

Delaware Caregivers Support Coalition's

FINAL REPORT:

*A report of the work of the Coalition
assessing the needs of respite care in Delaware*

October, 2005



A REPORT COMPILED BY THE STAFF OF
EASTER SEALS DELAWARE AND MARYLAND'S EASTERN SHORE

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Executive Summary

Building on the momentum created by the work of the Respite Care Task Force convened by the University of Delaware (UD)'s Center for Disability Studies, Delaware Caregivers Support Coalition, organized by Easter Seals, began meeting in January, 2004. Their primary focus was follow-up on one of the Task Force's recommendations for a statewide needs assessment of respite care.

Caregiving and Respite in Delaware

The coalition sponsored two surveys: one of caregivers/consumers and one of service providers. The results of these surveys along with a study of caregiving conducted by AARP in 2004 provided information to form a picture of caregiving and respite in Delaware.

Currently, 130,000 or 22% of adult Delawareans provide unpaid care to a relative or friend 18 or older. Caregivers provide care for a variety of disabilities including developmental disabilities, mental illness, autism, mobility impairments, to name a few. Most caregivers are caring for a family member, and quite often this care takes place in their home.

Problems that caregiver respondents identified resulting from their caregiving responsibilities can be summarized as follows:

- Families' relationships and functioning are strained.
- Physical and mental health of primary caregiver may be compromised.
- Persons with disabilities may need to be placed in residential care sooner if caregivers and consumers do not receive the support they need to continue care at home.
- Primary caregivers and consumers may experience difficulties meeting work responsibilities.

Caregivers also indicated that they needed help with caregiving, but many did not get the help they need. In trying to understand why respondents may not get the help they need, four major issues were identified:

- Lack of information and an easy, centralized source for information about respite
- Lack of adequate supply of respite both in terms of amount and types of respite
- Concern for the level of quality of care
- Lack of resources to fund respite

Vision

What the coalition envisions for a respite care system is stated as follows:

**People with disabilities in Delaware and their caregivers
will have easy access to quality, affordable respite services.**

Next Steps

The next steps involve planning a respite care system and making it operational.

History of the Coalition

In the fall of 2003, The Center for Disabilities Studies at the University of Delaware (UD), published a report documenting the work of the Respite Care Task Force. The report, "Respite Care in Delaware: A Critical Need for Change", included four key recommendations which resulted from the discussions of the task force. They included:

- 1) Support a State Law mandating Lifespan Respite Care.
- 2) Conduct a statewide needs assessment to examine the level of unmet need for respite care.
- 3) Develop a comprehensive directory of all available respite services and programs in the State serving as a resource for families and case managers.
- 4) Support a "Family Support Medicaid Waiver" which provides additional Federal funds for respite services.

Building on the momentum of the respite task force and committed to addressing the recommendations of the report, Easter Seals Delaware & Maryland's Eastern Shore established a coalition to continue discussion of the respite care issue in Delaware.

The group consists of individuals representing caregivers and consumers, service providers, and state agencies. A listing of the specific individuals who are part of the coalition is found in Appendix A. The group is led by Dr. Timothy Brooks of the UD's Center for Disabilities Studies. The group began meeting in January, 2004, and developed a team charter which defined its goal, mission, and objectives. A copy of the team charter can be found in Appendix B.

The primary objectives of the coalition focused on the second recommendation of the Respite Care Task Force's report, "conducting a statewide needs assessment." Specifically, the task force worked to:

- Define the population that needs the service
- Define the current service delivery system
- Define a vision for an improved respite care service delivery system
- Develop a business plan for a pilot respite care demonstration project

The first two objectives were addressed by conducting two surveys: one for caregivers and consumers, and another for service providers. The results of the surveys are described in more detail in the section entitled "Caregiving and Respite in Delaware."

Upon completion of the surveys, the coalition discussed the results in order to understand more fully their meaning in light of other caregiving research.

Caregiving and Respite in Delaware

Caregiving

A 2004 survey conducted by AARP, *Caregiving in the US: Spotlight on Delaware*, estimated that approximately 130,000 or 22% of adult Delawareans provide unpaid care to a relative or friend 18 or older. 83% of care is for a family member and 17% for a friend or neighbor. Almost 90% of respondents to the coalition survey were family members, with only 8.9% providing care to a non-relative.

Caregivers and consumers surveyed by the coalition indicated that those for whom they provided care had varying levels of care needs. Almost half (48%) indicated that they provided “routine assistance and supervision” for moderate disabilities. The other half of surveyed caregivers and consumers were almost evenly split between those providing extensive or continuous assistance for severe disabilities (27%) and those providing occasional assistance and supervision for mild disabilities (25%). Providing care for an individual can include activities such as bathing and dressing the individual, cooking and feeding, administering medicines, transporting to appointments and activities, and arranging and supervising services from an agency.

Types of disabilities indicated by caregivers and consumers in the coalition survey included:

Developmental Disability	57%
Mental Illness/Emotional Disturbance	27%
Autism	20%
Mobility	19%
Chronic Illness	15%
Vision Loss	15%
Alzheimers	5%
Stroke	3%
Traumatic Brain Injury	3%
AIDS	<1%

Of most interest for understanding the need for respite care, however, is how caregivers and consumers in both the AARP and coalition survey described the impact of caregiving on themselves, their families, and their ability to handle responsibilities at home and work.

Caregivers and consumers responding to the coalition survey described the following as problems created by providing care:

Emotional strain/burnout	68%
Not having enough time for other activities	55%
Physical health strain	33%
Financial strain	30%
Conflict in your family	30%
Conflict with job	29%
Others (conflict in school, agency, legal)	18%

