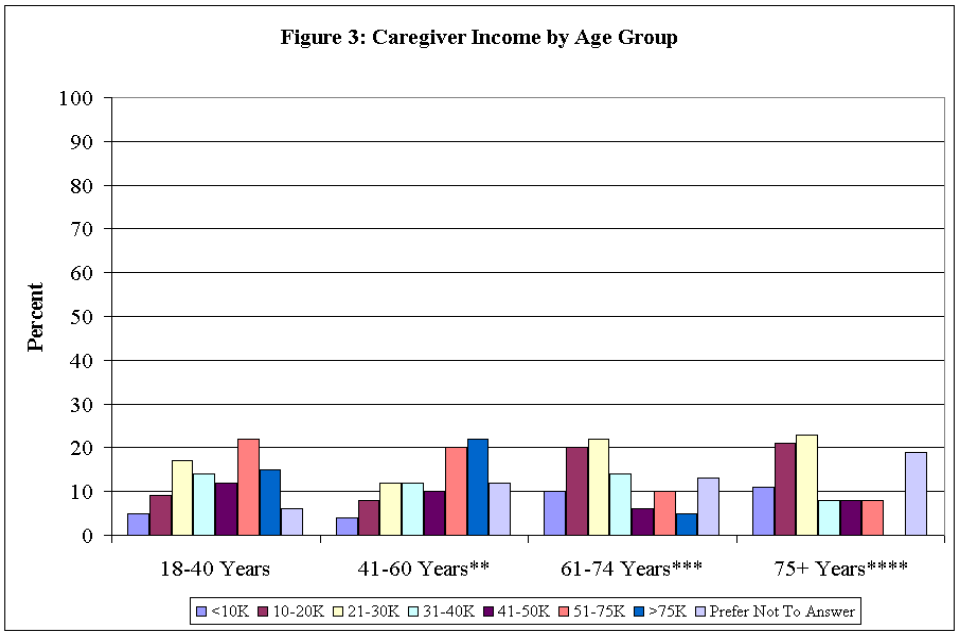
The majority of survey respondents were in the 41-60 year old age group (57 percent). (Figure1).



Education levels among caregivers are similar, except that caregivers aged 61 and over are less likely than younger age groups to have finished high school, completed college, or pursued higher education. Compared to other age groups, caregivers aged 75 and over have the highest college/post-college attainment (41 percent) (Figure 2).

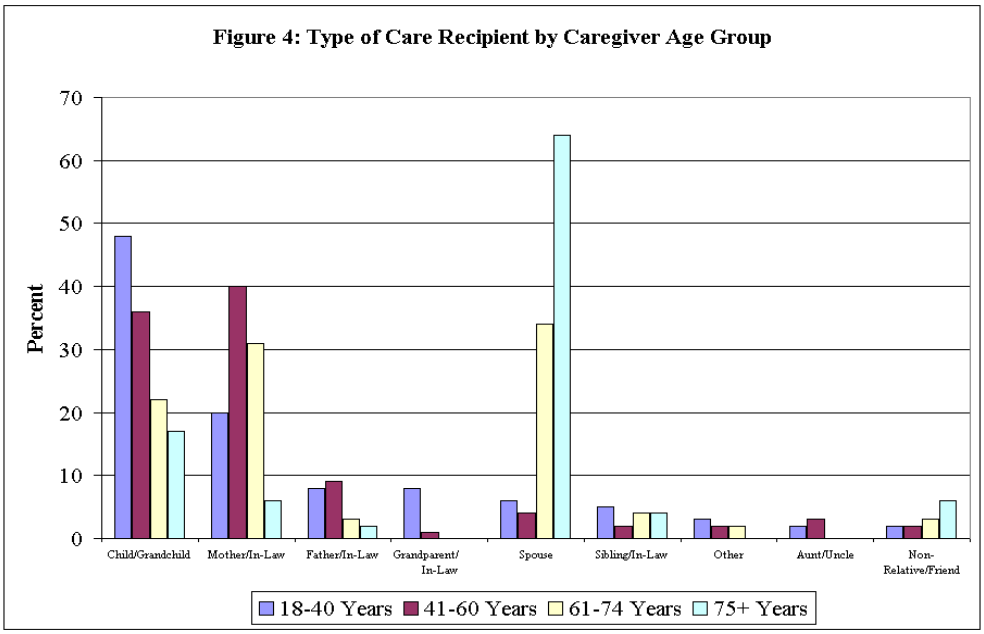


Caregivers in older age groups are less well-off economically. Those over the age of 61 are more likely than younger age groups to earn $20,000 or less per year, and are less likely to earn $41,000 or more (Figure 3).



The large majority of caregivers under age 61 are employed full-time (18-40 years: 65 percent, 41-60 years: 61 percent). Approximately half of the caregivers 61 years or older are retired. See Table 3 at the end of this section for more detail.

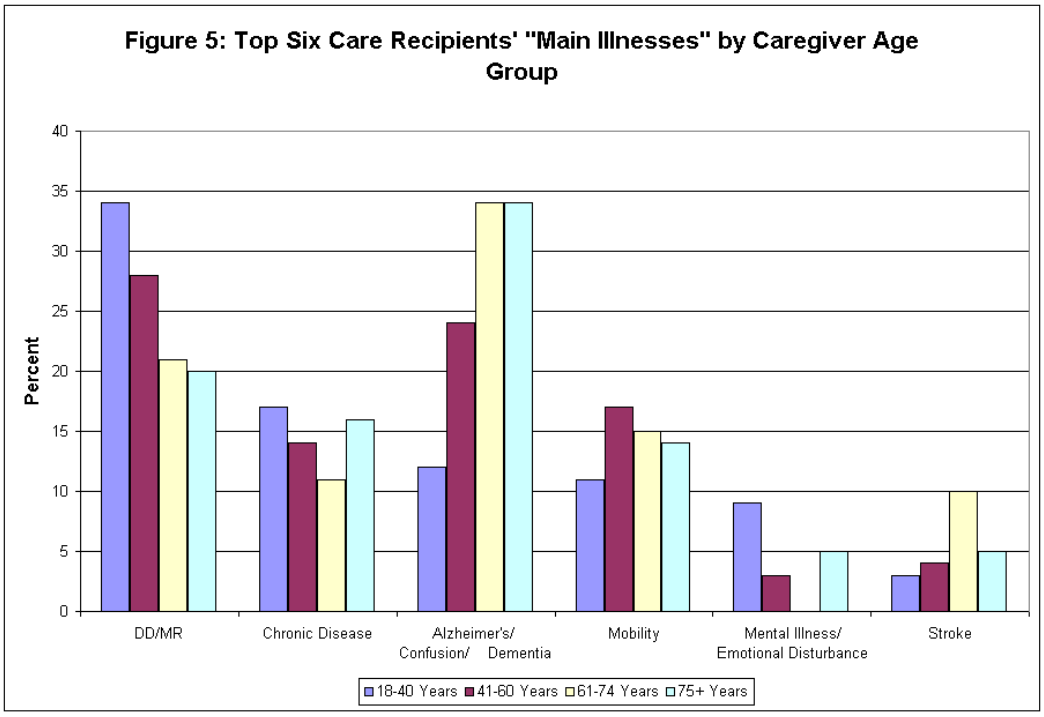
Across age groups, caregivers most often provide care to a mother/mother-in-law, child/grandchild, or spouse. The majority of caregivers aged 60 or younger provide care to a child/grandchild or mother/mother-in-law, whereas most caregivers aged 61 or older care for a mother/mother-in-law or spouse. The percentage of caregivers assisting a spouse nearly doubles with increasing age, from 34 percent of 61-74 year olds to 64 percent of 75+ year olds. See Figure 4. (Also see Table 4 at the end of this section.)



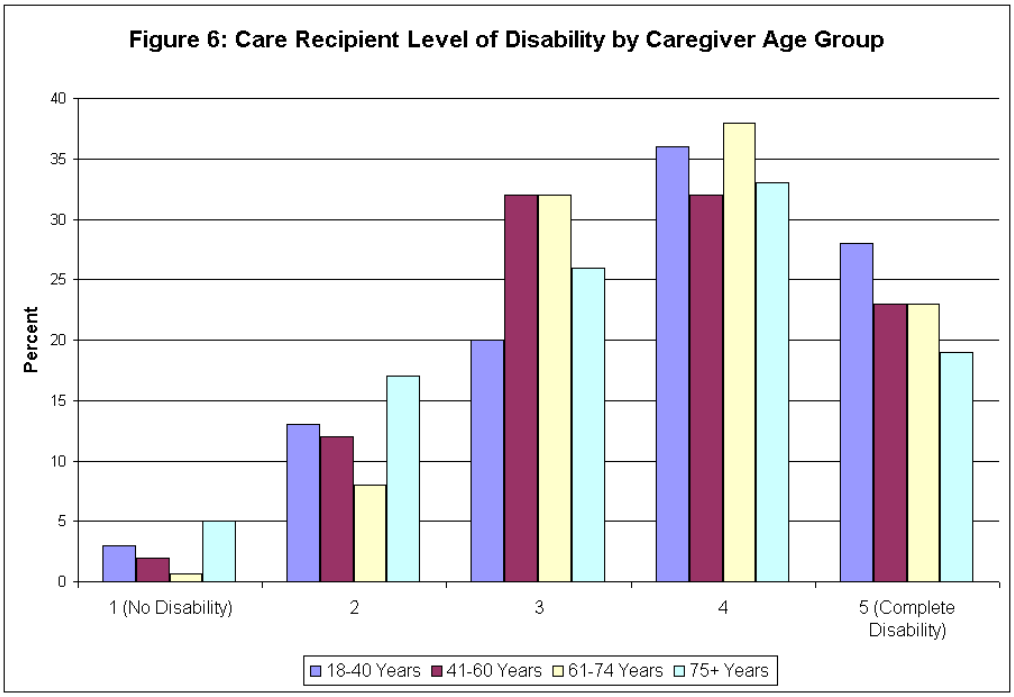
Care Recipient Characteristics

> *"I wish I could [have] just a little quiet time to rest, but this is my son, whom [I] love more than anything … I just … do the best I can under very difficult circumstances … At times I think the state should do more to help people like me who are trying to do this alone."*
>
> *Words of a Maryland Caregiver, 2002*

Care recipient characteristics are relevant to caregiver needs as needs vary according to the care they must provide. While developmental disabilities and mental retardation (and other cognitive impairments such as Alzheimer's in seniors) are major conditions among care recipients, the manifestation of these illnesses and the care required will vary depending on the age of the care recipient, including the care recipient's developmental needs. Care recipients in this survey ranged from infants to seniors. It was difficult for respondents to select a "main" illness as many care recipients have multiple conditions that require caregiving. Figure 5 only reports the "main" illness, which does not allow us to make statements about the complexity of care many care recipients require.



Care recipient disability level is relatively consistent across the age groups of caregivers, though, predictably, more than half of care recipients fall in the nearly completely disabled and completely disabled categories (Figure 6).



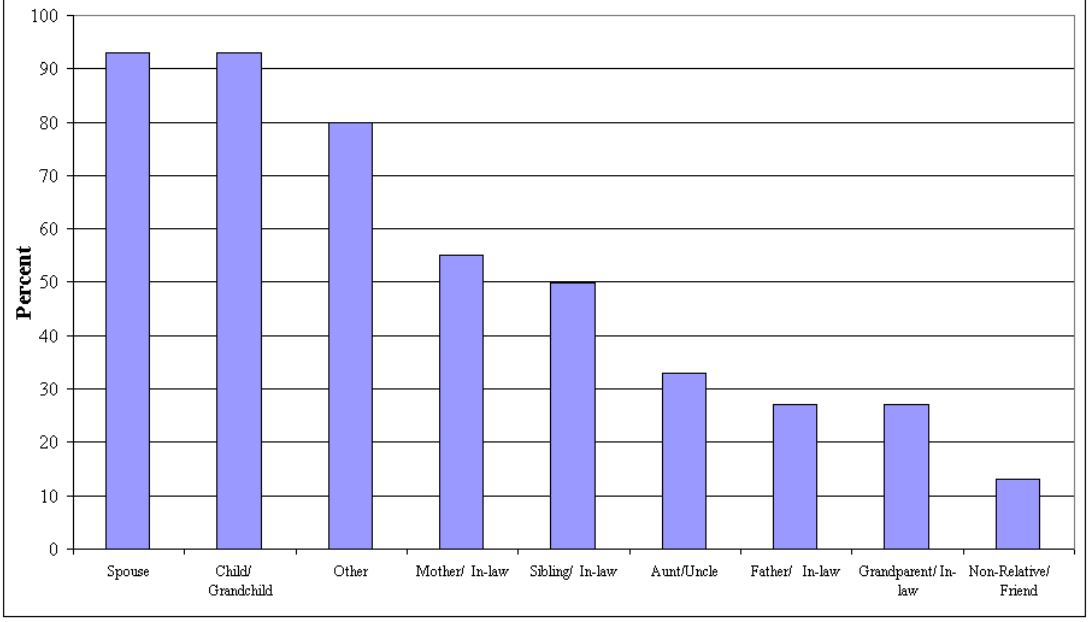
Duration of Care

The majority of caregivers (87 percent) have provided care to an individual for more than a year. Sixty-one percent of care recipients who receive care for an extended period of time are over age 50, and 39 percent of them are under age 50. For some caregivers, caregiving is a lifelong commitment. According to survey responses, 100 percent of the 1-5 year olds, 95 percent of the 6-17 year olds, and 86 percent of the 18-50 year olds have received lifelong care from their caregivers. As caregivers age, these individuals will require other means of support, and in some cases, new living arrangements.

Living Arrangements

The majority of care recipients (70 percent) live in the caregiver's home. For example, 93 percent of child care recipients and also of spousal care recipients live with their caregiver. Moreover, mother/mother-in-law care recipients (55 percent) are more likely than father/father-in-law care recipients (27 percent) to live in the caregiver's household (Figure 7). It is also common for the care recipient to live in close proximity to the caregiver. Eighteen percent of care recipients live within 20 minutes of the caregiver's home. Less than four percent of caregivers reported caring for someone who lives more than an hour from their home.

Figure 7: Care Recipients Who Live With Their Caregiver by Type of Relationship



Care Recipient Condition and Level of Disability

Most care recipients' conditions are considered to be chronic or long-term in nature (88 percent). Caregivers report that they provide assistance to individuals who primarily suffer from Alzheimer's Disease (26 percent), a developmental disability/mental retardation (27 percent), mobility problems (15 percent), or a chronic disease (14 percent). Survey responses indicate that 62 percent of care recipients under the age of 18, and 74 percent of care recipients in the 18-50 year age group have developmental disability/mental retardation. For care recipients of older age groups, Alzheimer's Disease (51-80 years: 33 percent, 81+ years: 45 percent) and chronic disease (51-80 years: 25 percent, 81+ years: 15 percent) are identified as main illnesses. In addition, mobility is reported as the main illness for 22 percent of care recipients aged 81 and older.

On a five-point scale ranging from no disability to complete disability, the majority of care recipients (57 percent) are severely or completely disabled. The level of disability is also inversely related to age. Fewer care recipients in older age groups (51-80 years: 19 percent, 81+ years: 16 percent) are completely disabled compared to younger age groups (6-17 years: 32 percent, 1-5 years: 44 percent). Older care recipients, however, are likely to have intermediate levels of disability (51-80 years: 67 percent, 81+ years: 70 percent).

Forty-five percent of respondents report providing constant care to the care recipient. Of those who report less than constant care, 23 percent report providing 40 or more hours of care per week. Depending on whether the caregiver works full- or part-time, this 40 or more hours may actually constitute "constant care." That is, most of the caregiver's free time (non-work/non-sleep time) is used to provide care.

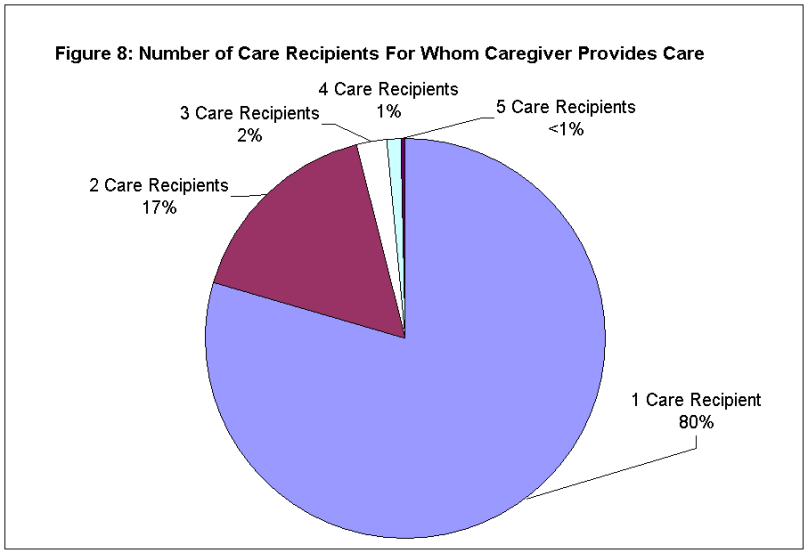
Impact of Caregiving on Caregivers

> *"My child is only 5 and I am exhausted and over burdened. What will I do as she grows up and gets more demanding … I'm so afraid I don't know what's going to happen from day to day."*
>
> *Words of a Maryland Caregiver, 2002*

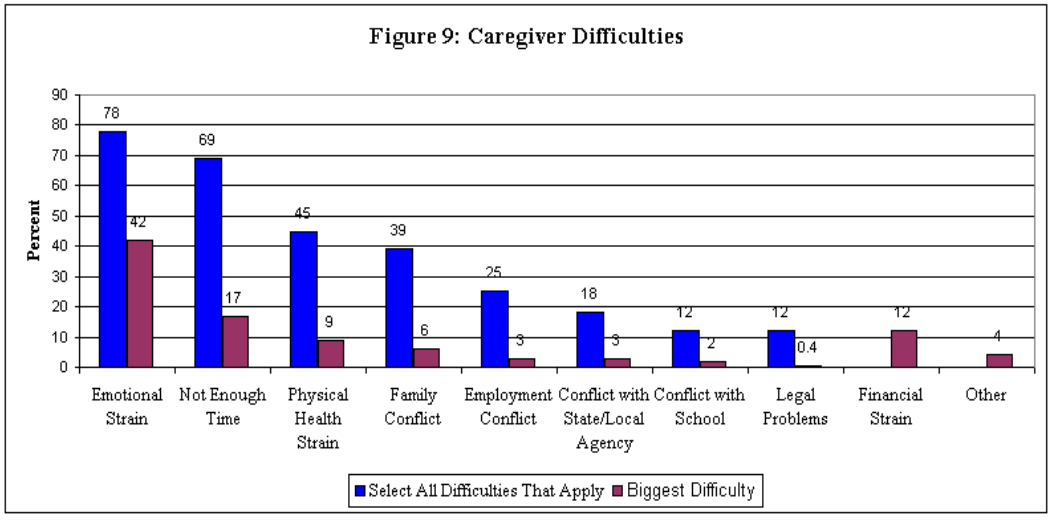
Sometimes, the positive feelings that come from helping someone are accompanied by negative outcomes as a result of the resources (time, money, energy, etc.) that must be expended for these activities. When trying to understand how caregiving affects those who are providing care, and determining how to help them, negative outcomes must be considered. Financial issues can include job reduction or loss, extended financial obligations that may be beyond the means of the caregiver and care recipient, and the stress of securing and of receiving financial assistance. Lack of time for recreation, personal renewal, other relationships, or

even rest is taxing to the caregiver. Relating to an ill or disabled person requires extra effort, and some caregivers may have multiple caregiving relationships to balance.

Caregivers may be "sandwiched," taking care of older and younger generations simultaneously. "Club sandwich" is a term coined to describe caregivers who are not sandwiched by single generations on each side, but instead are sandwiched by two (either two older and one younger (parents, grandparents, and children), or two younger and one older (parents, children, and grandchildren). In this study, most caregivers (80 percent) cared for one care recipient, 17 percent cared for 2 care recipients, and approximately 3 percent cared for more than 2 care recipients (Figure 8).



When asked to select all of the issues that impact their lives as caregivers, 78 percent selected "emotional strain," 69 percent indicated "not having enough time for other activities," and 45 percent reported "physical health strain." When asked to select the single "biggest" difficulty, 42 percent selected emotional strain, followed by not enough personal time and financial strain at 17 and 9 percent, respectively. Emotional strain is the most often reported difficulty and also the single biggest difficulty. See Figure 9.



Emotional strain is especially a problem for caregivers of mothers/mothers-in-law, reporting 42 percent compared to 26 percent for children/grandchildren, 18 percent for spouses, 7 percent for fathers/fathers-in-law, 3 percent for siblings/siblings-in-law, and less than 2 percent for other relationships.

According to this study, 88 percent of respondents indicate that they have had to compromise their work schedule in order to provide assistance to their care recipient by going to work late, leaving work early, or taking time off. Substantial percentages of caregivers have also had to take a leave of absence from work (39 percent) and/or reduced the number of hours worked by changing from a full-time job to a part-time job.

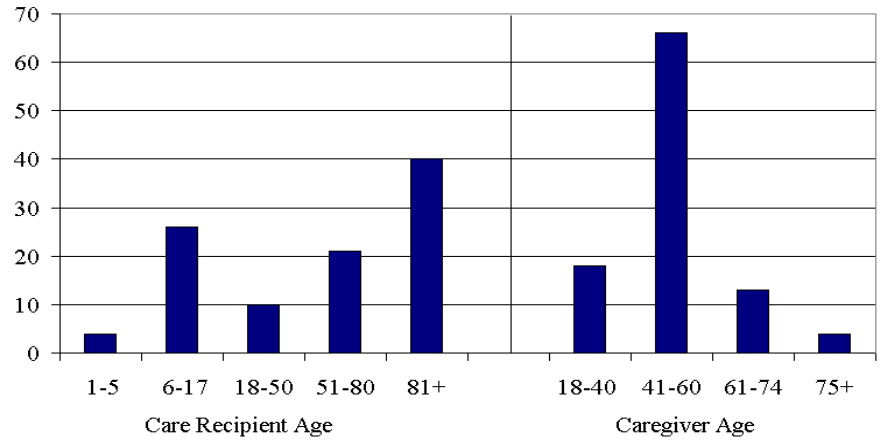
> *"I'm not well either and it is a heavy burden on my old age … well to have to care for a disabled person 24-7 … Sooner or later it'll break you down physically and mentally. More help is truly needed, since this is primarily a way of life from now on."*
>
> *Words of a Maryland Caregiver, 2002*

When asked about their needs as a caregiver, the majority of respondents indicated that respite (62 percent), financial support (45 percent), and a central information source (40 percent) would be helpful in providing care. These needs were commonly cited across geographic regions and care recipient age (See Tables 6 and 7 at the end of this section).

Family Conflict

The highest amounts of family conflict were reported among caregivers of care recipients in the 81+ year old group. Caregivers in the 41-60 year old group reported "a lot" of family conflict more than three times 18-40 year old group (66 percent compared to 18 percent). See Figure 10.

Figure 10: Percent of Caregivers Reporting "A Lot" of Family Conflict by Care Recipient Age and by Caregiver Age



Family conflict appears to be associated with whether or not others are doing their fair share. Thirteen percent of survey respondents report "a lot" of family conflict due to caregiving. Among this group, 33 percent indicate that others are "*not doing* their fair share of caregiving," compared to 39 percent who indicate that others are "*doing* their fair share." Conversely, in families with no conflict (45 percent), 61 percent report that others are "*doing* their fair share" and only 6 percent report that others are "*not doing* their fair share."

Retired caregivers report the least amount of family conflict, though it is still present. Thirty-two percent of retired caregivers report "a lot" or "some" family conflict, compared to 56 percent of caregivers working full-time and 57 percent of caregivers working part-time.

Fifty-two percent of caregivers who provide constant care to a care recipient report "a lot" or "some" conflict, while 44 percent report no family conflict. Paradoxically, family conflict seems to decline as more hours are spent in care.

Caregiver Employment

Employment and time spent providing care are inversely related. Full-time workers provide the fewest hours of care per week (42 percent provide 1-10 hours of care), and hours of providing care increase as hours of work decrease. This may be an indication that employed persons have less time to provide care, and those who need to provide high levels of care decrease their employment to enable them to do so. The latter case is consistent with other findings in this survey, with comments received during regional public forums, and with comments provided by caregivers.

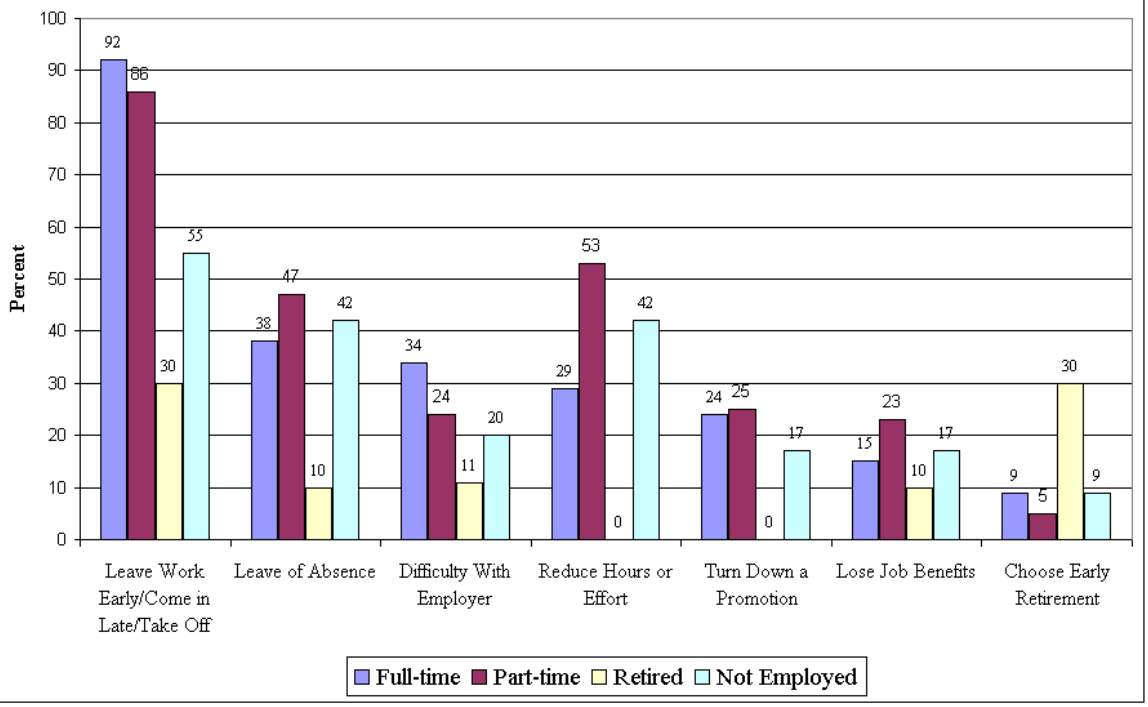
> *"We always spend more time away from work than [would be] needed if we had only been given the correct information in the first place. A central place of information would help considerably."*
>
> *Words of Maryland Caregiver, 2002*

The more hours that caregivers work, the more they have needed to modify their work hours to perform their caregiving responsibilities. Ninety-two percent of full-time workers and 86 percent of part-time workers report going to work late, leaving early, or taking time off. Moreover, more part-time employed caregivers have needed to take leaves of absence (47 percent) or reduce work hours (53 percent) than full-time employed caregivers (38 percent and 29 percent, respectively). Overall, 8 percent of survey respondents chose to retire early as an outcome of their caregiving. Thirty percent of caregivers report having difficulty with their employers. More caregivers employed full-time (34 percent) have had difficulty with their employer than those employed part-time (24 percent). Sixty-one percent of

caregivers between the ages of 18 and 60 are employed full-time, while most caregivers aged 61 and older are retired (52 percent). See Figure 11.

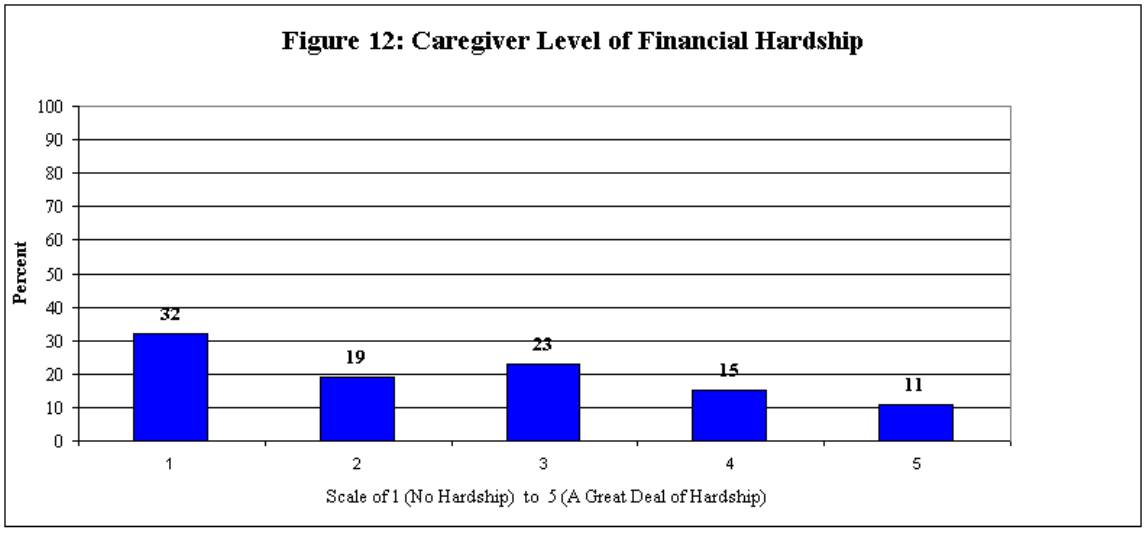
> *"I have to work to get insurance that cannot discriminate against my sons. My big concern is when they deteriorate to the point where I can't leave long enough to work. How are we going to live?"*
>
> *Words of a Maryland Caregiver, 2002*

Figure 11: Impact of Caregiving on Caregivers' Employment



Financial Hardship

Average financial hardship is 3.65 on a scale of 1 to 5 (with 1 being "no burden" and 5 being "a great deal of burden"). Nearly 50 percent of respondents report a level of 3 or more for financial hardship (Figure 12). Financial hardship is positively correlated with caregivers who report not having enough time as a source of difficulty. This may be illustrative of caregivers who have to work more to manage the economic facets of caregiving. Caregivers who experience the highest level of financial hardship were nearly two to four times as likely to report employment conflict, conflict with state or local agencies, conflict with schools, and legal problems.



> *"I feel like there is no 'me' anymore …"*
> *Words of a Maryland Caregiver, 2002*

To cope with the impact of providing care, caregivers use a variety of strategies. The most frequently cited approaches to dealing with the demands of caregiving are talking with friends (96 percent), praying (83 percent), exercising (64 percent), and having hobbies (57 percent).

D. Findings

The primary finding from this survey is the great emotional strain caregivers experience, including caregiver age, care recipient age and condition, income level etc. From caregiver comments and survey data, caregivers are uniformly committed to their calling but are challenged by emotional and financial strain, not only from the act of providing care, but also from external factors such as complex and unresponsive systems, employment difficulties, and family conflict.

This study gives a picture of the experience of some caregivers in Maryland. While a few respondents expressed feelings of gratitude for the occasional person or program that was critical to their success as a caregiver, others pled for assistance, seeming to be at the end of the ability to cope. Additional studies could examine the inter-relationships among these factors to understand the extent to which particular factors contribute as primary issues. However, the issues are clear.

The burden that caregivers feel manifests primarily through emotional strain, not enough time for themselves, physical health strain, and family and employment conflict.

In this survey, caregivers' top five needs (Figure 13) are in respite services, central information services, financial needs, keeping informed about changes in laws and programs, and some consideration of a tax break to help make caregiving needs more affordable.

Figure 13: Pyramid of Caregivers' Needs

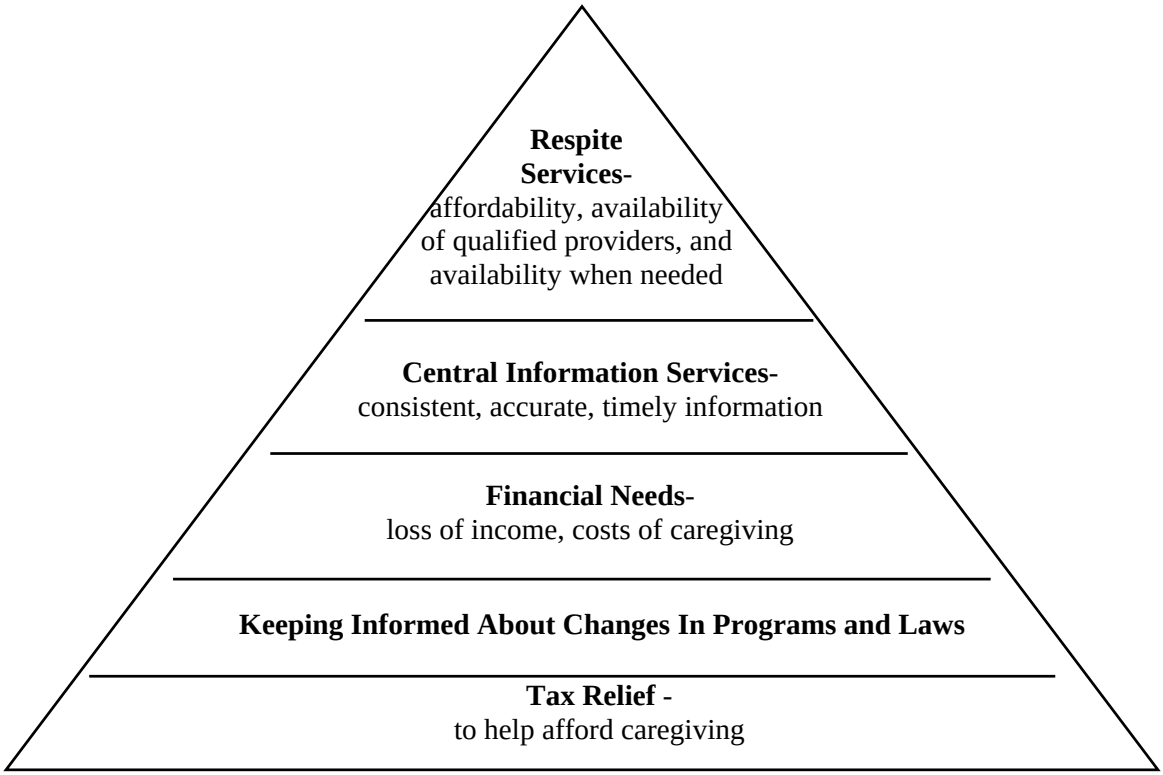


Table 3: Caregiver Characteristics by Age Group (Percent)

Caregiver Age		18-40 Years*	41-60 Years**	61-74 Years***	75+ Years****
Proportion of Respondents		11%	57%	24%	8%
Education	<HS	2	4	20	20
	HS	38	38	40	27
	Some College	22	21	17	12
	College	23	20	13	27
	Post-College	15	18	11	14
Income	<10K	5	4	10	11
	10-20K	9	8	20	21
	21-30K	17	12	22	23
	31-40K	14	12	14	8
	41-50K	12	10	6	8
	51-75K	22	20	10	8
	>75K	15	22	5	0
	Prefer Not To Answer	6	12	13	19
Employment Status	Full-time	65	61	21	3
	Part-time	15	22	14	14
	Retired	2	5	47	68
	Not Employed	18	12	18	16

* Young adults and adults, working, with children aged 0-25 and parents aged ~55-85
** Early to middle aged adults, working, with children aged 0-45 and parents aged 56-100+
*** Middle-age to senior, working/retired, with children aged 46-59 and parents aged 76-100+
**** Seniors, mostly retired

Table 4: Type of Care Recipient by Caregiver Age Group (Percent)

	18-40 Years	41-60 Years	61-74 Years	75+ Years
Child/Grandchild	48	36	22	17
Mother/In-Law	20	40	31	6
Father/In-Law	8	9	3	2
Grandparent/In-Law	8	1	0	0
Spouse	6	4	34	64
Sibling/In-Law	5	2	4	4
Other	3	2	2	0
Aunt/Uncle	2	3	0	0
Non-Relative/Friend	2	2	3	6

Table 5: Characteristics of Care Recipients by Caregiver Age Group (Percent)

Caregiver Age		18-40 Years	41-60 Years	61-74 Years	75+ Years
Care Recipient Main Illness	DD/MR	34	28	21	20
	Chronic Disease	17	14	11	16
	Alzheimer's/Confusion/Dementia	12	24	34	34
	Mobility	11	17	15	14
	Mental Illness/ Emotional Disturbance	9	3	0	5
	Other	9	7	6	7
	Blindness/Vision Loss	3	2	3	0
	Stroke	3	4	10	5
	AIDS	2	0.6	0	0
	Don't Know	0	0.3	0	0
Care Recipient Disability Level	1 (No Disability)	3	2	.68	5
	2	13	12	8	17
	3	20	32	32	26
	4	36	32	38	33
	5 (Complete Disability)	28	23	23	19

Table 6: Caregivers' Ranked Needs by Region (Percent)

Baltimore City	**%**	**Capital Area** (Prince George's & Montgomery)	**%**	**Central Maryland** (Anne Arundel, Baltimore, Carroll, Frederick, Harford, & Howard Counties)	**%**	**Eastern Shore** (Caroline, Cecil, Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico, & Worcester)	**%**	**Western Maryland** (Allegany, Garrett, & Washington)	**%**	**Southern Maryland** (Calvert, Charles, & St. Mary's)	**%**
Respite	**67**	Respite	**65**	Respite	**61**	Respite	**61**	Respite	**73**	Respite	**56**
Bureaucracy	**52**	Financial Need	**53**	Financial Need	**44**	Financial Need	**44**	Financial Need	**52**	Financial Need	**36**
Financial Need	**50**	Central Information Source	**53**	Central Information Source	**40**	Central Information Source	**43**	Info of Changes in Program/Laws	**42**	Tax Break	**35**
Central Information Source	**42**	Changes in Program/Laws	**41**	Bureaucracy	**40**	Tax Break	**43**	Tax Break	**42**	Understanding Paying for NH	**31**
Transportation	**42**	Counseling/ Support	**37**	Changes in Programs/Laws	**37**	Changes in Program/Laws	**42**	Bureaucracy	**40**	Central Information Source	**31**
Changes in Programs/ Laws	**38**	Tax Break	**37**	Tax Break	**36**	Bureaucracy	**33**	Understanding Paying for NH	**39**	Selecting NH	**26**
Tax Break	**29**	Transportation	**33**	Understanding Paying for NH	**29**	Personal care	**31**	Central Info	**37**	Bureaucracy	**26**
Counseling/ Support	**27**	Bureaucracy	**33**	Trans	**26**	Understanding Paying for NH	**31**	Selecting NH	**29**	Personal care	**25**
Understanding Paying for NH	**23**	Personal care	**31**	Selecting NH	**23**	Counseling/ Support	**23**	Personal care	**27**	Changes in Program/Laws	**22**
Personal care	**21**	Understanding Paying for NH	**31**	Personal care	**22**	Transportation	**20**	Counseling/ Support	**26**	Transportation	**18**
Selecting NH	**17**	Selecting NH	**27**	Counseling/Support	**21**	Selecting NH	**19**	Transportation	**24**	Counseling/ Support	**13**

(NH=Nursing Home)

Table 7: Caregivers' Ranked Needs by Care Recipient Age (Percent)

1-5 Years	%	6-17 Years	%	18-50 Years	%	51-80 Years	%	81 + Years	%
Respite	**78**	Respite	**80**	Respite	**57**	Respite	**57**	Respite	**61**
Central Information Services	**61**	Financial Need	**68**	Changes in Programs/Laws	**47**	Financial Need	**49**	Central Information Services	**38**
Changes in Programs/Laws	**61**	Bureaucracy	**54**	Bureaucracy	**46**	Tax Break	**42**	Tax Break	**38**
Bureaucracy	**56**	Changes in Programs/Laws	**49**	Financial Need	**43**	Understanding Paying for NH/Other Services	**38**	Financial Need	**34**
Financial Need	**44**	Central Information Services	**46**	Central Information Services	**42**	Central Information Services	**37**	Understanding Paying for NH/Other Services	**34**
Housekeeping	**39**	Tax Break	**40**	Tax Break	**29**	Bureaucracy	**33**	Changes in Programs/Laws	**31**
Tax Break	**33**	Counseling/Support	**36**	Transportation	**28**	Housekeeping	**33**	Bureaucracy	**28**
Personal Care	**28**	Transportation	**31**	Understanding Paying for NH/Other Services	**25**	Personal care	**31**	Personal Care	**25**
Counseling/Support	**22**	Housekeeping	**27**	Selecting NH/Other Facility	**23**	Changes in Program/Laws	**30**	Selecting NH/Other Facility	**24**
Understanding Paying for NH/Other Services	**22**	Personal Care	**26**	Counseling/ Support	**19**	Transportation	**27**	Housekeeping	**24**
Transportation	**17**	Selecting NH/Other Facility	**16**	Personal Care	**18**	Selecting NH/Other Facility	**25**	Transportation	**21**
Selecting NH/Other Facility	**11**	Understanding Paying for NH/Other Services	**14**	Housekeeping	**18**	Counseling/ Support	**20**	Counseling/Support	**21**

V. Next Steps

The Maryland Caregivers Support Coordinating Council began an ambitious first year with convening an interagency group of professionals and a cadre of diverse community representatives with their own unique interests and perspectives on caregiving. Having established their Core Values and Guiding Principles, surveyed the community, and performed due diligence in understanding the local, state, and national context of caregiving, the Council will proceed with the mandate before them in the remaining two years of their tenure.

In the first year of activity, the Council has established the groundwork for change and improvement. The Council will continue to address issues encountered in the committees throughout the next two years.

> *"I feel penalized for not signing my child over to state custody and choosing to care for her at home ... I cannot do it all- so I do what I can. Financially, we are going down rapidly ... I survive by not thinking about it."*
>
> *Words of a Maryland Caregiver, 2002*

Challenges for the Next Two Years

The Council will continue to work on its legislative mandates. Based on the extensive research and the experiences of Council members, it has been decided that:

- **More in-depth exploration and discussion is required prior to recommending a caregiving model for Maryland**

  This conclusion is based on a decision made early on, to avoid the temptation to simply overlay an idealized model of caregiver support on to an already existing, albeit partially fragmented, set of programs. Many of these programs are currently providing quality respite and other supports to caregivers in Maryland. Failing to be realistic or taking premature action could do more harm than good with regard to the needs of caregivers. The Council will continue to monitor the model programs identified nationally to gather more information about their applicability to Maryland and its evolving system.

  The Council will gather additional information on best practices in Maryland programs, particularly in the area in which federal, state, or local government-funded, caregiver support programs intersect with informal associations, grassroots organizations, or faith-based communities. Information on the program evaluation components of existing Maryland programs and on the existing mechanisms for improving quality across the various programs will be reviewed in order to increase overall effectiveness and coordination of all programs.

- **A gradual quality improvement approach of system development is the preferred course of action**

  An administrative infrastructure must be designed to support the development and implementation of caregiver support programs at the state level. Based on the information gathered from the public forums and the survey, the Council will further describe a structure and process to articulate public policies to support caregivers. The focus will be to refine and improve current support programs, improve coordination among existing programs, address substantive barriers encountered by caregivers, and expand the availability, accessibility, and quality of caregiver support provided in Maryland.

- **Maryland should develop a centralized information and referral resource for caregivers, which goes beyond the handbook approach required in the legislation**

  This information and referral system should include use of electronic information retrieval systems and trained information and referral specialists. The purpose of this resource would be to assist caregivers in coping with the frustration that results from fragmentation of existing support systems. This new system would provide useful information on accessing services and telephone counsel to resolve issues that caregivers experience.

- **A concurrent outreach and public awareness effort should be made**

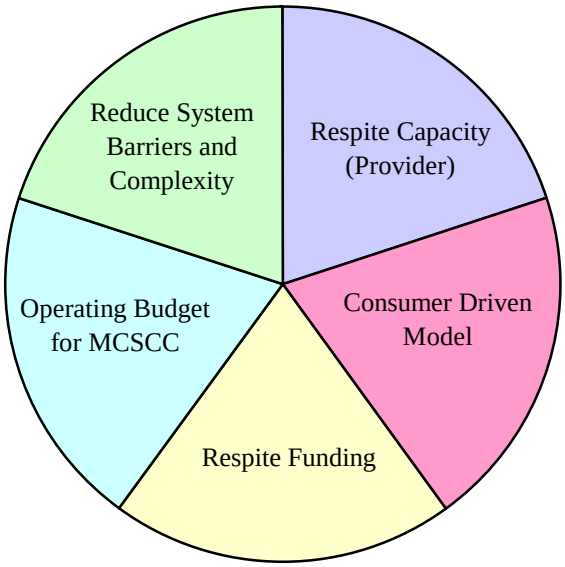
  Outreach is needed to promote (and encourage caregivers to use) the information and referral resource noted above, and to increase knowledge in the general public about the central issues related to caregiving.

The Council has identified a longer list of issues that need to be addressed in Maryland, and from that list, has identified five areas for follow-up.

Five Areas to be Addressed in 2002 and 2003

The five issue areas to address in the next two years are shown in Figure 14.

Figure 14: Issue Areas to be Addressed by MCSCC During 2002 and 2003



1. Develop and implement an operating budget to allow the Council to work effectively and accomplish its mandated function.

   An operating budget would allow the Council to acquire staff, support the implementation of a "best practices" model of caregiving, increase awareness efforts, conduct annual public forums, complete a more rigorous study of caregiver needs that will serve as a baseline for evaluation, and provide technical and/or financial assistance to caregiving activities/groups.

2. Continue model development and ensure that it is "consumer driven."

   Through the comments and testimonies of caregivers from around the state, the Council learned that caregivers often suffered because of the inflexibility of mandated approaches to resource access. That is, if the consumer (caregiver) could determine how funds allocated for their use in caregiving would be spent, or experienced fewer restrictions on who they could retain to provide care, then they could more effectively relieve caregiving burdens.

3. Build respite provider capacity (quantity, qualifications, and training).

   Repeatedly, caregivers informed the Council that respite providers were inadequately trained, particularly in the specific needs across the lifespan, such as the unique needs of children with mental health problems, and the special needs of the elderly. Capacity building includes identification of potential providers, training/certification, and verification of the background of potential providers.

4. Improve respite services funding and flexibility.

   In addition to building capacity, respite services need to be more affordable and flexible so that services can be accessed on a “when needed” basis by caregivers. Caregivers report that respite services are often too little and too late; often needs cannot be anticipated.

5. Reduce system barriers and complexities.

   The Council plans to address the personal loss, difficult circumstances, and grave barriers that caregivers face on a daily basis as a result of the burden imposed by systemic inefficiencies. System challenges include the Medicaid Waiver, Department of Social Services, courts (and other legal entities), and schools. Also, many caregivers expressed that the staff of many of the agencies/programs designed to help seemed overworked, inadequately trained, unfamiliar with rules/regulations/laws, ineffective, and, at times, even rude.

Appendix 1: Enabling Legislation

SENATE BILL 567

Unofficial Copy 2001 Regular Session
J1 (1lr2197)

ENROLLED BILL
-- Economic and Environmental Afairs/Environmental Matters --

Introduced by **Senators Frosh, Hollinger, Pinsky, and Ruben**

Read and Examined by Proofreaders:

_____
Proofreader.

_____
Proofreader.

Sealed with the Great Seal and presented to the Governor, for his approval this _____ day of _____ at _____ o'clock, _____M.

_____
President.

CHAPTER_____

AN ACT concerning

Maryland Caregivers Support Coordinating Council

FOR the purpose of establishing the Maryland Caregivers Support Coordinating Council; providing for the purpose of the Council; providing for the composition of the Council and the appointment, compensation, and terms of Council members; requiring the Department of Human Resources to provide certain staff support to the Council; requiring the Council to gather certain information from caregivers through certain methods; requiring the Council to develop and distribute a handbook of certain caregiver services; requiring the Council to review certain caregiver support programs; requiring the Council to develop a model caregiver support program; requiring the Council to coordinate activities of certain caregiver services; requiring the Council to conduct certain research; requiring the Council to report to the General Assembly and the Governor on or before a certain date; and generally relating to the Maryland Caregivers Support Coordinating Council.

BY adding to

Article 88A - Department of Human Resources
Section 129A
Annotated Code of Maryland
(1998 Replacement Volume and 2000 Supplement)

Preamble

WHEREAS, Respite is the occasional, short-term, temporary relief or rest for family caregivers who provide care for children or adults with developmental disabilities, funtional disabilities, challenging behaviors, or age-related disorders and diseases; and

WHEREAS, Supporting the efforts of families and caregivers to care for individuals with special needs at home is efficient, cost effective, and humane; and

WHEREAS, Families receiving occasional caregiver support services are less likely to request institutional care at public expense for an individual with special needs; and

WHEREAS, Caregiver support services reduce family and caregiver stress, enhance family and caregiver coping ability, and strengthen family ability to meet the challenging demands of caring for individuals with special needs; and

WHEREAS, Caregiver support services reduce the risk of abuse and neglect of children, senior citizens, and other vulnerable groups; and

WHEREAS, Coordinated, noncategorical caregiver support services must be available locally to provide reliable short-term relief when it is needed by families and caregivers regardless of where they live in Maryland; now, therefore,

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:

Article 88A - Department of Human Resources

129A.

(A) (1) THERE IS A MARYLAND CAREGIVERS SUPPORT COORDINATING COUNCIL IN THE DEPARTMENT OF HUMAN RESOURCES.

(2) THE PURPOSE OF THE COUNCIL IS TO COORDINATE STATEWIDE PLANNING, DEVELOPMENT, AND IMPLEMENTATION OF FAMILY CAREGIVER SUPPORT SERVICES.

(B) (1) THE COUNCIL SHALL CONSIST OF THE FOLLOWING MEMBERS, APPOINTED BY THE GOVERNOR:

(I) ~~ONE REPRESENTATIVE~~ TWO REPRESENTATIVES FROM THE DEPARTMENT OF HUMAN RESOURCES;

(II) THREE REPRESENTATIVES FROM THE DEPARTMENT OF HEALTH AND MENTAL HYGIENE;

(III) ONE REPRESENTATIVE FROM THE DEPARTMENT OF AGING;

(IV) ONE REPRESENTATIVE FROM AN AREA AGENCY ON AGING;

~~(IV)~~ (V) ONE REPRESENTATIVE FROM THE GOVERNOR'S OFFICE FOR INDIVIDUALS WITH DISABILITIES;

~~(V)~~ (VI) ONE REPRESENTATIVE FROM THE MARYLAND RESPITE CARE COALITION;

~~(VI)~~ (VII) TWO CONSUMERS OF RESPITE SERVICES;

~~(VII)~~ (VIII) THREE FAMILY CAREGIVERS; AND

~~(VIII)~~ (IX) ~~THREE~~ ~~TWO~~ *THREE* REPRESENTATIVES OF ORGANIZATIONS THAT PROVIDE OR HAVE INTEREST OR EXPERTISE IN RESPITE SERVICES.

(2) IN APPOINTING MEMBERS TO THE COUNCIL, THE GOVERNOR, TO THE EXTENT POSSIBLE, SHALL CONSIDER GROUPS REPRESENTING INDIVIDUALS WITH:

(I) ALZHEIMER'S DISEASE AND RELATED DISORDERS;

(II) DEVELOPMENTAL DISABILITIES;

(III) PHYSICAL DISABILITIES;

(IV) CHRONIC ILLNESSES;

(V) MENTAL OR EMOTIONAL CONDITIONS THAT REQUIRE SUPERVISION; AND

(VI) VULNERABILITY TO ABUSE OR NEGLECT.

(3) A MEMBER OF THE COUNCIL SHALL SERVE A 3-YEAR TERM AND MAY BE REAPPOINTED.

(4) THE GOVERNOR SHALL APPOINT A CHAIRMAN OF THE COUNCIL FROM AMONG THE MEMBERS.

(5) THE DEPARTMENT OF HUMAN RESOURCES SHALL PROVIDE STAFF SUPPORT TO THE COUNCIL, INCLUDING AN INDIVIDUAL FROM THE DEPARTMENT TO SERVE AS EXECUTIVE DIRECTOR OF THE COUNCIL.

(6) MEMBERS OF THE COUNCIL SHALL SERVE WITHOUT COMPENSATION EXCEPT THAT THE MEMBERS MAY BE REIMBURSED FOR EXPENSES

UNDER THE STANDARD STATE TRAVEL REGULATIONS, AS PROVIDED IN THE STATE BUDGET.

(C) THE COUNCIL SHALL:

(1) SOLICIT AND GATHER CONCERNS OF CAREGIVERS BY CONDUCTING SURVEYS, HOLDING PUBLIC HEARINGS, ESTABLISHING A TELEPHONE HOTLINE FOR PUBLIC ACCESS, AND OTHER APPROPRIATE MEANS;

(2) DEVELOP AND DISTRIBUTE TO INTERESTED PARTIES A HANDBOOK OF CURRENT RESPITE AND OTHER FAMILY CAREGIVER SERVICES AVAILABLE IN THE STATE;

(3) REVIEW SUCCESSFUL RESPITE CARE PROGRAMS IN OTHER STATES;

(4) DEVELOP A MODEL FAMILY CAREGIVER SUPPORT PROGRAM THAT INCORPORATES BEST PRACTICES FROM EXISTING PROGRAMS IN THE STATE AND IN OTHER STATES;

(5) COORDINATE ACTIVITIES OF EXISTING AND PROPOSED FAMILY CAREGIVER SUPPORT SERVICES AMONG THE STATE AND LOCAL PUBLIC AGENCIES;

(6) RESEARCH AVAILABLE FUNDING SOURCES AND EXPLORE POSSIBILITIES FOR ADDITIONAL FUNDS; AND

(7) IDENTIFY UNMET NEEDS AND PRIORITIES FOR ADDITIONAL FUNDS.

(D) THE COUNCIL SHALL SUBMIT TO THE GOVERNOR AND, SUBJECT TO § 2-1246 OF THE STATE GOVERNMENT ARTICLE, TO THE GENERAL ASSEMBLY AN ANNUAL REPORT ON ITS ACTIVITIES.

SECTION 2. AND BE IT FURTHER ENACTED, That, on or before October 1, 2002, the Council shall submit a report to the Governor and, subject to § 2-1246 of the State Government Article, to the General Assembly with a plan of action for family caregiver support services.

SECTION 3. AND BE IT FURTHER ENACTED, That this Act shall take effect July 1, 2001.

Appendix 2: Matrix of Maryland's Health and Human Service Agencies

DEPARTMENT	MISSION	PROGRAMS OFFERED	POPULATION SERVED	ELIGIBILITY
Department of Aging (MDOA)	To provide leadership and advocacy for older Marylanders and their families through information, education, programs, and services that promotes and enhances choice, independence and dignity.	Senior Care, The National Family Caregiver Support Program, Senior Information and Assistance, Home Delivered Meals and Nutrition Programs, Senior Legal Assistance, Senior Health Insurance Assistance Program, Senior Center Plus, Long Term Care Ombudsman and Elder Abuse Prevention, Housing Services, Medicaid Waiver. Location Served: Each programs is administered at the local level in each of Maryland's jurisdictions.	Senior Care serves people age 65 or older that meet functional and financial eligibility requirements. (Served 3,995 individuals in FY 2001) The National Family Caregiver Support Program serves two categories of caregivers: 1) Caregivers of any age who are caring for people who are age 60 or older, 2) Family caregivers age 60 or older who are caring for children age 18 or under.	An individual is eligible for Senior Care if he/she needs assistance due to a medical condition or disability that places him or her at risk of having to enter a nursing. No eligibility requirements for the NFCSP other than the age restrictions.
Maryland State Department of Education (MSDE)	To provide home and community based waiver services for children with Autism Spectrum Disorder.	Respite Care, Environmental Accessibility Adaptations, Family Training, Service Coordination, Residential Habilitation, Supported Employment, Day Habilitation.	Children who are diagnosed with Autism Spectrum Disorder.	Children with Autism Spectrum Disorder, defined in the DSM-IV as 299.00 & 299.80. Limited to 250 children for the 1st year, 300 for the 2nd year, and 350 children for the 3rd year.

DEPARTMENT	MISSION	PROGRAMS OFFERED	POPULATION SERVED	ELIGIBILITY
Department of Health and Mental Hygiene (DHMH) Developmental Disabilities Administration (DDA)	To provide leadership to assure the full participation of individuals with developmental disabilities and their families in all aspects of community life and to promote their empowerment to access quality supports and services necessary to foster personal growth, independence and productivity.	Residential Program Services, Day Program Services, Services Coordination/Targeted Case Management, Purchase of Care Services, Summer Programs, Individual Family Care, Individual Support Services, Family Support Services, Behavioral Support Services, Community Supported Living. Location Served: Rosewood Center, Owings Mills, Holly Center, Salisbury, Potomac Center, Hagerstown, Brandenbury Center, Cumberland.	Individuals with development disabilities. 30,000 individuals served by 172 providers in Fiscal 2001.	An individual is eligible if he/she has a severe chronic disability.
Department of Health and Mental Hygiene (DHMH) Family Health Administration (FHA)	1) To reduce death, illness and disability from genetic disorder, birth defects and chronic diseases and injuries and to improve the quality of life for these individuals. 2) To protect and promote the health of Maryland's children with special health care needs by assuring a family-centered, community-based, comprehensive, coordinated and culturally appropriate system of special health care.	Respite Services for Children. Funding is offered to local departments for needs assessment, capacity building, activities, and the provision of respite services.	Each county receiving monies for respite services defined the children with special health care needs population within their jurisdiction who would be eligible for services. Over 150 teens and adults were trained to provide respite services and 388 children received respite services.	Eligibility is determined by each county's service offerings.

DEPARTMENT	MISSION	PROGRAMS OFFERED	POPULATION SERVED	ELIGIBILITY
Department of Health and Mental Hygiene (DHMH) Mental Hygiene Administration (MHA)	To create and manage a coordinated, comprehensive, accessible, culturally sensitive and age appropriate system of publicly funded services and supports for individuals who have psychiatric disorders and in conjunction with stakeholders, provide treatment and rehabilitation to promote resiliency, health and recovery.	Respite care for residential facilities, respite homes, in the caregiver's home and at other locations in the community.	Families of children and adolescents with serious emotional disturbances and the caregivers of adults with serious and persistent mental illness.	Eligibility is determined by the population definitions and by referral guidelines established for this service by MHA.
Department of Human Resources (DHR) Office of Adult Services (OAS)	To serve the elderly, disabled, vulnerable person and family members through a home and community based delivery system that protects vulnerable persons, promotes self-sufficiency, and avoids or delays unnecessary institutional care or other out-of-home placements. The services embody the principles of personal dignity, quality of life, privacy and the right to make choices.	Adult Protective Services, In-Home Aide Services, Project Home, Respite Care Services, Social Services to Adults, Adult Public Guardianship.	Respite Care serves individuals or family members who have been diagnosed with a developmental or functional disability. (Served 1,410 in FY 2001). In-Home Aide Program serves adults who have functional disabilities and need assistance with personal care, chores and/or activities of daily living in order to remain in their own home. (Served 4,085 in FY 2001).	Eligibility for Respite Care is determined by the Respite Care Services Fee Scale. Eligibility for In-Home Aide is determined by In-Home Aide Services Income Levels, and In-Home Aide Services Fee Schedule.

DEPARTMENT	MISSION	PROGRAMS OFFERED	POPULATION SERVED	ELIGIBILITY
Department of Human Resources (DHR) Office of Family & Children Services	To support and enable local departments of social services, in cooperation with community partners, to employ strategies to prevent child abuse and neglect, protect vulnerable children, support family stability and promote customer independence.	Kinship Care Support Services, Foster Care Support Services, Adoption Support Services.	Formal Kinship provider: A relative caring for a state committed child. (served 3,500) Informal Kinship provider: A relative not involved with the child welfare system. (served 10,000) Foster Parent: A caregiver approved as Maryland foster parent. (served 4,900) 2181 Adoptive parents.	Meets the definition of kinship care provider and approved as a foster and adoptive parent within the state of Maryland.
Department of Human Resources (DHR) Office of Personal Assistance Services (OPAS)	To ensure the coordination of personal assistance services and explore alternative service delivery methods that will both increase and enhance Maryland's current services.	Living at Home: Maryland Community Choices, Attendant Care Program, Nursing Home Transition Grant	Living at Home: Maryland Community Choices served adults with physical disabilities aged 21-59 years. Attendant Care Program served adults with physical disabilities aged 16-64 years. (served 76 individuals).	Adults with physical disabilities that need assistance with daily living activities. Eligibility for services is determined by state and physician certification. Gross Income of less than $39,000 per year and at least one of the following:

DEPARTMENT	MISSION	PROGRAMS OFFERED	POPULATION SERVED	ELIGIBILITY
			Nursing Home Transition Program served adults with physical disabilities aged 21-65.	employed or seeking employment; enrolled in an institution of post secondary or higher education; nursing facility resident or at risk of nursing facility placement. Living in a Maryland nursing facility; receive or are eligible for Medical Assistance.

Appendix 3: Public Forum Reports

Appendix 4: Survey

MARYLAND CAREGIVERS SUPPORT COORDINATING COUNCIL

DHR
Maryland's Human Services Agency

Stacey Beall
Community Member

Gisele Murphy Booker
Community Member

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
MD Respite Care Coalition, Inc.

Denese F. Maker, Chair
Community Services
Administration, DHR

Sandra J. Malone
Office for Genetics & Children
with Special Health Care Needs,
DHMH

Connie Marth
Delmarva Community Services

Tom Merrick
Mental Hygiene Administration,
DHMH

Linda Mouzon
Social Services Administration,
DHR

Elizabeth Skates
Community Member

Constance L. Urquhart
Developmental Disabilities
Administration, DHMH

Bobette T. Watts
Governor's Office for Individuals
with Disabilities

Susan J. Vaeth
Department of Aging

Dorinda A. Adams,
Council Staff
Office of Adult Services
Community Services
Administration, DHR

John Kardys
Advisory Staff to Council
Office of Adult Services
Community Services
Administration, DHR

James Reinsel
Advisory Staff to Council
Community Services
Administration, DHR

June 2002

Dear Maryland Caregiver:

The Maryland Caregivers Support Coordinating Council is undertaking this survey. The Council has 17 members from several State offices, community groups, and people who are caregivers and care recipients. The purpose of this survey is to help the Council understand the circumstances of Maryland caregivers and to help the Council form recommendations for their agencies, the Governor, and the Maryland Assembly.

This is an important survey. Your answers will be reported along with those of other caregivers across Maryland. **DO NOT PUT ANY IDENTIFYING INFORMATION SUCH AS YOUR NAME, ADDRESS, or PHONE NUMBER** on this survey. You will not be matched with your survey information in any way. The survey takes approximately 10-15 minutes to complete.

If you wish to speak to someone about this survey or other concerns that you have as a caregiver, you may contact Virginia Thomas at 410-455-6857, e-mail vthomas@umbc.edu, or write to her at 1000 Hilltop Circle, SSB 309, Baltimore, Maryland 21250. You may also send any written comments that you have about your experience as a caregiver. Please keep this letter in case you want to contact the researchers at a later time.

THANK YOU FOR YOUR HELP WITH THIS SURVEY AND FOR ALL THAT YOU DO AS A MARYLAND CAREGIVER!

WE APPRECIATE THAT YOU ARE GIVING OF YOUR TIME TO COMPLETE THIS SURVEY. COMPLETED SURVEYS MUST BE RECEIVED NO LATER THAN **JULY 26, 2002**. SURVEYS CAN BE MAILED, **POSTAGE PAID**, TO THE ADDRESS ON THE BACK OF THIS SURVEY, OR FAXED TO 410-455-6850. IF YOU HAVE QUESTIONS OR NEED THIS SURVEY IN OTHER FORMATS, PLEASE CALL VIRGINIA THOMAS AT 410-455-6857. **THANK YOU!**

SHOULD YOU COMPLETE THIS SURVEY?

Caregiving may include helping an adult with personal needs or household chores, or providing care to a child with special needs. It may be taking care of a person's finances, arranging for outside services or visiting regularly to see how they are doing. This person need not live with you.

If you provide(ed) this kind of **unpaid** help to a relative or friend, now or in the last 12 months, please complete this survey.

THE CAREGIVER/CARE RECIPIENT RELATIONSHIP

1. For how many people do you provide this care (now or in the past 12 months)?

   _____ # people

THE NEXT QUESTIONS ARE ABOUT THE PERSON FOR WHOM YOU PROVIDE CARE. IF YOU PROVIDE CARE FOR MORE THAN ONE PERSON, FOCUS ON THE ONE FOR WHOM YOU PROVIDE THE **MOST** ASSISTANCE:

2. What is this person's relationship to you? CIRCLE ONLY ONE.

   a. Spouse
   b. Mother/Mother-in-law
   c. Father/Father-in-law
   d. Son/Daughter/Grandchild
   e. Brother/Sister or Brother-in-law/Sister-in-law
   f. Grandparent/Grandparent-in-law
   g. Aunt/Uncle
   h. Non-relative/friend
   i. Other (SPECIFY) _____

3. Where does this person live? (CIRCLE ONE ANSWER.)

   a. In your household → GO TO QUESTION 3a.
   b. Within 20 minutes of your home
   c. Between 20 minutes and an hour from your home
   d. One to two hours from your home
   e. More than two hours away

   → GO TO QUESTION 4

3a. Was this living arrangement established because of the needs of the person you help?

   a. Yes
   b. No
   c. Don't know

   GO TO QUESTION 5

4. With whom does this person live?

   a. Alone
   b. With a spouse/family member or friend
   c. In a boarding or group home, or an assisted living facility
   d. In a nursing home
   e. Don't know
   f. Other (SPECIFY) _____

ABOUT THE CARE RECIPIENT

5. What would you say is the **main** illness or problem of the person you help? CIRCLE ONE.

   a. AIDS
   b. Alzheimer's/Confusion/Dementia/Forgetfulness/Senility
   c. Developmental Disability/Mental Retardation
   d. Blindness/Vision Loss
   e. Chronic Disease (Cancer, Diabetes, Heart Disease, High Blood Pressure, Lung Disease)
   f. Mental Illness/Emotional Disturbance
   g. Mobility (Can't get around because of Arthritis, Paraplegia, broken bones or some other problem)
   h. Stroke
   i. Other (SPECIFY) _____
   j. Don't know

6. Using a scale from 1 to 5, where 1 is no disability at all and 5 is completely disabled, how disabled is the person you help due to his/her condition? CIRCLE ONE NUMBER.

   No Disability ← → Complete Disability

1	2	3	4	5

7. How old is the person you help? (Your best estimate is fine.)

   a. _____Years old
   b. Don't know

8. For how long have you been providing help to this person? (Your best estimate is fine.) CIRCLE ONE.

   a. Less than six months
   b. Six months to one year
   a. More than 1 year (_____ # Years)

9. What is the condition of the person you help?

   a. Short-term in nature (3 months or less)
   b. Chronic, or long-term in nature
   c. Episodic (on and off)
   d. Don't know

10. About how many hours do you spend assisting this person in an average week?

    a. _____ Hours per week
    b. Constant care
    c. Don't know

11. Place a mark next to each service that you provide(ed).

Help to…	Provide(ed) This Type of Assistance
a. Get in and out of beds and chairs	
b. Get dressed	
c. Get to and from the toilet	
d. Bathe or shower	
e. Deal with diapers, or remind to go to the bathroom	
f. Eat	
g. Take medicines, pills, or injections	
h. Manage finances (example: paying bills, filling out insurance claims)	
i. Grocery shopping	
j. Do housework, such as dishes, laundry, or straightening up	
k. Prepare meals	
l. Get places, either by driving or helping him/her public transportation	
m. Arrange or supervise outside services	
n. Other (SPECIFY):	
o. Other (SPECIFY):	
p. Other (SPECIFY):	

12. Do you need information or training in any area of caregiving?

    a. Yes
    b. No

12a. If you answered YES to Question 12, SPECIFY the area(s) in which you need information or training.

1._____ 2._____ 3. _____

MEDICATIONS

IF YOU HELP BY GIVING PILLS/MEDICINES/INJECTIONS, ANSWER QUESTION 13. OTHERWISE, SKIP TO QUESTION 14.

13. Do you know…
    CHECK YES OR NO FOR EACH ITEM.

	Yes	No
a. What each medicine is for?		
b. Possible side effects of each medicine?		
c. How the medicines may react with each other?		
d. How to give the medicines as prescribed (on time, the right amount)?		

OTHER CAREGIVER SUPPORT

14. If others are involved in the care of the person you help, do you feel that they are doing their fair share of caregiving?

    a. Yes
    b. No
    c. Does not apply/No other caregivers

15. To what extent has there been conflict in your family regarding your caregiving?

    a. A lot of conflict
    b. Some conflict
    c. None at all
    d. Don't know

16. Due to the behavior of the person that you help, have you ever been concerned … CHECK YES OR NO FOR EACH ITEM.

	Yes	No
a. For your own safety?		
b. For the safety of others in the household?		
c. For the safety of the person you help?		
d. About damage to personal belongings or property?		

17. While you were providing care for the person you help, were you ever:

    a. Employed full-time
    b. Employed part-time
    c. Retired ←
    d. Not employed ←

IF YOU ANSWER C OR D, SKIP TO QUESTION 19.

INFORMATION/SERVICES: USE, SOURCE, AND USEFUNESS

25. Have you ever arranged for any of the following services when providing care? **CHOOSE A NUMBER** FROM THE YES OR NO LIST AND WRITE IT IN THE SPACES BELOW.

YES LIST	NO LIST
1. A church/synagogue/ mosque or other religious organization 2. A government agency 3. A community agency 4. Your employer 5. An individual or private agency for which you are paying 6. A doctor, pharmacist, social worker, other health provider 7. Other (SPECIFY in the appropriate square below.)	1. Had no need for it 2. Service is not available 3. Not aware of service 4. Cost/can't afford 5. Can't find qualified people 6. Don't want an outsider coming in/ strangers 7. Bureaucracy too complex, hassle, couldn't access service 8. Language barrier 9. Not eligible, make too much money, income too high 10. No special reason/never thought of it 11. Other (SPECIFY in the appropriate square below.)

	If Yes, who provided this service?	**If No, why not?**
a. Financial assistance for caregiving needs		
b. A service to temporarily take care of the person you help so that you get some time away?		
c. A program outside the home such as a day care or senior center		
d. Personal care or nursing care		
e. Housework at the place where the person you help lives		
f. An outside service deliver meals		
g. An outside service provide transportation		
h. Modifications made in the house to make things easier		
i. Assistive devices (wheel chairs, walkers, etc.) for the person you help		
j. Home-based schooling		
k. Other (SPECIFY)		

26. Please think about your situation and indicate any kinds of help, information, or support that you need and do not have as a caregiver. CIRCLE ALL THAT APPLY.
   a. Extra money; more money to help pay for things; financial support
   b. Free time; time for yourself, a break
   c. A central place to go to/call to find out what kind of help is available/where to get it
   d. Someone to talk to/counseling/support group
   e. Help providing housekeeping
   f. Help shopping
   g. Help providing transportation
   h. Help providing meals
   i. Help with bathing, dressing, grooming, toileting, feeding, other personal care
   j. Help with medicines (giving, side effects, etc.)
   k. Information about your relative's or friend's condition
   l. Information about developments or changes in programs or laws
   m. Help in understanding how to select nursing home/group home/other facility
   n. Help in understanding how to pay for nursing homes, day care, or other services
   o. Information about services for persons with Alzheimer's/ memory problems
   p. Help dealing with bureaucracy to get services
   q. Tax break, stipend, government subsidy
   r. Other (SPECIFY) ________________
   s. None

26a. Of the items that you circled in Question 26, what are the three most important to you: ____________________

◆◆

NOW, PLEASE TELL US A LITTLE ABOUT YOURSELF

27. Please circle your racial group.
   a. White
   b. Black/African-American
   c. Asian/Chinese/Pacific Islander
   d. Native American/American Indian/Alaskan Native
   e. Other (SPECIFY) ____________________
   f. Prefer not to answer

28. Are you of Hispanic origin or background?

a. Yes
b. No
c. Prefer not to answer

29. Is there another adult in your household who shares household responsibilities?

a. Yes
b. No

30. Do you have responsibility for any children or grandchildren living in your household who are under 18 years of age?

a. Yes
b. No

31. What is the last grade of school /degree that you completed? _____

32. Is your total annual household income from all sources…

a. Less than $10,000
b. $10,000 or more, but less than $20,000
c. $20,000 or more, but less than $30,000
d. $30,000 or more, but less than $40,000
e. $40,000 or more, but less than $50,000
f. $50,000 or more, but less than $75,000
g. $75,000 and over
h. Prefer not to answer

32a. How many people does this income support?_____ (Number of adults and children.)

33. How old were you on your last birthday? _____ Years

34. What is your sex?
a. Male
b. Female

35. What county or jurisdiction do you live in?

Allegany		Charles		Prince George's	
Anne Arundel		Dorchester		Queen Anne's	
Baltimore City		Frederick		St. Mary's	
Baltimore County		Garrett		Somerset	
Calvert		Harford		Talbot	
Caroline		Howard		Washington	
Carroll		Kent		Wicomico	
Cecil		Montgomery		Worcester	

36. What is your zip code? _____

OTHER COMMENTS YOU WOULD LIKE TO MAKE:

Thank you very much for your time. Your responses will be very important to the Council's work in planning for caregivers in Maryland.

Please return this survey no later than **July 26, 2002.**

Seal the three open sides by using staples or tape.

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