

*Delaware Caregivers Support Coalition*

# **The State of Respite Care in Delaware:**

## **A Report of Caregiver and Provider Perceptions of Respite Care**

October 2005

Conducted by the Delaware Caregivers Support Coalition, an organization of  
Delaware Family Members, Consumers and Providers Dedicated to  
Improving the Availability of Respite Care in Delaware

Report Compiled by Sara Whitehead and Verna Hensley of  
Easter Seals Delaware and Maryland's Eastern Shore, Inc.  
and the Staff of the Center for Disabilities Studies at the University of Delaware

---

## INTRODUCTION

“How do I find help that is qualified and in a safe environment for my son?” “I have already tried everything in caring for my sister – to the point where I am not able to ask for anything. How do I pay for help and where do I find it?” These two quotations illustrate the concerns and fears stated by many of the 282 family members who responded to a Delaware statewide survey of those caring for family members with chronic health concerns, developmental and related disabilities, and disabilities resulting from aging. The fear of not being able to care for and support their loved ones was the overriding theme of the survey comments from parents, other family members and friends.

In the Spring of 2003, the Family Support Initiative of the Center for Disabilities Studies at the University of Delaware released a report entitled *Respite Care in Delaware: A Critical Need for Change*. The report concluded that “lifespan respite care is an essential family support...and is efficient, cost-effective, and humane” (p. 12). The report made four recommendations:

- support a state law mandating lifespan respite care;
- conduct a state-wide assessment to determine the level of unmet need for respite services;
- develop a comprehensive directory of all respite services in the state; and
- support a “family support Medicaid waiver” which would provide support for further respite services.

In response to these recommendations, the Center for Disabilities Studies and Easter Seals Delaware and Maryland’s Eastern Shore formed the Delaware Caregivers Support Coalition (DCSC). The Coalition is composed of family members, consumers, caregivers, health care providers, professionals, and disability advocates working to expand respite services throughout Delaware. In addition to family caregivers and consumers, the members of the Coalition represented the following groups:

- The Arc of Delaware,
- the Autism Society of Delaware,
- Bayada Nurses,
- the Center for Disabilities Studies at the University of Delaware,
- Chimes Delaware,
- the Delaware Autism Program,
- the Delaware Department of Education,
- the Delaware Department of Health and Social Services,
- the Delaware Developmental Disabilities Council,
- the Delaware Division of Child Mental Health,
- the Delaware Division of Developmental Disabilities Services,
- the Delaware Division of Public Health,
- the Delaware Division of Services for the Aging and Adults with Physical Disabilities,
- the Delaware Division of Substance Abuse and Mental Health Services,
- the Delaware Ecumenical Council for Children and Families,
- Delaware Elwyn, Inc.,

- the Delaware Health Care Facilities Association,
- Eastern Seals of Delaware and Maryland’s Eastern Shore, Inc.,
- Family Voices,
- the Mary Campbell Center, and
- the Multiple Sclerosis Society.

The goal of the DCSC is to create a service delivery system that will provide Delawareans with disabilities and their caregivers with easy access to quality respite services.

The Coalition established a mission and created a vision statement (see Appendix A). As part of the group’s objectives they chose to implement the recommendations of the *Respite Care in Delaware* report: the survey of respite needs and existing services. The DCSC decided to survey both families and current providers about respite services in order to gain a better understanding of the state of respite care in Delaware. The remainder of this document reports how those surveys were conducted and the findings from those surveys.

## **TABLE OF CONTENTS**

<b>Caregiver Survey</b> .....	3
Overview of Responses to the Caregiver Survey.....	3
Age of Caregivers and those Cared for and Length of Care Relationships....	5
Types of Care and Support Provided by Caregivers.....	5
Concerns and Worries of Caregivers.....	6
Difficulties Providing Care.....	6
Need for Assistance and Respite Care.....	7
Respite Care Cost.....	8
Summary of Caregiver Survey Responses.....	8
<b>Provider Survey</b> .....	10
Respite Services Provided.....	10
Cost of Respite Services.....	12
Need for, Availability of, and Barriers to Providing Respite Services.....	12
Recommendations.....	13
<i>Appendix A: Delaware Caregivers support Coalition Vision Statement</i> .....	14

## CAREGIVER SURVEY

To better understand caregivers' needs for respite care, the Coalition created a caregiver survey by adapting a survey developed in Maryland. The 18-question survey was distributed to over 1,500 family caregivers of persons with disabilities across the state. The surveys were distributed during the months of June, July, and August 2004 by representatives of the Delaware Alzheimer's Association, the Delaware Division of Child Mental Health (CMH), the Delaware Autism Program (DAP), the Division of Developmental Disabilities Services (DDDS), the Division of Services for the Aging and Adults with Physical Disabilities (DSAAPD), the Division of Substance Abuse and Mental Health (DSAMH), Easter Seals of Delaware & Maryland's Eastern Shore, and the Multiple Sclerosis Society. Of the 1,500 surveys distributed, 282 were returned and had at least portions of the survey that were usable.

While this strategy for sampling the needs of family caregivers was neither random nor necessarily representative of all families needing respite services, the sampling method does provide a clear picture of the needs of families with adults with long-term health or disability concerns and for children with developmental delays and/or autism. Children with special health care needs and other specific populations of children (e.g., children with cerebral palsy or other physical disabilities) were not systematically included in the sampling. The responses from the survey should be considered in this context.

### Overview of Responses to the Caregiver Survey

Of the 282 individuals responding to the survey, almost all (over 91%) were related to the person for whom they provided care. Almost two thirds of caregivers (65.6%) reported providing care to their biological or adoptive children. The next most common family relation for whom caregivers provided support was sibling (7.4%). The percentage of caregivers providing support for non-relatives was 8.9% (see Table 1 for details).

**Table 1. Relation of Survey Respondent to Individual Being Cared For (N=282)**

<b>Relation</b>	<b>Number</b>	<b>Percentage</b>
Parent/Guardian	185	65.6%
Sibling	21	7.4%
Spouse	19	6.7%
Grand or great grandchild	13	4.6%
Other Relative	10	3.6%
Son/Daughter	9	3.2%
Non-relative	25	8.9%
<b>Total</b>	<b>282</b>	<b>100.0%</b>

Almost all of the caregivers responding to the survey reported that they lived with the person for whom they provided care (almost 90%). The other ten percent of individuals being cared for lived in group homes, nursing homes, or with other family members (see Table 2 for details).

**Table 2. Residency of Person Being Cared For (N=282)**

	<b>Number</b>	<b>Percentage</b>
Live with caregiver	252	89.4%
Live with another family member	18	6.4%
Group home or boarding home	6	2.1%
Independently (alone)	3	1.1%
Nursing home	2	0.7%
No answer	1	0.1%
<b>Total</b>	<b>282</b>	<b>100.0%</b>

The caregivers responding to the survey were asked what disabilities, health problems or other concerns necessitated on-going care for their relatives. They identified 480 concerns, almost two per individual cared for. The most frequently identified disability was a developmental delay or cognitive disability (n=161, 57.1%).

**Table 3. Disability or on-going health concern necessitating care**

<b>Disability/Health Concern</b>	<b>Number*</b>	<b>Percentage*</b>
Developmental delay/Cognitive disability	167	59.2%
Chronic mental illness	76	27.0%
Mobility or physical disability	65	23.0%
Autism Spectrum Disorder	55	19.5%
Chronic disease (e.g., cancer, multiple sclerosis)	41	14.5%
Visual impairment	22	7.8%
Alzheimer/Dementia	14	5.0%
Seizure disorder	11	3.9%
Traumatic brain injury	7	2.5%
Other chronic concerns	22	7.8%

\*While 282 respondents provided answers to this question, the total N is greater than 282 and the overall percentage is greater than 100% because respondents often indicated more than one disability, delay or concern.

Caregivers were also asked to rate the intensity of need for support that the person they were caring for needed. When asked to rate if their relative's need for care and support was occasional, routine or extensive, 134 of the 278 respondents (over 48%) indicated that the care needs of the person they supported was at a moderate level. (See Table 4 for details.)

**Table 4. Respondents' Perception of Level of Care Needed by Person They Cared For**

<b>Level of Care</b>	<b>Number</b>	<b>Percentage</b>
Needs occasional supports	69	24.8%
Needs routine assistance	134	48.2%
Needs extensive/continuous support	75	26.0%
<b>Total</b>	<b>278</b>	<b>100.0%</b>

### **Age of Caregivers and those Cared For and Length of Care Relationships**

The average age of the 282 caregivers responding to the survey was 50 years of age. However, the range of the age of caregivers was as young as 16 years of age and as old as 89 years of age. The average age of those being cared for was 27 years of age with the oldest person being cared for being 90 years of age and the youngest being two years of age.

The caregivers who responded to the survey indicated that they had been caring for a family member for an average of 17 years with the range being as few as two years and as long as 55 years. The amount of time per week spent on caregiving varied widely with some caregivers providing support and care for as few as three hours per week and for some caregivers providing as many as 140 hours per week. While the average number of hours of support and care provided by caregivers per week was 63, almost a quarter of the respondents (n=66) could not estimate how many hours per week of care they provided. Over 55% (n=156) stated that they provided “constant care” for their family members.

### **Types of Care and Support Provided by Caregivers**

The caregivers responding to the survey indicated that they provided numerous types of care and support. These ranged from activities of daily living (e.g., bathing, toileting, grooming), transfers and transitions (e.g., getting in and out of bed), communication, and supporting positive behaviors. The most common types of support reported by the caregivers were preparing meals (84.8%) and transportation (80.5%). (See Table 5 for details.)

**Table 5. Type of Care Provided by Caregivers (n=282)\***

<b>Type of Care</b>	<b>Number</b>	<b>Percentage</b>
Prepare meals	239	84.8%
Transportation (driving or arranging for transportation)	227	80.5%
Assisting with medications and health procedures	204	72.3%
Assisting with daily household chores (e.g., dishes, laundry)	199	70.6%
Assisting with grocery shopping	193	68.4%
Assisting with management of finances	186	66.0%
Companionship	185	65.6%
Encouraging positive behaviors/managing challenging behaviors	183	64.9%
Assisting with communication	180	63.8%
Assisting with errands	153	54.3%
Assisting with bathing	149	52.8%
Assisting with dressing	118	41.8%
Assisting with toileting	77	27.3%
Assisting with eating	66	23.4%
Transferring to and from bed or other furniture	50	17.7%
Assisting with getting to and from the toilet	45	16.0%
Specialized medical care	30	10.6%

\*While 282 respondents provided answers to this question, the total N is greater than 282 and the overall percentage is greater than 100% because respondents often indicated more than one disability, delay or concern.

Almost all caregivers answering the survey questions indicated that they were providing multiple types of care and support for the individuals for whom they were caring. In some cases, caregivers were providing all of the types of care listed in Table 5.

### **Concerns and Worries of Caregivers**

**O**f the 282 caregivers answering the survey, many identified concerns and worries about the individuals for whom they provide care. These included concerns about personal safety, finances, and the long-term quality of life for those for whom they care.

Almost 45% of those responding to the survey were concerned about the safety of the individuals for whom they were caring. At a much lower rate, caregivers also worried about their own safety (17.0%) and the safety of others living in their households (23.0%). In addition to these concerns, the respondents were also worried about those they cared for being taken advantage of or of self-injury.

### **Difficulties Providing Care**

**T**he respondents to the survey indicated that they often have difficulties providing support and care for their family members. These difficulties were related to such issues as finances, conflicts with jobs and/or school, and time and emotional demands. The caregivers identified “emotional strain/burnout” as the greatest difficulty related to providing care (n=192, 68.1%). Table 6 details the difficulties related to providing care as identified by the caregivers.

**Table 6. Difficulties providing care as identified by caregivers (n=282)\***

<b>Identified Difficulty</b>	<b>Number</b>	<b>Percentage</b>
Emotional strain/ burnout	192	68.1%
Not having enough time for other activities	155	55.0%
Physical health strain	92	32.6%
Conflict in your family	86	30.5%
Financial strain	84	29.8%
Conflict with job	82	29.1%
Legal problems	22	7.8%
Conflict with school	21	7.4%
Conflict with state or local agency	9	3.2%

\*While 282 respondents provided answers to this question, the total N is greater than 282 and the overall percentage is greater than 100% because respondents often indicated more than one disability, delay or concern.

When caregivers were asked to identify the single greatest concern in caring for their family members, they reported eleven different difficulties. Twenty-three percent of the caregivers did not identify a difficulty. The other 77% of caregivers reported that “emotional strain” was the greatest difficulty in caring for their family members, followed by lack of time and financial difficulties. Table 7 contains the report of the greatest single difficulty as identified by caregivers.

**Table 7. Greatest single difficulty related to providing care as identified by caregivers**

<b>Identified Difficulty</b>	<b>Number</b>	<b>Percentage</b>
Emotional strain	90	31.9%
Not enough time	43	15.3%
Financial	26	9.3%
Conflict with job	15	5.4%
Physical strain	11	3.9%
Conflict with family	10	3.6%
Both emotional and physical strain	9	3.3%
Lack of assistance in caregiving	8	2.9%
Conflict with agency	2	0.2%
Conflict with school	1	0.1%
Legal problems	1	0.1%
No answer	66	24.0%
<b>Total</b>	<b>282</b>	<b>100.0%</b>

### **Need for Assistance and Respite Care**

Caregivers were asked about the amount of help they were receiving as they cared for their family members, how much assistance they would like to receive and what they would like from a respite program.

Respondents to the survey indicated that they received very little assistance in the care they provided. Less than 13% of the respondents indicated that they received daily assistance from someone as they provided care. Less than 11% indicated that they received help from others once or twice a week. Less than 4% reported that they received help from others if they needed to go out of town or to travel. Only 25.9% of the caregivers stated that they received help during emergency situations. Only 5.7% reported that they were able to receive assistance when they needed a break. Almost 14% of respondents said that they never receive any help as they supported and provided assistance to those for whom they provided care. (See Table 8 for details.)



**Table 8. Frequency of Caregivers Receiving Assistance**

Frequency of Assistance	Number	Percentage
Every day	61	21.6%
Once or Twice a Week	44	15.6%
On Weekends	9	3.2%
Three to Five Times a Week	17	6.0%
Once or Twice a Month	12	4.3%
Once or Twice a Year	15	5.3%
Never	12	4.3%
When I Need a Break	16	5.7%
For Unexpected Events	7	2.5%
When He/She Is Out of School	4	1.4%
On an Emergency Basis	73	25.9%

The caregivers were also asked what their concerns were about a possible respite care system that would support them. By far, the caregivers who responded to the survey stated that they were most concerned for the safety of their family members. That they wanted to be sure that those they cared for would be safe during respite care in the short-term *and* that they would be cared for in the long-term when the caregivers were no longer able to provide support and care or the caregivers died. Trustworthiness of the respite providers was the number one requirement mentioned by the caregivers when asked about their major concerns with a respite system.

### **Respite Care Cost**

The caregivers who responded to the survey talked about the cost of respite services. When asked what they felt respite should cost their families, the average response was \$9.00 per hour or \$47.00 per day. When asked about overnight respite support, the caregivers stated, on average, that the cost should be \$65.00. These responses about the fees charged for respite services ranged from a low of \$2.00 per hour to a high of \$30.00 per hour. However, 53.2% (n=150) of the respondents indicated that they could not pay for the cost of respite from their own family budgets.

### **Summary of Caregiver Survey Responses**

The 282 caregivers who responded to the survey were primarily family members (over 91%) caring for a child, sibling, spouse or parent. Almost 90% of those being cared for were living with their caregivers. The types of disabilities and health concerns represented by the respondents were varied with almost 60% caring for a person with a developmental disability. Almost 50% of those cared for needed routine assistance with such daily living activities as meal preparation, toileting, bathing, and transportation.

Over two thirds of the caregivers reported that the demand of the care they provided caused an emotional strain in their lives and that they were experiencing burnout from the care they were providing. They reported that this strain affected their jobs, their family life, their health and their finances.

Very few of the caregivers received daily support and assistance from anyone else as they provided care to their family members. Only 25.9% reported that they could receive assistance from others even in the time of an emergency.

When asked what they thought the fee for respite services should be, the caregivers responded with an average fee of \$9.00 per hour. However, over half of the caregivers reported that they could not afford *any* fee for respite services because of their already strained family budgets.

The caregivers were, overwhelmingly, concerned about the safety of those for whom they provided care and for ensuring that they were able to find competent, supportive respite care services. One caregiver stated, "I'm very protective because my son cannot protect himself."

The caregivers' concerns were linked to a number of issues. The inability to speak or communicate by many of those for whom they cared was of concern. One caregiver said that "His medical needs and inability to speak are concerns." Another reported that "[My son] does not complain or communicate. He can easily be ignored - that's my fear."

An additional concern regarding respite care was the medical needs and procedures of those for whom they provided care. One caregiver said, "I know there are a lot of nice respite providers out there but I am very concerned when it comes to [my son's] seizures. That's why I prefer family [members] who are familiar with what to do."

Finally, and perhaps most importantly, the caregivers responding to the survey reported concerns related to their own aging and emergency situations. Many of them were concerned with the long-term care for their family members needing support as well as what would happen to them when a medical or other emergency occurred and the caregiver could no longer provide care. One caregiver stated that "In an emergency situation, we have no one to call to care for our son if anything should happen to us..." Another caregiver said that, "I'm very lucky to have my sisters' assistance, but I do worry as we all get older in what the future holds."

The results of the caregiver survey clearly indicate that respite support is needed and that the current network does not provide that support.

## PROVIDER SURVEY

**A**s a companion to the caregiver survey, the Delaware Caregivers Support Coalition also undertook a respite providers survey in the summer of 2004. The 18 question survey was sent to providers of respite services in the state. Responses were received from 17 providers of respite services. The responding groups were:

- Brandywine Assisted Living at Seaside Pointe,
- Chimes Delaware,
- Courtland Manor Nursing & Convalescent Home,
- Delaware Autism Program (DAP),
- Department of Services for Children, Youth, and Their Families (DSCYF),
- Delaware Ecumenical Council,
- Division of Developmental Disabilities Services (DDDS),
- Division of Services for the Aging and Adults with Disabilities (DSAAPD),
- Easter Seals Delaware & Maryland's Eastern Shore,
- Griswold Special Care,
- Harbor Healthcare,
- Home Health Services by TLC,
- The Lorelton,
- Mary Campbell Center,
- Mosaic,
- Multiple Sclerosis Society (DE chapter), and
- Pressley Ridge.

### Respite Services Provided

**T**he 17 organizations reporting that they provided respite services indicated that they served individuals with various disabilities and health concerns. These included those who are elderly, have chronic mental illness, have physical disabilities and have developmental delays. (See Table 9 for details.)

**Table 9. Number of Organizations Providing Respite Services for Persons with Specific Disabilities or Health Concerns**

<b>Disability or Health Concern</b>	<b>Number of Providers (n=17)</b>
Physical disabilities	10
Developmental delays	8
Elderly	8
Alzheimer's	8
Chronic illnesses	7
Significant medical needs	6
Challenging behaviors	5
Chronic mental health concerns	3

The agencies reported that they provided respite services to individuals of a variety of ages. Of the reporting agencies, there was a trend toward providing respite for adults and those who were aging. Only three agencies reported providing respite services for infants and toddlers (see Table 10 for details).

**Table 10. Number of Organizations Providing Respite Services by Age**

Age of Individual for Whom Respite Services are Provided	Number of Providers (n=17)
Birth to two years	3
Three to five years	6
Six to 18 years	10
19-64 years	12
65 years or older	14

The agencies reported that they provided respite services in a variety of settings, including the family home, adult care facilities, nursing homes and camp settings. No respite services were reported to be provided in church or hospital settings (See Table 11 for details.)

**Table 11. Locations Respite Services are Provided**

Location of Respite Services	Number of Providers (n=17)
Family's/consumer's home	9
Nursing home	4
Camp setting	3
Respite provider's home	2
Adult care facility	2
Child care facility	1
Senior center	1
Group home	1
Assisted living facility	1
Foster home	1

The availability of respite services from the agencies varied widely. Some agencies reported that they could provide respite services seven days a week, twenty-four hours per day. Other agencies reported that they had the capacity to provide respite services as few as 20 hours per week.

Agencies were also asked if they had waiting lists for services. Only three reported that they currently had a waiting list and all three indicated that the waiting list was short.

The types of respite services provided by the agencies also varied widely. Some agencies were able to provide only planned respite services while others were able to provide emergency services. Others were able to help build respite service capacity by providing training to prospective respite providers (see Table 12 for details).

**Table 12. Types of Respite Services Provided by Agencies**

<b>Types of Respite Services</b>	<b>Number of Providers (n=17)</b>
Planned respite services	16
Emergency respite services	10
Referral services	9
Information services	9
Training for prospective respite providers	6

### **Cost of Respite Services**

The agencies responding to the survey reported a wide range of charges for the respite services they provided. The agencies reported the hourly fee for respite services between \$6.00 and \$12.50 per hour. Some agencies reported daily rates that ranged from \$20 to \$192.50 per day. Only one provider reported having a sliding scale based on the family's ability to pay.

Provider agencies reported that they received payment for respite services from many sources. These included:

- Medicaid,
- private insurance,
- grants,
- state contracts, and
- private payments.

No agency reported receiving payment for respite services from the Supplemental Security Insurance program or the Disabled Children's program (SSI/SSDI).

### **Need for, Availability of, and Barriers to Providing Respite Services**

All of the agencies who responded to the survey indicated that there was a need for increased respite services in the state. The provider agencies identified a number of specific concerns they felt families had regarding respite services.

These included:

- cost of respite services,
- availability of services,
- safe and convenient services, and
- respite providers who understand the individual needs of their family members.

The provider agencies responding to the survey reported that finding individuals trained to be respite care workers was very difficult. The agencies reported that the specific skills needed by a respite provider included knowledge and understanding of disabilities, and basic first aid and CPR. In addition to these baseline skills, the respite worker might need specific knowledge and

training related to individual consumers' medications, medical procedures (e.g., tracheotomies), and the specific methods for communicating with the individuals for whom they are providing support and care.

The agencies responding to the survey indicated that there were many barriers to providing respite services for families. These included:

- recruiting and training respite providers;
- coordinating services among the current providers;
- developing an understanding and awareness of the concept and need for respite services among the general public, families, and legislators; and
- finding on-going funding sources to support the services.

Five of the agencies reported that they would be willing to expand respite services if the funding sources were available.

## **Recommendations**

**T**he representatives from the agencies responding to the survey were asked for their recommendations regarding respite services in the state. Their recommendations included the following:

- Build the availability of trained respite workers, with a particular focus on respite care that requires a medical component;
- Increase hourly wages for respite workers so that they can be retained and the position is seen as a valued job;
- Develop a volunteer network of individuals who are willing to provide respite care;
- Develop the capacity to provide more in-home respite care;
- Ensure that those providing respite care have the proper training in first aid and CPR as well as the specific needs of individuals for whom they are caring;
- Institute background checks for respite care providers; and
- Develop a state-wide unit to coordinate respite services.

## Appendix A

### **Delaware Caregivers Support Coalition Vision Statement**

The pilot respite delivery system will be a 24-hour service delivery system dedicated to helping people to identify and secure the appropriate form of respite care from the broad spectrum of options available to them. Caregivers will be able to make arrangements through system support staff or directly with respite care providers and will be able to rely on staff recommendations or make their own choices from a range of options, selecting long-term or short-term, in-home or in a center, with trained nurses or training family friends, or anything in between, regardless of disability type or financial status. The system will recognize the value of the respite care providers and support staff as well, providing training, competitive salaries, and opportunities for advancement.



Center for Disabilities Studies  
University of Delaware  
166 Graham Hall  
Newark, DE 19716  
(302) 831-6974  
[www.udel.edu/cds](http://www.udel.edu/cds)

---

**AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYER** The University of Delaware is committed to assuring equal opportunity to all persons and does not discriminate on the basis of race, color, gender, religion, ancestry, national origin, sexual orientation, veteran status, age, or disability in its educational programs, activities, admissions, or employment practices as required by Title IX of the Education Amendments of 1972, Title VI of the Civil Rights Act of 1964, the Rehabilitation Act of 1973, the Americans with Disabilities Act, other applicable statutes and University policy. Inquiries concerning these statutes and information regarding campus accessibility should be referred to the Affirmative Action Officer, 305 Hullihen Hall, (302) 831-2835 (voice), (302) 831-4563 (TDD).