

Georgia CARE-NET Coalition

The caregiver's advocate.



The Caregiver Crisis: Putting the Pieces Together

The Crisis

Imagine you are the first responder to an emergency. The situation is critical and requires an immediate, skilled response, but you have no tools and no training to address the problem. You call for assistance, but no one comes. You feel alone, and frightened. You do the best you can to comfort a patient at the scene. Surely there has to be a better way.

A “bad dream”? Perhaps, but this is the experience of thousands of Georgians confronting the sudden and unexpected onset of caregiving for a family member with a chronic illness or disability. Family members provide an estimated 80% of long-term care,¹ and the replacement cost in paid services is estimated to be \$257 billion per year.² But families are paying a high price for their service to family and society. A 25-year body of research shows that family caregivers are at risk for a wide range of problems in health, mental health, finances, employment, and retirement. One recent study found that more than a third of family caregivers of people with dementia suffer from clinical depression,³ and another that caregivers experiencing strain have a 63% higher risk of mortality than noncaregivers.⁴

Despite these risks, family caregivers are largely neglected by the health and long-term care systems; they are an “invisible workforce.” They are not trained on how to deliver complicated care, not treated as partners in the patient’s care, and not encouraged to maintain their own health. So, the question is this:

“When family members are no longer able to carry the load of chronic illness and disability care, who is going to replace them?”

Georgia CARE-NET Coalition

The Georgia CARE-NET Coalition believes that caregivers need an advocate. The CARE-NETs in Georgia are composed of family and professional caregivers who understand that, without change, caregivers in our state are at increasing risk of injury, stress-related illness, and grave financial harm. Coming together as a Coalition, the regional CARE-NETs intend to be a voice for a better way: a voice of reason, and a voice for caregivers. In this inaugural piece, we lay out what is wrong with current supports for caregivers and make a case for a better way that

can help avert the coming crisis.

Quality Support For Caregivers

As a framework for examining support for caregivers, we adopt the six dimensions of quality health care identified by the Institute of Medicine,⁵ and add two dimensions specific to long-term care (see box, right). We then analyze how well current efforts to support caregivers meet these eight quality standards, identify crisis points created by our failures, and point to opportunities for improvement.

1. Safe

Crisis points: Faced with insufficient resources and supports, lack of information, and increased levels of stress, families are often overwhelmed by the demands of care, with resulting injury to health and well being. Insufficient staffing patterns in community and institutional care settings due to current and growing workforce shortages create an additional crisis point. Consider this: while the number of elderly people with long-term care needs will double between now and 2030, direct care service positions will experience a likely increase of only 40%.⁶ The direct care workforce is also faced with high turnover rates of up to 75% per year.⁷ Workforce shortages lead to higher rates of injuries for both caregivers and receivers.

Action: Individualized training, counseling and support are essential to reduce family caregiver stress, improve the quality of care provided, and extend community tenure of care

Dimensions of Quality Care

Safe — avoids injuries to care-receiver and caregivers

Effective — provides services based on scientific knowledge

Personalized — provides care based on individual preferences, needs and values

Timely — reduces waits and harmful delays

Efficient — avoids waste

Equitable — provides care that does not vary in quality because of personal characteristics

Shared — provides adequate support, respite and assistance to family caregivers and shares objective burdens

Coordinated — assures that all providers are in regular communication and that services are carefully integrated.

-- Adopted from the Institute of Medicine

recipients. Respite care and day programs reduce the time spent by families in hands-on care and lower family burden. Workforce shortages must be tackled with a comprehensive state-level plan to improve recruitment, retention, and training of long-term care and direct care workers. Current workforce initiatives in Georgia must be expanded and innovative strategies implemented, including employee incentives, health insurance availability, and the establishment of paraprofessional job ladders. A fully funded ombudsman network is required to monitor the system to ensure safety.

2. Effective

Crisis point: Evidence-based caregiver programs have been shown to reduce burden, depression and injury of caregivers at the same time as they lead to a higher quality of care for the recipient. Unfortunately, these programs are unavailable to all but a few of Georgia caregivers and agencies are not prepared to offer them.⁸ An online survey of over 300 service providers in Georgia found that most were not knowledgeable about evidence-based practices in the field of caregiving. While 84% felt that there was value in adding such programs and services to support their clients and caregivers, less than half currently did so. Over 84% further indicated that they would be interested in receiving training but that lack of funding was a major barrier.⁹

Action: Standards must be developed that allow every family caregiver in Georgia to have access to an effective and individualized program of supports for the work they have undertaken. Intensive technical assistance and sufficient funding must be put in place to allow agencies to adopt and successfully offer the most effective programs available, including funding of startup costs, staff training and agency infrastructure for caregiver assessment and program evaluation.

3. Personalized

Crisis point: An “accurate and systematic” information gathering process must be in place to assess caregiver strengths, needs and resources and to identify specific interventions and supports needed by each family.¹⁰ The National Family Caregivers Association states that “an assessment of the family caregiver’s strengths, needs and preferences constitutes the foundation for developing

appropriate and quality long-term care.”¹¹ Services for caregivers in Georgia, when available, are not properly individualized, and full assessments are rarely completed for caregivers. Even when assessments are done, they are often completed for the sole purpose of constructing waiting lists and not designed to assure the identified needs are met.

Action: Full assessments of both caregiver and recipient needs must be a routine and funded part of the evaluation and intake process. Regular needs assessments for caregivers should be “rolled up” to identify gaps in community service. A state-wide data-base of caregiver needs should be maintained and accessible to the public.

4. Timely

Crisis point: Long waiting lists in Georgia prevent the timely provision of necessary services and supports and lead to dangerous conditions for caregivers and care recipients. The Statewide Independent Living Council of Georgia estimates that 189,342 non-institutionalized Georgians with long-term disabilities are eligible for but not yet receiving services through the Home and Community-Based service system,¹² and 6838 Georgians with developmental disabilities are on long-term care waiting lists.¹³ Nationally, one estimate finds that more than 285,000 people in 21 states are on formal waiting lists for people with disabilities needing community services or community-based homes.¹⁴

Action: In addition to addressing workforce shortages in the state, increased funding of community-based long-term care services is urgently needed. Adequate funding and state matching funds are needed for the National Family Caregiver Support Program, and the Lifespan Respite Act, among other initiatives. The state-wide data-base of caregiver needs should identify service gaps and efforts to fill them.

5. Efficient

Crisis points: Georgia’s long-term care system takes a “cookie cutter” approach to supporting caregivers. Because we fail to assess the real needs of a family, caregivers are often offered an array of services from a menu, many of which are inappropriate or unnecessary, while their true needs remain unmet. Full caregiver assessments combined with self-directed and consumer directed service models lead to greater

Our Mission:

To provide a unified voice for Georgia caregivers, to inform the public and law makers about their critical role and urgent needs, and to secure programs and policies that lead to their improved health and well being.

Our Vision:

A Georgia where caregiving is valued, families are fully supported in their caregiving roles, and individuals receive the best possible quality care in their homes and communities.

Our Goals:

- *Empowered, healthy and resilient family caregivers.*
- *A sufficient, well-trained, and effective direct care workforce.*
- *An informed and invested public.*
- *Availability of effective and accessible home and community-based care.*
- *A unified voice for Georgia caregivers.*

efficiency, increased consumer satisfaction and higher quality of care. In addition, family-directed service planning results in families making more personalized, often less costly, service selections.¹⁵ In addition, historic imbalances in long-term care remain in place and result in inefficiencies. One striking example is the fact that Georgia allocates more than 80% of its Medicaid long-term care spending to nursing homes, although Medicaid dollars can support almost three individuals in the community for every person placed in institutional care, and families largely prefer community care.¹⁶

Action: The current move to family-directed and self-directed services, in its infancy in Georgia, must be expanded and made the standard for all caregivers. A greater focus on outcome-based service evaluation and a reduction in trial and error approaches through the use of evidence-based programs must be put in place. Moving dollars from institutional to community care is necessary to better support families and better meet community needs.

6. Equitable

Crisis points: The current long-term care system in Georgia is highly inequitable, with families providing the lion’s share of care while receiving only a tiny fraction of resources to assist them. Recent estimates are that approximately 850,000 family caregivers in Georgia provide more than 900 Million hours of free care, valued at nearly \$12 Billion dollars.¹⁸ This finding is consistent with national studies that show 1 in 6 people in the U.S. provides care for a chronically ill, aged or disabled relative or other loved one without the use of any public funds.¹⁹ In addition to providing free care, families absorb 2.5 times more out-of-pocket medical expenses when the individual they are caring for needs help with activities of daily living.²⁰ Race and gender are also factors: ethnic minority caregivers provide more care than their white counterparts and report worse physical health than white caregivers.²¹ From 59 – 75% of all caregivers are female,²² and women caregivers are 2.5 times more likely to live in poverty when they become elderly than those without caregiving experience.²³ It is estimated that family caregivers, mostly women, lose more than \$25,000 in Social Security benefits, more than \$67,000 in pension benefits and approximately \$566,000 in lost wages due to their caregiving responsibilities.²⁴ Location is a factor in inequity too: the geography of Georgia, with its high-

density urban population and much larger rural areas, lends itself to disparities in availability of support services.

Action: The value of family caregivers to society needs to be fully recognized and adequate resources made available to support their work. Caregivers, regardless of income, demography, or location require and deserve access to effective and high quality programs and supports. To reach caregivers in rural areas, technology and internet solutions must be expanded, along with a greater use of mobile services, outreach and home visiting. The damaging impact of caregiving on family income needs to be acknowledged and steps taken to prevent a generation of caregivers from living their own “golden years” in poverty; e.g., expansion of Medicare and Medicaid benefits to better support family caregivers and caregiver tax relief measures. Sensitivity to ethnic and gender concerns must be a focus of training and support.

7. Shared

Crisis points: Every family caregiver in Georgia knows what it means to be part of “the invisible workforce,” working in isolation with little support. Like other first responders, their heroism goes unnoticed until the larger community is affected. To establish quality in long-term care requires that all sectors of the community lend a hand – government, business, faith communities, service organizations, and others— and play active roles in supporting family caregivers. “Caring communities” are those that work to identify inequities and gaps in services and take steps to resolve them. One study, for example, found that 42% of parents with special-needs children lack such basic workplace supports as paid sick leave or vacation time.²⁵ Businesses, as well as other community sectors, must find ways to do better. Family caregivers must know they are not alone and their work is valued.

Action: Dr. Barry Jacobs speaks of “honoring the caregiver’s mission”.²⁶ He points out that, as a society and as individuals, we often approach caregivers with well-meaning advice: “Don’t work so hard” or “Take some time off,” not recognizing that we have inadvertently diminished the value and importance of their work. To help caregivers requires that we begin by asking a simple question: “How can we help you continue what you are doing so well?”, or “What assistance can we provide, from mowing the lawn and cleaning gutters, to

Georgia:

Vital Signs

- *By 2025 it is estimated that the growth of elderly residents will double the number of people over 65 with disabilities in Georgia.*¹
- *The cost of Medicaid-support long-term care grew 82% in Georgia between FY 2000 and FY 2005.*²
- *An estimated 844,351 individuals throughout Georgia provide family care.*

- *At least 20% of Georgians over the age of 55 care for an individual aged 65 and above, and 12% for other adults or children, some with disabilities.*⁴
- *Georgia family caregivers are estimated to provide 904 million caregiving hours per year.*⁵
- *An estimated \$12.1 billion worth of unpaid care is provided annually by Georgia family caregivers.*⁶

running to the store for medicine, that would help you continue this critical work?”. Increased public awareness is needed along with a coordinated effort to teach all members of the community about the critical role of family caregivers and how to offer assistance. A statewide public education and awareness program around the needs of family caregivers and how to help is a critical first step in “sharing the care”.

8. Coordinated

Crisis points: Poorly integrated care is poor quality care. At a system level, an over-reliance on silos of care has led to dangerous levels of fragmentation in Georgia. A survey among physicians found that 44% believe that poor care coordination leads to unnecessary hospitalizations, and almost 25% felt that it also led to unnecessary nursing home stays.²⁷ The fragmentation of long-term care also prevents families from accessing needed services. One study found that 75% of caregivers did not know where to access services they needed.²⁸ While a seamless and carefully managed approach to transition planning is vital to assure that moves between home, hospital, nursing home and other long-term care facilities are safe and properly executed, this approach is rarely carried out.

Action: Along with the development of a seamless and coordinated system of care, families need training and assistance in managing care transitions in the currently fractured system. Services should be designed with the user in mind; e.g., families should have access to a system that has “no wrong door” — one in which they can receive critical information and referrals from a variety of sources, including the aging network, their primary care physician’s office, the internet, and their child’s school. The Coalition also supports the rapid development of “one stop shops” throughout the state to serve caregivers across the lifespan and across all categories of illness and disability. The expansion of Georgia’s Aging and Disability Resource Connection model statewide is a vital step in the work of “putting the pieces together” for caregivers. Finally, electronic health records should rapidly replace existing “paper records” to help assure care transitions occur safely and health care is well integrated and families providing long-term care should receive priority attention in this effort.

Next Steps

The caregiving crisis in Georgia will affect us all. As former first lady, Rosalynn Carter has said: *“There are only four kinds of people in the world—those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who need caregivers.”* Families carry the load when it comes to community-based care, and they are providing more complex and demanding care for a longer period of time than ever before. Many are at the breaking point and require assistance to carry on. Georgia’s caregivers need and deserve an advocate. The Coalition intends to work for the benefit of Georgia Caregivers and has already begun the work of developing an integrated policy and action agenda to flesh out its vision of quality supports for all Georgia caregivers (see box, right). If you are interested in receiving additional information on Georgia CARE-NET Coalition and its vision for a better Georgia, please contact:

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Phone: 229-928-1234
www.rosalynncarter.org/caregivercoalition/

NOTES:

Sources for all references are posted at the above web site.

Please watch for our upcoming policy paper outlining the Coalition’s action agenda, as well as fact sheets on each of the dimensions of quality care.

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Putting the Pieces Together

The Puzzle Pieces

First piece: An urgent, unmet need affecting large numbers of people; e.g.,

- Family and professional caregivers in Georgia suffer high rates of illness, injury and economic risk.

Second piece: Policy and program solutions that work; e.g.,

- Evidence-based program are proven solutions that can be implemented immediately.

Third piece: Leadership

- Georgia CARE-NET Coalition represents family and professional caregivers from all regions of Georgia, from across the lifespan and from all areas of health and disability, coming together to be a unified voice for caregivers.

Actions Taken

To address the growing crisis in caregiving, Georgia CARE-NETs and the new Georgia CARE-NET Coalition have addressed issues ranging from workforce development to evidence-based practices. Below are examples of some activities already underway:

- Annual Caregiver Summit at Georgia Southwestern State University
- Telephone learning series for both professional and family caregivers, with 11 programs to date
- Training in evidence-based practices throughout the state, including train-the-trainer activities:
 - Powerful Tools for Caregivers
 - Care Transitions Intervention
 - Savvy Caregiver
 - The Future Is Now
 - COPE Intervention for Cancer Caregivers
- Research on legislative foundations for caregiver support