



# 2016 Final Report

## Task Force on Family Caregiving and Long Term Supports

Submitted to:

**The Hon. Lawrence J. Hogan**  
*Governor of Maryland*

**The Hon. Thomas V. Mike Miller, Jr.**  
*President, Senate of Maryland*

**The Hon. Michael E. Busch**  
*Speaker, House of Delegates of Maryland*

**Members - Maryland General Assembly**

Pursuant to:

2015 Laws of Maryland, Chapter 155

## Table of Contents

|   |     |
|---|-----|
| Letter of Transmittal   | iii |
| Executive Summary   | v   |
| The Significance of Family Caregiving at the National Level         | 1   |
| Maryland Family Caregivers  | 2   |
| Economic Impact of Maryland Caregivers                              | 3   |
| Moves to Enhance Telemedicine Services                              | 5   |
| Maryland Medicaid Community-Based Waivers                           | 6   |
| Transportation Needs of Disabled Family Care Recipients             | 7   |
| Support Mental Health Caregivers                                    | 9   |
| Respite Care  | 11  |
| Adult Medical Daycare   | 13  |
| Critical Support Needed for Assistive Devices                       | 14  |
| Enhancement of the Maryland Caregivers Support Coordinating Council | 15  |
| Appendix A: Statutory Authority                                     |     |
| Appendix B: Task Force Membership                                   |     |
| Appendix C: Task Force Meeting Dates and Topics                     |     |



September 30<sup>th</sup>, 2016

The Honorable Lawrence J. Hogan, Jr, Governor State of Maryland  
The Honorable Thomas V. Mike Miller, President of the Senate  
The Honorable Michael E. Busch, Speaker of the House of Delegates  
The Honorable Members of the General Assembly

On behalf of the **Task Force on Family Caregiving and Long-Term Supports** we respectfully submit the task forces' final report and recommendations.

The task force was established by Chapter 155 of 2015. The law required that the task force consist of representatives from the Executive Branch, General Assembly, and public sector. The task force was required to:

1. Identify resources and programs available for family caregivers and care recipients and different policies that support family caregivers;
2. Create an inventory of resources, including policies and programs available to caregivers;
3. Gather testimony from family caregivers; and
4. Analyze and suggest actions the State could take on legislative and administrative levels to develop and train an in-home care work force.

This report provides information on the scope and needs of family caregivers especially in Maryland as well as impediments to safe, reliable and affordable resources for caregiving in Maryland. The recommendations in the Report are intended to address information and resource inadequacies and to enhance services to family caregiving. The report is intended to emphasize family caregivers in Maryland are a natural resource and save the State billions of dollars in informal care.

Sincerely,

Delores G. Kelley, Co - Chair

Angela Angel, Co - Chair



## **Executive Summary**

Senate Bill 297, enacted in 2015 as Chapter 155, created the Task Force on Family Caregiving and Long-term Supports. The bill took effect on July 1, 2015 and terminates on October 30, 2016. The task force is required to report to the Governor and General Assembly by September 30, 2016.

The 27-member Task Force included one member of the Senate and one member of the House of Delegates, who were designated as Co-Chairs. There was a representative of three State agencies, with significant responsibilities for programs and services of particular importance to the aging and disabled populations that are the main recipients of family caregiving in Maryland.

AARP Maryland agreed to staff this task force, to coordinate meetings, prepare minutes, and compile the final report. The Task Force first convened in July 2015 and met the following September, October, and November. In 2016, the task force met in February, March, April and May, to discuss and compile the findings detailed in this report. The eight (8) public meetings focused on identifying policies, resources and programs available to family caregivers. This report is a compilation of those findings and addresses solutions that Maryland should consider for Marylanders providing caregiving services to their loved ones.

The Department of Human Resources (DHR) staffs the Maryland Caregivers Support Coordinating Council (MCSCC), which became operational in 2001, but has insufficient staffing or other resources to design or implement the kind of comprehensive study which the Task Force on Family Caregiving and Long-term Supports was charged. The MCSCC is legislatively mandated to: solicit and gather concerns of family caregivers, promote the awareness of caregiver support services among state and local jurisdictions, review caregiver support systems and assess them for effectiveness and accessibility, and to coordinate barrier free systems. Additionally, the MCSCC is charged with researching available funding services, exploring caregiver support enhancements, and identifying unmet needs as well as priorities for additional funding.

The Department of Health and Mental Hygiene (DHMH) provides (or purchases) direct care services, which are Jointly regulated by the federal Centers for Medicare and Medicaid (CMS) and by DHMH, for several defined populations – including elderly and/or disabled Marylanders seeking institutional and outpatient services.

The Maryland Department of Aging (MDoA) administers numerous programs, mainly through local “area agencies on Aging,” which use State and federal funds to meet the advocacy, socialization, nutritional, and housing needs of both active and impaired senior citizens in each Maryland county.

The MCSCC statute requires that the Departments of Aging, Disabilities, Health and Mental Hygiene, and Human Resources be appointed as members of the MCSCC to ensure

that all family caregivers across the lifespan are represented by the programs administered by the four departments.

Chapter 155 of 2016 designated 21 Maryland organizations (including the three previously referenced State agencies, the Maryland Senate, and the House of Delegates) which were each allocated one or more members on the task force (see the list of all members in Appendix B). Some task force members changed their organizational affiliation during the life of the task force, but continued to serve since their new affiliations were still applicable to family caregiving.

The Task Force on Family Caregiving and Long-Term Supports has provided recommendations on pages 5, 7-9, and 11-14. The Task Force on Family Caregiving and Long-Term Supports respectfully considers these recommendations to provide a comprehensive approach in supporting Maryland's family caregivers and the care recipient.

## **The Significance of Family Caregiving at the National Level**

According to the National Academy of Elder Law Attorneys, about 90% percent of the long-term care services received in the United States is provided by informal, unpaid caregivers such as family members, friends, and neighbors. An estimated \$470 billion in provided services are performed by informal caregivers. National spending on long-term services and supports including Medicaid, private long-term care insurance, out-of-pocket, etc. is approximately \$310 billion; \$74.1 billion of Medicare spending is on post-acute care. These figures indicate that the existing support network of informal caregiving is the backbone of the nation's long-term care system. The existing support network enables individuals with disabilities to remain in their homes and communities and is fundamentally irreplaceable. Despite the tremendous responsibilities associated with caregiving, the role of informal caregivers has not been adequately acknowledged, and the public resources that would be needed to replace informal caregivers with paid workers would be exorbitant.

Inadequate respite care options have resulted in limited available resources for informal caregivers, and unpaid caregivers today often operate with inadequate support systems and lack information and skills. Given the current patterns, informal caregiving cannot be maintained nor sustained with the continued growth in the number of people requiring long-term care. Access to paid help needs to be expanded to more adequately complement the existing caregiving support system. States, public health officials, and advocates should seek to identify mechanisms to alleviate what has been termed as "Caregiver Stress Syndrome." Strategies are needed to help keep informal caregivers from burning out. Faced with competing pressures from paid employment and other family roles, an appropriate combination of informal and paid services would reduce and/or prevent some of the stress associated with bearing the whole caregiving responsibility themselves.

Federal law pertaining to Aging and Disability Resource Centers requires that multiple state agencies and partners work towards a "No Wrong Door" concept of service delivery that will provide a more comprehensive approach to an individual needing information or services to receive timely and accurate information on all aspects of the long term services system.



## **Maryland Family Caregivers**

Family caregivers are any relative, partner, friend or neighbor who has a significant relationship with, and provides a broad range of unpaid care and assistance for loved ones with chronic, disabling, or serious health conditions. Family caregivers provide services that would normally take a multidisciplinary team to accomplish. They make up the largest segment of the long-term care workforce in the nation but often go unrecognized. A study by the MCSCC in 2015 found that in Maryland, the average caregiver is an employed 49-year-old woman who spends nearly 20 hours per week caregiving and has been providing unpaid care for her mother for nearly 5 years.

According to a 2015 survey administered by the MCSCC, the majority (60%) of family caregivers in Maryland were employed either full-time or part-time. Job duties combined with family caregiving creates a juggling act in which the caregiver must balance demands from work, their own home and family life, social engagements, and caregiving responsibilities.

The complex management involved in caregiving creates stress for the family caregiver and can lead to poor physical and mental health, loss of productivity at work, and financial stress. Many medical and nursing tasks that were once done only in hospitals and nursing homes are now routinely done by family caregivers.

Forty percent (40%) of family caregivers expressed considerable stress and worry about making a mistake when performing necessary tasks, such as wound care, medication management, and help with assistive devices for mobility. One-third said their own health was fair to poor. This level of responsibility, along with the lack of training and support, has been shown to create stress in the family caregiver.

Along with the rest of the nation, Maryland is experiencing a shift in demographics. According to the 2010 United States Census, Maryland has nearly 1 million people aged 65 or older. By 2030, the United States Census estimates that the percentage of people 65 or older in Maryland will double. As this population increases in size, the need for caregivers increases as well. In Maryland, the family caregiver ratio was 8.3 potential caregivers aged 45-64 for every person in the high-risk years of 80 plus. In 2030, the ratio is projected to decline sharply to 4.4 to 1; and it is expected to fall to 3.4 to 1 in 2050 (Redfoot, Feinberg, & Houser, 2013).

## **Economic Impact of Maryland Caregivers**

Similar to caregivers in other states, many Maryland family caregivers assist their parents, neighbors, friends, spouses, and other relatives to enable them to remain at home. Indeed, over half (57%) of Marylanders ages 45 and older are currently providing or have provided unpaid care to an adult loved one who is ill, frail, elderly, or has a physical or mental disability. At least 7 in 10 are helping or have helped their loved ones with complex tasks such as medication management (73%) and other nursing and medical tasks (71%). Currently in Maryland, an estimated 771,000 caregivers contribute to an estimated 615 million unpaid care hours per year. According to the 2015 AARP Report: *Valuing the Invaluable*, the estimated annual economic impact of this care to the state totals \$9.3 billion.

Across Maryland we are seeing an increase in the number of people who need care as an opportunity, rather than solely a burden. While this changing demographic presents challenges, many state and local leaders should use this opportunity as a chance to implement innovative new programs and policies to embrace this change. In order to make caregiving easier, Maryland needs to establish disability-friendly communities, equipping patients and family caregivers to easily identify resources and services across the spectrum of caregiving and adopting innovative models of service, establishing new supports for the variety of caregiving roles, and incorporating new technology for our caregivers.

Maryland's Home and Community-Based Options Waiver (HCBOW) serves as an option, but is not without flaw(s). It services individuals who are medically, technically and financially eligible for Medicaid waiver services who have been transitioned or diverted from a nursing facility. Federal law allows Medicaid to waive some long-term care requirements which enables medical assistance long-term care benefits for individuals at home or in assisted living facilities. Under HCBOW, the federal government waives the requirement that services be provided in an institution. Although the U.S. Department of Justice has sued several states for violating the federal Olmstead Act by forcing elderly and/or disabled family care recipients to leave their community settings and to accept costly Medicaid subsidized nursing home slots as a prerequisite for assignment to a community-based waiver slot, Maryland continues to follow this legally risky and counterproductive practice.

Maryland's waitlist for community-based waiver slots is poorly maintained, and is not regularly purged to remove names of persons now dead or whose healthcare needs can no longer be adequately met in the community. When those on Maryland's waitlist are forced into costly and less personalized nursing home care as an intermediary step, they often lose family caregiving arrangements that cannot easily be restored later if the care recipient is ultimately able to return home as the result of being granted a waiver slot.

Medicaid-eligible Marylanders living in the State's nursing facilities are not aware that any home and community-based services are available. Neither these nursing home residents, nor their family members know that they have the option to choose to stay in their own homes. The State has no system to make Medicaid-eligible disabled persons aware of their available alternatives when they seek or are referred to nursing facility care. The unnecessary

segregation of elderly and/or disabled people in nursing facilities violates the federal Olmstead Act and wastes the precious resources of the State.

## **Moves to Enhance Telemedicine Services**

Three recently enacted laws were designed to remove unnecessary impediments to the appropriate use of telemedicine.

Chapter(s) 579 and 580 of 2012 required insurers, non-profit health service plans, and health maintenance organizations (HMOs) to cover and reimburse for appropriately delivered telemedicine services, with carriers having discretion over utilization review, including preauthorization. Chapter(s) 141 and 526 of 2014 clarify that coverage and reimbursement of the medical services apply to Medicaid, to the extent authorized by federal law or regulation, subject to State budget limitations. Also clarified, is that DHMH may authorize and reimburse for two particular telemedicine modalities: store and forward technology, and remote patient monitoring for Medicaid recipients.

Because the telemedicine services which DHMH actually covers for Medicaid recipients is much less expensive than the range of services allowed under federal law and State law, the General Assembly passed additional legislation on Medicaid telemedicine services in the 2016 Session (Chapter 366). The 2016 law repeals a DHMH regulation which had denied reimbursement to primary care physicians for telemedicine services to Medicaid recipients.

The 2016 law also requires DHMH in consultation with the Maryland Health Care Commission to submit a report by October 1, 2016 to the Senate Finance Committee and to the House Health and Government Operations Committee. The report must assess “the telehealth policies of select Medicaid programs in other states, including reimbursement for telehealth services provided in a home setting” and must also detail “planned enhancements to the Maryland Medicaid telehealth program.”

### Recommendations

1. That DHMH include in its October 2016 Report, its plan for the expansion of Medicaid coverage for telemedicine services to all regions of Maryland, and not just to rural areas.
2. A reconsideration of the current “spoke and wheel” paradigm as the only delivery system for Medicaid telemedicine services; and
3. Requirements for strict reporting of all telemedicine encounters to a patient’s “medical home,” so that all visits, prescriptions, lab work, and follow ups are carefully coordinated.

## **Maryland Medicaid Community-Based Waivers**

A presenter from the Maryland chapter of the National Academy of Elder Law Attorneys made a strong case for significantly more HCROW slots in Maryland and for a decrease in the number of nursing home beds. DHMH has had insufficient resources for management of its multi-year registry of over 30,000 elderly and/or disabled Marylanders seeking a waiver slot in order to avoid long term nursing home care. Prompted partially by testimony offered before the task force, DHMH indicated that it would consider whether compensation for Support Planning Agencies can be increased to \$75 per hour to better serve the information needs of waiver slot seekers who want clarity regarding long term care service and support options available to them, given their individual medical and financial circumstances.

Subsequently, in December 2015, DHMH began the first real “scrubbing” of its multi-year registry of waiver slot seekers. So long as there is such a registry, there will be a need to periodically evaluate:

1. Which names on the waitlist should be struck due to the placement of persons with declining health and reduced functionality into nursing homes;
2. Elderly and/or disabled persons who no longer reside in Maryland; and
3. A systematic match of names with Maryland issued death certificates (revealing that the persons are deceased).

According to DHMH, efforts to update the waiver registry have begun, but are not yet completed. The first wave of letters to screen people on the registry went out the week of July 18, 2016. There will be several waves of mailings and DHMH expects the full process of contacting each person on the registry to take six months. DHMH has removed individuals who are deceased and are in the process of referring those who are in nursing facilities to the Maryland Access Point sites for options counseling; removal of names does not happen until options counseling has been received. While these efforts will take several more months to complete, the registry was reduced from nearly 33,000 to just under 27,000 individuals through this year’s efforts.

As the termination date of the task force approaches, the members appeal to the Governor, the General Assembly and State agencies with any jurisdiction over issues covered in this report to take the bold steps necessary to insure that Maryland family caregivers have 24 hour real-time access to relevant information and a comprehensive array of State- offered or State-vetted services such as: respite care, assistive technology, emergency responses systems, adult day care, telehealth, meal delivery services, and medical transportation within reasonable reach of family care recipients in every county.

## Transportation Needs of Disabled Family Care Recipients

There is spotty and inadequate government-sponsored transportation available for many elderly and/or disabled Marylanders. Some, but not all counties provide County Ride, or Maryland Transit Administration (MTA) Mobility service for which eligible community-based care recipients can apply.

In counties where MTA operates paratransit service, the pickup and drop off locations are fixed, with no deviations available even for applicants who must use wheelchairs or other durable medical equipment to reach the nearest fixed pickup/drop off points, an impossibility for many who would have to navigate busy highways or narrow country roads with no sidewalks to reach these points.

Additional MTA-imposed barriers impact disabled care recipients because of MTA's inconvenient, intrusive, and cost-prohibitive requirement that already medically-certified family care recipients with disabilities must visit MTA offices where MTA-employed physical and/or occupational therapists make duplicative assessments of disabilities already attested to by health care providers licensed in Maryland.

The MTA's 20-page application<sup>1</sup> requires a disabled applicant for transportation services to tell the MTA whether the applicant can read or write, has panic attacks, hallucinations, delusions, paranoia, short term memory loss, bipolar disorder or schizophrenia (all conditions which ought not to be provided to a government-sponsored transportation service with no legitimate need for such personal and intrusive information). The Baltimore Sun paper's January 2015 article<sup>2</sup> describes the rationale offered by MTA riders with disabilities for suing the Maryland Transit Administration. Also, see the April 2016 Federal Transit Administration's Baltimore Paratransit Compliance Review Report and the response from MTA Mobility<sup>3</sup>.

### Recommendations

1. That the State of Maryland collaborate with county area agencies on aging, with the Department of Disabilities, and DHR, to design and specify the budget required for door-to-door paratransit service with deviation as necessary, for all low and moderate income disabled Marylanders, including such essential services as medical transportation.
2. That MTA Mobility and the other government-sponsored paratransit services be required to accept signed, attestations by an applicant or user's licensed medical provider(s) regarding their functional eligibility for paratransit service, without invading the privacy of such applicants or users.
3. That the State conserve limited financial resources by eliminating the slots of MTA Mobility's physical and occupational therapy unit.

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<sup>1</sup> <https://mta.maryland.gov/sites/default/files/mta-mobility-application.pdf>

<sup>2</sup> <http://www.baltimoresun.com/news/maryland/bs-md-mta-mobility-lawsuit-20150121-story.html>

<sup>3</sup> <https://www.transit.dot.gov/sites/fta.dot.gov/files/docs/MTA%20Final%20ADA%20Report.pdf#page=9>

4. That MTA Mobility and other government-sponsored paratransit services include deviated fixed routes, with deviations no greater than 2 miles from any existing deviated fixed route, except for good cause.

## Support Mental Health Caregivers

Mental health caregivers give significant time and financial support to help millions of Americans living with mental illness but need help knowing what services are available, how to get them and how to be included in care. Mental health caregivers also need education and support on caring for themselves and loved ones. Further, NAMI Maryland recognizes that the proportion of older adults with mental illnesses will increase as the proportion of older adults in the overall population disproportionately increases. Older age presents added challenges for persons with mental illnesses, especially serious mental illnesses. Treatment must be monitored and adjusted with respect to the metabolic changes that come with aging. Treatment and support need to take into consideration limiting physical, social, economic and other conditions associated with aging. Certain circumstances of aging, such as loss of family, social isolation and infirmity can be triggers for the onset of mental illnesses, including alcoholism and serious depression, among older people. Older persons with mental illnesses also face the loss of family and other caregivers as well as an insufficient number of geriatric health practitioners, including mental health practitioners (NAMI Public Policy Platform. Revised Eleventh Edition, December 2015).

It is essential to provide effective basic training to health care staff and other providers regarding *why* to engage family caregivers; and *how to* effectively engage, educate and include family caregivers in treatment planning as well as discharge planning. At least 4 to 8 hours of training should be provided to behavioral health staff and other community service providers who provide supports and services to individuals with mental illness. In addition, hospitals and emergency room department staff must be provided training to improve the experience of individuals with behavioral health issues and family caregivers, so that they are treated with compassion, dignity and respect. Such staff should be familiar with and able to provide referrals to community-based services and supports for individuals with behavioral health issues, their community providers and family caregivers. All trainings should include information about the stigma associated with mental illness and activities that increase empathy and sensitivity skills for both the individual and the family caregiver. Providers should also receive information and education about HIPPA and the type of information a provider can share about an individual with a family caregiver. Family caregivers and affected individuals should assist in training of health care staff and providers.<sup>4</sup>

### Recommendations

1. The State should implement and fund training programs for family members that include caregivers of a loved one with a mental illness. Training should include education, support and skills for peer mentorship. Once trained, they should be paired with other family caregivers with less experience. Trained peer caregivers can be found through nonprofit organizations, such as NAMI Maryland, with a track record of effective and successful models for peer-to-peer and family support and education.

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<sup>4</sup> NAMI Maryland provides such programs as Ambassadors and In Our Own Voice: Living with Mental Illness, through which intensively trained affected individuals and family caregivers deliver effective workshops for providers.



2. State Mental Health Family Caregiver Programs that make grants to family organizations with expertise in working with family caregivers of adults with mental illness should provide:
  - a. Information about mental health services, supports and coverage;
  - b. Assistance to accessing services and supports and navigating the mental health system; and
  - c. Education for family caregivers on mental health conditions, effective treatment options, medications and side effects, communication and problem-solving skills, coping skills and, where available, peer-led family caregiver support groups (NAMI Caregiver Fact Sheet, March 2016).
  
3. Amend the current COMAR definition of “functional disability” to include an individual with a “serious mental illness”. Currently, the definition states “an individual with a severe, chronic disability that: (1) is attributable to a mental or physical impairment or a combination of mental and physical impairments, including a head injury;” (§ 7-202 of the Human Services Article).

## Respite Care

Respite care in its most basic definition is a break for the family caregiver from providing an array of supports and care for their family member (adult or child), friend, neighbor or other person in their life. Respite care service in its holistic/best practice approach, meets the need of the family caregiver to have a time of renewal, while also considering the needs of the care recipient – ensuring that they are being supported with an opportunity to design how they will spend their time while their family member is utilizing respite.

Often articles on respite care state that respite care is one of the primary supports that family caregivers indicate they need but often do not have access. A survey done by MCSCC of 1,800 family caregivers in Maryland from November 2014 through January 2015, indicated that 52% of survey participants identified the need for free time (or a break) as their number one concern as a family caregiver; 48% reported that they have no access to any form of respite care.

Maryland has provided funding for respite care for over 35 years within the DHR's Respite Care Services Program. Current funding is \$1.4 million annually, the program provided 17,710 hours of respite care in fiscal 2015 to families caring for an adult or child living with a developmental disability, or to families of an adult living with a functional disability. Additional funding for respite care is also provided through the National Family Caregiver Support Program which is administered by MDoA. The National Family Caregiver Support Program provides limited respite service for family members caring for an older adult or for grandparents who are caring for children or adults with disabilities. In fiscal 2015, the program spent \$1 million and served 1,455 caregivers who support adults as well as spending \$8,000 to support 491 caregivers who are grandparents.

DHMH, through the Developmental Disabilities Administration, administers the Low Intensity Support Services Program and offers individuals and families the opportunity to access funding for requests that includes respite care services.

Currently, DHMH operates seven Medicaid 1915(c) waivers. Three waivers provide services only to children, three provide services only to adults, and one provides services to eligible individuals regardless of age. Targeted populations include those with: autism, special health care needs, intellectual and developmental disabilities, traumatic brain injury, behavioral health needs, and physical disabilities. In addition, Medicaid offers state-funded options which are: the Community First Choice program, the Community Personal Assistance Services program, and State Plan amendments offering respite for children in the behavioral health system.

Maryland's respite care services appear to be similar to many offerings in other states. There is no scorecard ranking the states on their respite care services, but New York, Utah, and Wyoming all increased their funding of respite care in 2015 by more than 10%.

## Recommendations

1. Given that respondents to the 2015 Maryland Respite Caregiver Survey advised that 48% of these family caregivers currently have no access to respite care (a situation which likely increases stress and morbidity among a significant proportion of caregivers and care recipients), Maryland should develop a state plan for building needed capacity in this area.

DHR applied in June 2016 for the federal Lifespan Respite Grant. This grant would support family caregivers, fund training for respite care providers, expand public awareness of respite care services in Maryland, develop training and socialization opportunities for family caregivers and care recipients, as well as establish a Respite Care Training Consortium in Maryland. Maryland should be notified by mid-September 2016, as to whether it is selected as a grant recipient. Even if Maryland does not win the 3-year grant, the MCSCC should use the grant application as a likely road map for more robust and better advertised respite services in Maryland.

2. That at least an additional \$1.4 million be budgeted annually for respite services available through the DHR; and

3. That the three Maryland agencies offering some respite services to family caregivers (i.e. DHR, MDoA, and DHMH) develop a joint advertising program targeted to senior centers, the faith community, area offices on aging, non-profits serving senior and/or disabled populations, as well as to widely distributed senior newspapers such as The Beacon.

## **Adult Medical Daycare**

Adult medical daycare services are an absolute necessity for many of the thousands of Maryland's elderly, disabled, and/or functionally impaired family care recipients whose caregivers must report regularly to their paid employment outside the home. Without adult medical daycare, many of Maryland's family care recipients would suffer from 8 to 10 hours per day of social isolation, inadequate nutrition and hydration, greater potential for falling, inability to follow even a carefully laid-out medication management plan, lack of prescribed exercise or rehabilitation, a decline in cognitive functioning, an increased probability of depression and/or other behavioral health problems, and poor hygiene.

According to testimony provided by the President of the Maryland Association of Adult Daycare Services, almost all of the 120 centers serve care recipients with Alzheimer's disease, while 94% serve care recipients who are incontinent, and 85% of the Maryland centers have staff nurses who dispense medications. The majority of centers with nurses on staff also provide monitoring of vital hygiene, meals and snacks, personal care, wound and respite care services, while 38% provide rehabilitation services. All centers provide door-to-door transportation.

The average cost of adult day care (\$74.50 per day) pales beside the cost of feasible alternatives, including \$6,235 per month for a semi-private nursing home unit, \$3,293 per month for a bedroom in an assisted living facility, and \$21 per hour for a home health aide. Adult day care centers serve persons whose care is paid for in various ways, including Veteran benefits, private pay, and by Medicaid (for care recipients whose monthly income is no greater than \$2,199 and assets less than \$2,000). When Medicaid pays the cost of adult daycare for low-income medically-eligible individuals, significant tax dollars which would otherwise be used to pay for much higher costs delivered in less ideal out-of-home settings such as nursing homes, are saved.

Maryland's adult medical daycare centers are struggling with increasing labor costs, while reimbursement rates remain inadequate. While federal and State regulations do not presently accommodate several of the rate reforms recommended by spokespersons for adult daycare centers, the task force, after consulting with DHMH, does strongly recommend the following two changes at this time.

### Recommendations

1. That for days when a participant attends an adult day care facility for less than four hours due to inclement weather, a facility needs to provide return transportation before travel conditions become too treacherous. That DHMH seek a waiver amendment subject to approval by the federal centers for Medicare and Medicaid to reimburse adult daycare facilities for services received by a care recipient for less than four hours; and
2. That DHMH reimburse a daycare facility which serves a care recipient on a given day for less than four hours because of the care recipient's illness, or medical emergency – including circumstances requiring a hospital visit.

## **Critical Support Needed for Assistive Devices**

Many relatively low or moderate income caregivers struggle not only with trying to lift, turn, bathe, dress, and feed care recipients, but also with the development and maintenance of substitute arrangements that work when the caregivers have to leave recipients alone in order to shop, go to work, or handle necessary business.

Both caregivers and care recipients who are cogent, are stressed about the safety and reliability of substitute care systems designed by caregivers for the provision of nutrition, hydration, hygiene, medication management, and even wound care while caregivers are away because of employment outside of the home.

### Recommendations

1. Caregivers need State-vetted information regarding available assistive devices (including response and monitoring systems available online). Such information should be widely available in simple and intuitive online platforms, as well as print formats, available at senior centers, libraries, congregate eating programs, faith-based institutions, hospital emergency rooms, urgent care centers, area offices on aging, DHR, and at County health departments.
2. The Governor and the General Assembly should agree on a plan of sales tax relief for low and moderate income family care recipients or their family caregivers who purchase assistive devices and/or related online services, including meal delivery services, online monitoring of vital signs, "nanny cams," electronic pillboxes, emergency response systems, and PDAs that permit nonverbal care recipients to communicate by touchscreens, etc.
3. DHMH should explore with its federal partner, the need to cover a more comprehensive list of assistive devices, durable medical equipment, as well as specified online services that promote cognitive stimulation and reduce social isolation and depression of family care recipients when caregivers are away because of outside employment or other specified necessities.

## **Enhancement of the Maryland Caregivers Support Coordinating Council**

The MCSCC was established in 2001, MCSCC works to identify the needs and challenges faced by informal family caregivers for those across the lifespan, advocating for and empowering through policies that support them, and making recommendations for the coordination of services. MCSCC consists of 17 members appointed by the Governor, representing State agencies, family caregivers, service providers, and advocacy groups. MCSCC's statute requires five family caregiver members. DHR provides staff to IMCSCC.

### Recommendations

1. Extend and expand the authority of MCSCC to monitor implementation of the adopted recommendations and provide ongoing analysis of best practices in support of Maryland family caregivers.
2. Review the design and delivery of caregiver services, with a goal of promoting quality outcomes for caregivers, including: respite services across the lifespan and to persons of all levels and types of care.
3. Monitor implementation of the adopted recommendations.
4. Implement immediately the statutory requirement ([Chapter 401, 2001](#)) that MCSCC have a full-time Executive Director and staff by June 30, 2017.
5. Expand representation to include a member of the Maryland Senate Maryland House of Delegates.
6. Change name of Maryland Caregivers Support Coordinating Council to Maryland Caregivers Commission.



## Appendix A: Statutory Authority

LAWRENCE J. HOGAN, JR., Governor

Ch. 155

– 1 –

Chapter 155

(Senate Bill 297)

AN ACT concerning

### Task Force on Family Caregiving and Long-Term Supports

FOR the purpose of establishing the Task Force on Family Caregiving and Long-Term Supports; providing for the composition, staff, and ~~dates~~ *duties* of the Task Force; prohibiting a member of the Task Force from receiving certain compensation, ~~but~~; authorizing the reimbursement of certain expenses for certain members of the Task Force; requiring the Task Force to report its findings and recommendations to the Governor and the General Assembly on or before a certain date; providing for the termination of this Act; and generally relating to the Task Force on Family Caregiving and Long-Term Supports.

#### Preamble

WHEREAS, Some 770,000 Marylanders are taking care of loved ones, including those who are aging or have failing health; and

WHEREAS, The vast majority of older adults who need assistance with activities of daily living want to remain in their homes and communities; and

WHEREAS, Providing services and supports to older adults in their homes and communities is generally much less expensive than nursing home care or adult day care; and

WHEREAS, Almost three-fourths of older adults living in their homes and receiving personal assistance rely exclusively on unpaid caregivers for help; and

WHEREAS, Older adults who receive cost-effective services in their homes are much less likely to need public assistance; and

WHEREAS, To successfully address the surging population of older adults who have significant needs for long-term services and supports, the State must encourage families to assist their aging relatives and develop ways to support families in that undertaking, as well as enhance efforts to recruit and retain a qualified, responsive in-home care workforce; now, therefore,

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND,  
That:

(a) There is a Task Force on Family Caregiving and Long-Term Supports.



(b) The Task Force consists of the following members: Ch. 155 2015 LAWS OF MARYLAND

– 2 –

- (1) one member of the Senate of Maryland, appointed by the President of the Senate;
- (2) one member of the House of Delegates, appointed by the Speaker of the House;
- (3) one representative of the Department of Human Resources, appointed by the Secretary of Human Resources;
- (4) one representative of the Department of Aging, appointed by the Secretary of Aging;
- (5) one representative of the Department of Health and Mental Hygiene, appointed by the Secretary of Health and Mental Hygiene;
- (6) one representative of MTA Mobility, appointed by the Secretary of Transportation;
- (7) the health officer or the health officer's designee from a county from each of the following areas:
  - (i) the Eastern Shore;
  - (ii) a suburb of Washington, D.C.;
  - (iii) Western Maryland; and
  - (iv) the Baltimore region;
- (8) one representative of AARP Maryland, appointed by the AARP Maryland State President;
- (9) one representative of the March of Dimes Maryland–National Capital Area, appointed by the Executive Director of the March of Dimes Maryland–National Capital Area;
- (10) one representative of the Alzheimer's Association, Greater Maryland Chapter, appointed by the Executive Director of the Alzheimer's Association, Greater Maryland Chapter;
- (11) one representative of the Mental Health Association of Maryland, appointed by the Chief Executive Officer of the Mental Health Association of Maryland;
- (12) one representative of the Health Facilities Association of Maryland, appointed by the President of the Health Facilities Association of Maryland;

– 3 –

(13) one representative of the National Alliance on Mental Illness of Maryland, appointed by the Executive Director of the National Alliance on Mental Illness of Maryland;

(14) one representative of the Hospice and Palliative Care Network of Maryland, appointed by the President of the Board of Directors of the Hospice and Palliative Care Network of Maryland;

(15) one representative of the Maryland Gerontological Association, appointed by the President of the Board of Directors of the Maryland Gerontological Association;

(16) one representative of the Maryland Hospital Association, appointed by the President of the Maryland Hospital Association; ~~and~~

(17) one representative of the Maryland Caregivers Support Coordinating Council, appointed by the Chair of the Maryland Caregivers Support Coordinating Council;

(18) one representative of LeadingAge Maryland, appointed by the President of LeadingAge Maryland;

(19) one representative of the Maryland–National Capital Home Care Association, appointed by the President of the Maryland–National Capital Home Care Association;

(20) one representative of the Maryland Association of Adult Day Services, appointed by the President of the Maryland Association of Adult Day Services; ~~and~~

*(21) one nurse with experience in providing caregiver and long–term supports, appointed by the Maryland Nurses Association; and*

~~(17) (21)~~ (22) three family caregivers, appointed by AARP Maryland.

(c) AARP Maryland shall provide staff for the Task Force.

(d) (1) A member of the Task Force:

~~(1)~~ may not receive compensation as a member of the Task Force; ~~but~~.

(2) A State–agency affiliated member of the Task Force is entitled to reimbursement for expenses under the Standard State Travel Regulations, as provided in the State budget.

(e) The Task Force shall:

(1) identify policies, resources, and programs available for family caregivers and find additional innovative and creative means to support family caregivers in continuing to provide needed in-home care and assistance for older adults;

(2) receive testimony on the needs of family caregivers, including designation of caregivers, training, respite services, medical leave policies, delegation of tasks to nonmedical aides, and other related policies;

(3) compile an inventory of the resources available to family caregivers; and

(4) evaluate and recommend actions the State could take, including legislative and administrative actions, to develop, train, and retain a qualified and responsive in-home care workforce.

(f) On or before September 30, 2016, the Task Force shall submit a report of its findings and recommendations to the Governor and, in accordance with § 2-1246 of the State Government Article, the General Assembly.

**SECTION 2. AND BE IT FURTHER ENACTED,** That this Act shall take effect July 1, 2015. It shall remain effective for a period of 1 year and 4 months and, at the end of October 30, 2016, with no further action required by the General Assembly, this Act shall be abrogated and of no further force and effect.

**Approved by the Governor, May 12, 2015.**

## **Appendix B Task Force Membership**

Senator Delores G. Kelley, Co-Chair  
Delegate Angela Angel, Co-Chair

AARP Maryland  
Tammy Bresnahan  
Renee Fredericksen

Alzheimer's Association  
Ilene Rosenthal (Greater MD)  
Michele Douglas

Family Caregivers  
Dr. Odessa Dorkins  
Kelli Meginnis

Department of Aging (MDoA)  
Teja Rau  
Emily Miller

Department of Health and Mental Hygiene  
(DHMH)  
Terah Tessier (DDA)  
Nancy Hatch

Department of Human Resources (DHR)  
Dorinda Adams

LeadingAge Maryland  
Jill Schuman  
Ann Patterson

Maryland Caregivers Support Coordinating  
Council  
Elizabeth Weglein

Maryland Gerontological Association  
Virginia M. Thomas

Maryland Health Departments  
Arnold Eppel (Baltimore City)\*  
Cynthia A. Brown (Baltimore Region)  
Deborah McGruder (Prince George's)  
Gail Yerkie (Eastern Shore)  
Patricia Fletcher (Prince George's)

Maryland Hospital Association  
Dr. Dan Hale

Maryland National-Capital Homecare  
Association  
Ann Horton  
Gwen Turner

Maryland Nurses Association  
Karen Evans

Maryland Transit Administration (MTA)  
Mobility  
Daniel O'Reilly

Mental Health Association of Maryland  
Kim Burton

National Alliance on Mental Illness of  
Maryland (NAMI)  
Kate Farinholt  
Jessica Honke

\*Subsequently associated with Catholic Charities

**Appendix C**  
**Task Force on Family Caregiving and Long-Term Supports**  
**Meeting Dates and Topics**

**Monday, July 6, 2015**

Organizational Meeting

Maryland Statewide Survey on Caregiving

- Naomi Duffort, MSW Researcher Maryland Department of Human Resources

**Monday, September 28, 2015**

Maryland Access Point Presentation /Caregiver Services and Resources

- Emily Miller, Maryland Department of Aging
- Mary Chaput, Anne Arundel County Department of Aging
- Karrisa Gouin, Anne Arundel County Department of Aging
- Karen Narwanrocki, Elizabeth Cooney Agency

**Monday, October 26, 2015**

Private/Public guardianships

Trusts

Powers of Attorney

Advances directives/Health care surrogates

Representative payees

- Social Security benefits
- Pension benefits
- Veterans benefits
- Significance of Family Caregiving
- State and Federal Programs
- Home and Community Based Options Waiver

National Academy of Elder Law Attorneys (NAELA)

- Jason Frank, Attorney
- Catherine Stavely, Attorney

Maryland Department of Human Resources

- Valerie Colmore, Program Specialist, Adult Protective Services
- Greg Sesek, Program Specialist, Adult Public Guardianship

**Monday, November 16, 2015**

Transportation

- Dan O'Reilly, Director of Mobility Operations Maryland Transportation Administration
- Laura Riley, Baltimore County CountyRide Program

Time Banks

- Sandra Shirley and Dr. Christine Gray, TimeBanksUSA
- Dr. Renee Fredericksen and Megan Mahedy, Village People Exchange, Maryland Active Citizens, Salisbury, Maryland

**Monday, January 25, 2016**

Cancelled due to Weather

**Monday, February 22, 2015**

Housing/Architectural/Structural and Design

- Chelsea Hayman, Cities for All Ages, Civic Works, Inc.

Barriers to Aging in Place

- Jennifer Eastman, Maryland Department of Disabilities

Telemedicine

- Dr. Rosemarie DiMauro Satyshur, PhD,RN., Assistant Professor, University of Maryland School of Nursing Department of Family and Community Health Center for Biological and Behavioral Change Across the Life Span

**Monday, April 25, 2016**

Mental Health of Recipient and Caregivers and other household members

- Kate Fairnholt, National Alliance Mental Illness
- Ann Squire, Aware of your Care
- Ilene Rosenthal, Alzheimer's Association (Services and Programs)
- Kathleen Ward, Project Home, Maryland Department of Human Resources

**Monday, May 23, 2016**

Health Care Regulations

- Paul Parker, Director for Health Care Facilities Planning and Development, Maryland Health Care Commission

Residential Services Agencies

- Dr. Tricia Nay, Executive Director Office of Health Care Quality, Maryland Department of Health and Mental Hygiene

Community Choice Waiver

- Mark Leeds, Director Long Term Care & Community Support Services Administration, Maryland Department of Health & Mental Hygiene

Fiscal Impact of Adult Medical Day Care

- Wayne Pulliam, Owner/Operator, Golden Doves Adult Medical Daycare

**Monday, June 27, 2016**

Discussion of Final Report

- Task Force Members