

Delaware Lifespan Respite Care Network

Report To Delaware Community Foundation

INSIDE:

Introduction.....	1
Operations and Governance	1-2
Services.....	2-3
Outreach	3
Second Year Focus – Recruitment & Training of Providers.....	4
Funding – Lifespan Respite Care Act/ADRC	4-5

Appendix A: Key Accomplishments January – June, 2009

Appendix B: Website Home Page

Appendix C: Key Statistics

Appendix D: Outreach Activities

Appendix E: Governor’s Commission Healthcare Committee’s
Guiding Principles and FY 11 Priorities

October, 2009

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Introduction

The Delaware Lifespan Respite Care Network is a result of six plus years of work of the Delaware Caregiver Support Coalition to support family caregivers through provision of respite care services. In Delaware, approximately 160,000 adults provide unpaid support and care for a relative or friend aged 18 and older (AARP, 2007). This care is often 24-7, 365 days a year producing great stress to the family that results in physical, emotional, relational, and work difficulties.

One important way of supporting these caregivers is to provide respite services that temporarily relieve caregivers and families of those with disabilities, chronic or terminal illnesses, or the elderly from the burdens of this responsibility. However, many caregivers in Delaware have difficulty engaging respite services due to a lack of centralized information to find respite services, an inadequate supply of quality respite care providers, and a lack of resources to pay for services.

The Network's purpose is to assure that people with disabilities and their caregivers will have easy access to quality, affordable respite care by meeting three identified needs –

- Access to information about respite care services
- Affordability of respite care services
- Adequate supply of quality respite care services

Operations and Governance

The focus of the first year of the Network was to develop the systems and infrastructure of an organization, and to begin providing services. During the first six months of this year, activities were focused on building a system including:

- Establishing an Advisory Committee
- Hiring staff
- Securing contracts
- Developing policies and procedures
- Developing materials for public awareness/outreach
- Continuing Fundraising

Appendix A provides a listing of the various activities of the Network during the first six months.

The Advisory Committee has met three times during the year. The group has been involved in setting policies, and providing input for outreach, fundraising and other key issues.

In addition, a Financial Assistance Committee was established to develop a procedure for implementing the policies for distribution of funds to families as well as establishing an efficient process for reviewing applications. After one face-to-face meeting, the group has handled all

business via email, a method that has expedited review and been very time saving for committee members.

An ad hoc committee of the Advisory Committee also met two times in June to review the RFP for the federal Lifespan Respite Act program, and developed a concept for a potential proposal. In the end, a proposal was not submitted, but the process helped to formulate a plan for operational focus in Year 2 of the project.

We anticipate the development of several other ad hoc committees to address other issues including Outreach, Program Development (Provider Training), and Funding/Public Policy.

Services

Two services were identified as critical to implement during the first year including:

- Providing information & referral both through a website & a toll-free phone number
- Providing financial support through small grants to family caregivers

Beginning on July 1, the Network launched a website, www.delrespite.org (see Appendix B) that not only provided information about the network, but also gave the public access to an online respite database, information on how to access a toll-free phone number, and an application for financial assistance.

I & R service description

In May, the Lifespan Respite Care Network entered into a contract with Children & Families First to provide the following services:

Database Management:

- 1) Maintain and expand “Respite Online”, a database of respite care providers in Delaware developed through a grant from the Developmental Disabilities Council and currently accessed through Children & Families First website.
- 2) Assure linkage of the database to other data sources (e.g. ARCH – National Lifespan Respite Network, which maintains a National Locator for respite care services) to assure full utilization of the information.

Referral Services:

- 3) Provide caregivers with access to information about respite care through website and phone (800 number).
- 4) Provide sufficient consultation to caregivers seeking help to refer them to resources which match their needs through a “phone only” process.
- 5) Provide, as needed, information about how to choose a provider.
- 6) Provide, as applicable, information about possible funding sources for respite services, including vouchers from the Lifespan Respite Network.

Attached in Appendix C, you will find statistics about the use of the website to access information as well as the number of information and referral cases.

Financial Assistance

Following a discussion of the Advisory Committee about policies for distribution of funds to families to help in paying for services, a Financial Assistance Committee was established and met in June to outline procedures and review a draft application for caregivers to complete.

Eligibility guidelines were established as follows:

1. Individuals who are not eligible for or receiving respite services from another organization, agency, or state-sponsored program are eligible for financial assistance
2. There must be a demonstrated need for caregiver relief.
3. The person has completed all required application forms.
4. Consideration may be given when funding from other approved sources is exhausted, the consumer still has a need for respite services, and respite dollars are still available.
5. Consideration may be given when individuals are in a transitional stage; i.e. moving from a nursing home to community and do not have in-home services in place yet

Eligible persons can receive up to \$500.00 annually with payments being made in increments no smaller than \$25.00 per disbursement. Payments are made directly to agencies, unless a friend or family member provides respite. In that case, payment is made to the family caregiver.

Families access the application through the Network's website and can either complete it online or download it and mail to the Network office. To date, over 25 families have applied for financial assistance, all are families caring for children with disabilities, and many were helped by discussions with the I & R services to link to additional resources including direct services and respite assistance for which care recipients might be eligible.

Outreach

In order to make sure that caregivers are aware of the Network's services, the services of Miller Mauro Group were contracted to develop a tool kit of materials. These include developing a logo, the website, an information piece (flyer), a display board, and a PowerPoint template.

Coalition members were asked to disseminate information about the service via links to their website, articles in newsletters, and presentations to groups. In addition, through contacts made by coalition members, presentations and connections have also been made to policy groups such as the Interagency Coordinating Council (Birth through Three services), the Governor's Commission for Community-Based Alternatives to People with Disabilities, and staff of the United Way of Delaware.

Fall, 2009 has and will continue to be busy with presentations, and with displaying at a variety of conferences and venues. A listing of outreach activities is in Appendix D.

Second Year Focus – Recruitment & Training of Providers

As planned, the Network intends to address the issue of lack of respite providers. Gaps exist such as in geographic areas (e.g. downstate particularly Sussex County), for particular disabilities (e.g. older children with autism who also have behavioral issues), and for certain types of care (e.g. complex medical needs and/or services needed in the home).

In order to most effectively increase the number of providers of respite care services, the Coalition staff will engage in tasks related to information gathering. This information will then be used to develop a plan. The information gathering process will include:

- 1) Assessing Needs: Update the data gathered by the Coalition in 2005 to identify gaps in service.
 - a) Use changes in populations (increases/decreases in certain populations – e.g. autism, aging, etc.)
 - b) Survey providers and consumers re. identifiable waiting lists, etc.
 - c) Use data from the website and 800#
 - d) Use focus groups of respite and other family support case managers

- 2) Identifying Current Options in State:
 - a) Utilize training that is already available in Delaware to train providers (including direct service providers for other disability services)
 - b) Identify exemplary respite care programs that exist in the state and determine if they can be replicated

- 3) Researching Other States: Identify and understand the actions needed and costs associated with implementing a variety of models for recruiting and training providers including:
 - a) E-learning (see Iowa's model)
 - b) University Collaborations (see Tennessee's model)
 - c) Cooperatives (see Arizona's Model)
 - d) Use of volunteers (faith-based groups such as Delaware Ecumenical Council and other groups such as AARP and WHY'Y's Coming of Age Initiative)

Based on the information gathered, a plan of action will be developed including the what, how, when, and cost of implementing training and other activities that will begin to address the need for more respite providers in gap areas.

Funding – Lifespan Respite Care Act/ADRC

As anticipated, the federal FY10 budget included appropriations for the Lifespan Respite Act. As a result, the Administration on Aging published a program announcement outlining requirements for application for funds. Because the language of the act and program announcement required the applicant to be a state agency, the Delaware Caregivers Support Coalition could not directly request funds. However, members of the group met three times with the state's Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) to explore collaborating with them as the lead agency and contracting with our group to accomplish some of the work. Although the meetings were productive and have set the stage for future collaboration, it became

clear this was not the year to apply. The issues were mainly ones of timing and the uncertainty of the state budget situation.

We now have a better understanding that this source of funding will not likely provide the extent or scope of support we had hoped for ongoing funding of the Delaware Lifespan Respite Care Network infrastructure. However, it will be a valuable resource among a number of kinds of support needed to make this project sustainable.

We will continue to explore other options for funding in the coming year including:

- Corporations
- United Way of Delaware
- Governor's Commission for Community-Based Alternatives for People with Disabilities (see Appendix E – Health Care Committee's priorities for FY11 including sustainability of the Network)
- Other foundations

Appendix A

Delaware Lifespan Respite Care Network Key Accomplishments January – June, 2009

Governance

- Established an Advisory Committee including consumers/parents, service providers and state agencies
- Adopted policies related to Advisory Committee, Database, and Financial Assistance

Services

- Researched other state-wide respite systems to garner information in development of the Delaware network (e.g. Iowa, Tennessee, New Jersey, Nebraska)
- Contracted with Children & Families First to maintain a database of respite care providers
- Contracted with Children & Families First to provide information & referral services
- Developed process for distribution of funds to assist families in paying for respite care including:
 - application
 - review by committee
 - accounting system for payment of grants

Outreach

- Contracted with Miller Mauro Group to design and develop a website, and outreach materials (e.g. flyers, PowerPoint, display materials)
- Promoted services through outreach efforts including:
 - Links on other websites
 - Inclusion in Coalition & other agency communications
 - Presentations to groups such as the Interagency Coordinating Council, Coordinating Council for Children with Disabilities

Funding

- Developed a concept paper for second-year funding focus (recruitment & training of providers)
- Explored federal funding through the Lifespan Respite Act, but could not apply directly

Miscellaneous

- Secured membership with ARCH, National Respite Coalition. Provides Technical Assistance, Public Policy updates and connections to other state systems
- Received and accepted invitation to present at the National Respite Coalition Conference in September, 2009 in California

APPENDIX B

[Jump to Main Content](#)

[Home](#)
[About Us](#)
[History](#)
[Families](#)
[Providers](#)
[Advocacy](#)
[Contact](#)
[RespiteOnline](#)

Delaware Lifespan Respite Care Network

Welcome to Delaware Lifespan Respite Care Network

From time to time, families with caregiving responsibilities need opportunities for a break from caring for their loved one. The Delaware Lifespan Respite Care Network is here to help you find and finance respite opportunities so you have time to relax and rejuvenate.

We serve caregivers of children or adults with special needs, disabilities, and conditions associated with aging. Call (888) 610-5572 or New Castle County (302) 479-1690 to speak to a specialist who can help you find care and determine if you are eligible for help in paying for it.

Links to:

[Find Care](#)

[Financial Assistance](#)

[Advocacy](#)

[Advisory Committee \(PDF\)](#)



Delaware Caregiver Statistics

Over 130,000 adults in Delaware provide unpaid support and care for a relative or friend.

The average caregiver in Delaware is a 52-year old woman who has been providing care for an average of 18 years and provides an average of 65 hours per week of care for a person between the ages of 2 and 90.

The type of care provided by caregivers includes bathing, feeding, dressing, transportation, medical care, grocery shopping and household chores.

Caregivers identify their greatest concerns to be emotional strain, financial stress and conflict with employment (CDS, 2005)

Center for Disabilities Studies (U of DE) staff for publication in the Delaware Caregivers Support Coalition final report on respite care in December, 2007.

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Complies with W3C Standards. | [XHTML](#) | [CSS](#) | [site map](#)

**Appendix C
Delaware Lifespan Respite Network
Key Statistics
2009**

Month	Outreach	Website Page Views	Respite Online	I & R Cases	Fin Asst. Apps.	Dollars Used*
May	25					
June	65					
July	45	1,844	61	8	11	
August	0	1,142	53	8	6	\$ 60
September	85	1,225	26	6	12	\$ 545
October						
November						
December						
YTD TOTAL	220	4,211	140	22	29	\$ 605

Appendix D
Lifespan Respite Outreach Activities

Date	Group	Approx. #	Primary Person	Activity
5/7/2009	Inclusion Conference	20	Barb, Kathy Hyde	Display/jointly with CFF
5/19/2009	Elder Expo	5	Kathy Hyde	Display/jointly with CFF
6/23/2009	Easter Seals Executive Leadership Team	30	Barb	Presentation with flyer
6/26/2009	Respite Coalition	25	Barb	Emailed flyer
6/26/2009	Blue Rocks Disability Awareness Night	10	Beth Elswick/ES	Display - flyers
7/10/2009	Dept. of Public Health, Family Support Program	15	Walt Mateja	Emailed flyer
7/16/2009	Southeast Sussex Ministerium - Health Fair	10 orgs.	Leslie Gale/ES	Presentation/table
7/28/2009	Interagency Coordinating Council (DPH)	35	Barb	Presentation
7/13/2009	Parent Information Center (PIC)	4800	PIC staff	Link in Enewsletter
July	CHEER	7500	Arlene Littleton	Monthly Sr. Newsletter
9/16/2009	Christiana Care pediatric therapists & e.c. educators	14	Barb	Presentation
9/22/2009	Respite Coalition	25	Gerri	Emailed updated flyer
9/24/2009	Easter Seals "The Gift" Open House		Gerri	Display - flyers
9/25/2009	National Respite Conference breakout session	35	Barb	Presentation
9/28/2009	Governor's Commission for Community-Based Alternatives for People w/Disabilities	26	Barb	Presentation
October	Center for Disabilities Studies	3000	Michelle Sands	newsletter
10/1/2009	Delaware Aging Network (DAN)	26	Gerri	Presentation
10/8/2009	Division of Child Mental Health	10	Susan Schmidt	Mailed flyers
10/8/2009	St. Patrick's Senior Center		Bill Kooser	Emailed flyer
10/8/2009	Jewish Family Service	20	Kathy Samworth	Emailed and mailed flyer
10/8/2009	Alzheimers Assocation/DE Regional Office		Siobhan Gannon	Emailed flyer
10/8/2009	Elwyn Delaware	20	Donna Stowell	Mailed flyers
10/13/2009	Parent Information Center		Barb/Gerri	Audio-Conference
10/15/2009	Statewide senior center employees/volunteers	30	DAN members	DAN Training
10/21/2009	Brain Injury Conference		Carol Barnett/DSAAPD	Display - flyers
10/24/2009	MS Society Event at Christiana Care		Nancy Ranalli/ES	Display - flyers
11/4/2009	AstraZeneca Elder Care Fair		Gerri/Kesha	Display
11/17/2009	Alzheimers Association Conference		Gerri	Display/jointly w/Elwyn DE

WebLinks

Delaware Family to Family Health Information
MS Society

Ann Phillips
Katrina Holloway

Appendix E

Governor's Commission for Community-Based Alternatives for People with Disabilities Healthcare Committee's Guiding Principles and FY 11 Priorities

Guiding Principles:

1. Include Self-Direction in Waivers and services.
2. Enhance and expand non-residential community-based services.
3. Coordinate treatment of substance abuse, mental illness and addictions both during incarceration and after discharge.
4. Recruit qualified healthcare providers and promote a climate that makes it conducive to healthcare providers to work in Delaware.
5. Develop a strategy to increase the epidemiologic capacity (i.e. health statistics about the health status and risks of people with disabilities).
6. Expand access to family support services.
7. Promote deinstitutionalization of people with disabilities.

FY 2011 Priorities

1. Implement a Medicaid Buy-In program for children: Reduce under-insurance for children and youth with special healthcare needs.
2. Increase funding for PAS (personal attendant services).
3. Recruit qualified primary care physicians, dentists, psychiatrists, and other mental health professionals to Delaware's identified health professional shortage areas (Kent & Sussex Counties, and parts of Wilmington). Address limitations, caps and other barriers in Medicaid, Medicare, SCHIP and private health insurance companies that prevent people with disabilities from receiving quality healthcare.
4. Review existing data collection and data sharing capacities of state and community organizations that serve individuals with disabilities and special health care needs.
5. Increase funding for, and access to, Assistive Technology.
6. Expand mental health courts to all 3 counties (currently only in NCC).
- 7. Sustain or increase funding for Lifespan Respite Care Network.**
8. Sustain MWD (Medicaid for Workers with Disabilities).