

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

Delaware Caregivers Support Coalition Final Report October, 2005

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%

While the AARP survey found that only 16% of respondents said they were “very stressed,” it found that the greater the intensity of care, the more likely caregivers and consumers were to identify themselves as stressed. Caregivers and consumers identified their most unmet need for help or information as:

Finding time for myself	41%
Balancing responsibility	35%
Keeping person safe at home	30%
Easy activities	29%
Managing stress	29%

In the AARP survey, 60% of respondents also said that caregiving effected their work either causing them to be late or leave early from work or having to take off time to provide care. 15% also said they took a leave of absence, and 10% reported having taken a less demanding job or having gone from full-time to part-time work.

These findings suggest that lack of support for families with their caregiving responsibilities may result in the following:

- Families' relationships and functioning are strained.
- Physical and mental health of primary caregivers 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 may experience difficulties meeting work responsibilities.

Use of Respite

Respite Care, as defined by the National Lifespan Respite Coalition, a coalition of over 135 national and state organizations working for national respite legislation, is “planned or emergency short-term relief to caregivers from the demands of ongoing care for an individual with special needs or at risk of abuse or neglect.” In other words, respite care provides caregivers with relief from the rigors and responsibilities of continuous caregiving. On a national level, respite care is being recognized as a vital strategy toward strengthening and preserving families who have a loved one with a disability. In a study of the care and needs of individuals with disabilities conducted by the Longwood Foundation of Delaware and Easter Seals, respite was cited as a need essential to maintaining quality care. Respite services are lifespan services, meaning that they are essential for individuals with disabilities and their families throughout their lifetime; respite care benefits every age group, from infants to the elderly.

Of respondents to the coalition survey, 55% indicated that they provide constant care. Of those who indicated the number of hours of care they provide, the average hours per week was 63 with 70 being the most common response. Fourteen (14) percent indicated that they never get help in caring for this person. This closely matches the AARP survey result of 16%.

The coalition survey also asked “how often do you currently get help caring for this person” vs. “how much do you currently need help caring for this person.” The difference between these two responses is reflected below:

<u>How often need help</u>	<u>% Need Help</u>	<u>% Get Help</u>	<u>Gap</u>
Every day	22%	12%	10%
Once or twice a week	16%	11%	5%
On an emergency basis	26%	26%	0%

These gaps indicate a clear need for providing help to caregivers and consumers especially with those caregivers and consumers who need it the most.

Current Respite Supply

A number of Delaware organization provide respite care, including state agencies, and for-profit and nonprofit organizations providing services for people with disabilities, special needs, and for those who are aging. Examples of Delaware respite providers include: The Delaware Autism Program (DAP), the Division of Developmental Disabilities Services (DDDS), the Division of Family Services (DFS), the Division of Services for Aging and Adults with Disabilities (DSAAPD), the Department of Education, Easter Seals, United Cerebral Palsy, the Mary Campbell Center, and Nurses ‘n Kids.

Of 23 service providers who were contacted, 17 (74%) responded to the coalition’s survey. Results of the survey show that respite services are available to individuals of all ages with disabilities of all types, but opportunities increase with age (82% serve 65+ while only 18% serve 0 to 2 year olds).

Survey results show that certain disability types are more served than others as follows:

Physical disabilities	59%
Alzheimer’s	47%
Frail/elderly	47%
Chronically ill	41%
With medical needs	35%
With behavioral disorders	29%
With mental illness	18%

Respondents also indicate that services are provided at a wide variety of locations although out-of-home services (76%) outweigh those that are in-home (53%) (Note: Some providers provide both in-home and out-of-home services so percentages do not total 100%). Caregivers often prefer in-home care since people with some disabilities (e.g. mental retardation and developmental disabilities) are more comfortable with a substitute caregiver if the care is provided at home in a familiar setting.

Services are also provided equally during weekday, evening and weekend hours (82%). Providers are also more likely to provide planned respite (94%) rather than emergency respite (59%).

Identified Shortcomings of System

Several “themes” related to issues or shortcomings of the current respite care system emerged through the two surveys and discussions of coalition. They include:

1) Information about respite

A general lack of awareness and understanding of the concept of respite by caregivers and consumers may keep them from trying to access needed relief. As an example, participation records from the Department of Health and Social Services (DHSS) illustrates the general lack of awareness regarding respite care. Of the 1,894 Delawareans eligible for respite care through DHSS, just 374, or 20% take advantage of this service. Approximately 23% of people caring for children under the age of 17 seek respite services through DHSS, and nearly 30% of people caring for adults over the age of 50, while just 17% of people caring for adults between the ages of 18 and 49 seek services from DHSS.

In addition, since there is not a central source of information about respite, caregivers and consumers may not know where to begin to identify options.

2) Adequate supply both in terms of number and type of respite

As identified earlier, research of current respite services has identified a number of less served populations. These include gaps for:

- Younger individuals (the younger the less options)
- Certain disabilities such as mental illness and behavioral disorders
- In-home care
- Emergency care

3) Quality of respite

While the amount of respite service available is likely inadequate to provide for all caregivers and consumers needing this kind of support, from the perspective of caregivers and consumers, an even larger issue is that of quality. According to the coalition caregiver survey, the major concerns of caregivers included:

- The safety of their loved ones when they are not present to supervise.
- What will happen to their loved ones when they are no longer able to provide care.
- Finding caring, compassionate caregivers who understand the person as well as the disability, and who will provide dignified care as well as stimulation.
- Finding trustworthy caregivers to provide care in case of emergency/for respite.

Caregivers said:

“I’m very protective because he cannot protect himself.”

“Will they love my child like I love him?”

“His medical needs and inability to speak are concerns.”

“Finding a competent person who will treat our son with respect and take care of his needs the same way we do.”

“I look for an individual with skills in caring for disabled persons, and who feels this is a mission for them. This person should love their work, and this should come across in their care.”

“Finding quality help, someone I can trust.”

Clearly, caregivers and consumers find it difficult to relinquish their caregiving responsibilities to providers other than those that they have complete trust and confidence that they will provide for the safety, physical, and emotional needs of the person they care for.

4) Affordability of respite

Respondents to the survey also indicated “finding adequate financial resources to fund respite care” as a major concern. Fifty-five (55) percent of respondents indicated that they would not be able to afford respite care. Many are already financially strained by the costs associated with the care. Also, financial support for respite is often tied to a specific disability, e.g. Alzheimer’s or Autism, rather than available to anyone.

Caregivers explained:

“We’re living on a limited income as I cannot leave her to work away from home.”

“You can’t pay for respite and still go out or away yourself.”

Vision for an Improved Respite System

The coalition developed the following statement of their vision for a respite care system:

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

Key characteristics of the system are that it:

- Is consumer-friendly
- Is available 24/7
- Provides a variety of options of where and when they are offered
- Provides for consumer choice of service provider
- Assures and increases quality of providers through pre-screening to be listed, training opportunities, and evaluation of care that is provided
- Provides funding options so the burden of finances is shifted from caregivers and consumers
- Builds on services and programs already existing in the community

Next Steps

The next phase is planning a respite care system and making it operational including:

- Developing a service delivery system
- Maintaining public policy initiatives
- Implementing the plan

Developing a Service Delivery System

In developing a respite system that embodies the characteristics outlined by the coalition, planners will need to:

- Address issues of:
 - Information availability
 - Adequate supply
 - Quality supply
 - Affordability of supply

(see Appendix C for outline of issues and questions to be addressed)

- Research models used in other states such as Nebraska and Michigan
- Add individuals representing needed expertise to coalition (e.g. legal, information and referral, licensing and accreditation)

Public Policy Initiatives

In order to make sure that caregivers' respite needs are adequately understood and supported, initiatives need to be developed to assure help for families with respite needs across the life-span. These initiatives will take place at the state level pressing toward passage of legislation not only supporting, but also providing funds for system development and implementation. Additionally, monitoring of federal legislation will be important especially as it relates to the potential for funding opportunities.

Implementation of the System

In order to implement the system, plans will need to be developed for:

- Operations of the system including staffing and other costs
- Promotion and marketing of the system
- Funding the system

Appendix A

Coalition Members

Members of the Delaware Caregivers Support Coalition (DCSC) include caregivers and consumers and individuals with disabilities as well as representatives from:

- Consumers: Aaron Deede, Luke McDonough, Liz McLaughlin, Pat Morris, Ann Phillips, Angela Sipple, Susan Wild
- ARC of Delaware: Barbara Allen
- Autism Society: Theda Ellis
- Bayada Nurses: Rosa Fournier
- Chimes: Peter Dakunchak
- Delaware Autism Program (DAP): Peter Doehring
- Delaware Ecumenical Council on Children and Families (DECCF): Robert Hall
- Delaware Elwyn: Eve Austin, Donna Stowell
- Delaware Department of Education (DOE): Kathy Goldsmith
- Delaware Department of Health and Social Services (DHSS): Carol Barnett, Mona Grier
- Delaware Division of Child Mental Health (CMH): Susan Schmidt
- Delaware Division of Developmental Disability Services (DDDS): Meghan Morgan, Roy Lafontaine
- Delaware Division of Public Health (DPH): Dennis Rubino
- Delaware Division of Services for Aging and Adults with Physical Disabilities (DSAAPD):
Albert Griffith, Allan Zaback
- Delaware Division of Substance Abuse and Mental Health (DSAMH): Ronya Anna
- Delaware Health Care Facilities Association (DHCFA): Yrene Waldron
- Easter Seals: Sandy Tuttle, Verna Hensley
- Family Voices: Beth MacDonald
- Mary Campbell Center: Joanne Arena
- Multiple Sclerosis Society: Ginger Stein
- Nurses 'N Kids, Inc.: Gina McCoy
- University of Delaware Center for Disability Studies: Tim Brooks

**Appendix B
Team Charter**

TEAM CHARTER

DELAWARE CAREGIVERS SUPPORT COALITION

GOAL – People with disabilities in Delaware and their caregivers will have easy access to quality respite services; Easter Seals will be a key player in organizing the service delivery model.

MISSION – To study and define the need for respite services by population (persons served), type of service needed, and volume; identify payment sources and current providers; discuss service delivery designs; and develop an action plan to support a pilot program to provide respite services statewide.

TEAM OBJECTIVES –

1. Define the population that needs the service by age, disability type, special care needs, type, and amount of service.
2. Define the current service delivery system, including: current funding sources and adequacy of the funding system, current respite providers, and the pros and cons of the existing service.
3. Define a vision for respite service delivery that meets the needs of people with disabilities and their caregivers and consumers.
4. Develop an action plan for a pilot respite demonstration project by summer 2004.
5. Track progress on State and Federal legislation related to respite issues

HOW THE TEAM WILL WORK TOGETHER –

At the initial meeting, the core team needs to address several issues, including:

1. A vision for respite care in Delaware
2. An assessment of the current status of respite care in Delaware
3. A determination of what additional information and resources are needed to develop an action plan for delivery of services

ACTION STEPS –

1. A survey will be distributed to all participants to help assess the current respite services available and the need for additional services. The team will help identify other organizations or groups that might have access to data. The results will be collated and distributed to the team.
2. Team members will review all existing data from the survey, current studies, etc., and identify additional needed information. A follow-up meeting will be scheduled to give feedback and agree on next steps to acquire additional information if indicated.

On a parallel track, research on funding sources will be completed by a staff person (with assistance from National Easter Seals) and an Easter Seals grant writer.

3. A consolidated report on the findings of the team and identified funding sources will be prepared. A conference call will be scheduled to review the report, discuss, and add to the information.
4. Staff will complete any additional information gathering. A team meeting (in person) will be held to review all of the information and begin to conceptualize the service delivery system. The team will define as specifically as possible a model for service delivery.
5. Additional expertise (i.e. data management, financial analysis, etc.) will be sought out to work with the staff to develop and draft the action plan. This would include studying existing models for respite service delivery.
6. Staff will document the action plan and present it to the team for review, input, and approval. The action plan should support a federal grant request and /or foundation request to design and demonstrate a unique respite provider system that is consumer focused.
7. The team members will help identify possible partners (i.e. State agencies, private foundations) and make contacts to solicit support for the proposal. (possible conference call meeting)

Updated: February 1, 2005

Appendix E

Tasks for Development of Service Delivery System

Determine Structure of System

Public or Private organization administering?
Contracts with providers or voucher system

Review other state models

Information About System

Develop database of current providers

Software development
Secure and input data (ongoing process for keeping

data current)

Develop system for interface w/customer

Phone system or web access?
Staffing (24-7?)

Adequate Supply

Measure supply against need
availability, etc.)

Use data developed for DB (check re. age, type,

Develop system for stimulating new/
expanded services

Review how other systems have provided
incentives and/or training to providers

Quality Supply

Develop regulations for listing or referring
providers to minimize liability

Review I & R agency policies (AIRS, NACCRA)

Develop system for training providers by
primary caregiver

Review what agencies are currently doing

Establish a system for evaluation of service

Review how agencies are currently evaluating

Affordability

Identify current & potential sources of funding

Survey providers, review other states models

Continue Public Policy Initiatives

Meet with state legislators

Monitor Federal legislative developments

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