

*Report to the Governor's Commission on Community-Based Alternatives  
for Individuals with Disabilities*

## **Respite Care in Delaware: The Delaware Lifespan Respite Information Network**

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## Executive Summary

### Delaware Lifespan Respite Information Network

The Commission on Community-Based Alternatives for Individuals with Disabilities awarded a contract to the Center for Disabilities Studies (CDS) to develop a plan to address the lack of coordination of and growing need for respite care services in Delaware. The Center for Disabilities Studies coordinated a coalition of consumers, service providers, and advocates to develop a plan for a statewide system in Delaware to provide respite across the lifespan from birth through aging and across all disability classifications.

Many caregivers in Delaware have difficulty engaging respite services due to a lack of centralized information to find respite services, an inadequate supply of respite care providers, a lack of quality care, and a lack of resources to pay for services. When resources are available, many caregivers are not aware of them. The Delaware Caregivers Support Coalition (DCSC) developed the *Delaware Lifespan Respite Information Network* to address the respite care needs of people with disabilities, chronic health conditions, and those who are aging throughout Delaware.

A three-year operational plan has been developed for the *Delaware Lifespan Respite Information Network*. The proposed system would include a central administrative office responsible for oversight of information and referral to respite services, caregiver and service recipient training, public relations, provider services (including training and quality assurance), and administrative services such as planning, program evaluation, fund development, financial management, and recordkeeping. Some of these functions, including information and referral and public relations, could be provided through subcontracts with other agencies. The primary activity in the first year is the development of the infrastructure including hiring staff, establishing contractual relationships, and developing policies and procedures. The second year would include building capacity by recruiting and training additional respite care providers. The third year would focus on developing services that are often more difficult to find, such as emergency care, and would move the system to operating 24 hours a day. The overall network would be governed by an advisory board that includes representatives of various constituents of the system, including people with disabilities, service providers, state agencies, and advocacy groups.

The estimated total cost for the first three years of operation is \$500,000. Initial funding will be sought from foundations and corporations supplemented by existing respite funding in state agencies and private organizations. Ongoing efforts will continue to influence state legislation and policies that recognize the value of family supports, including respite care.

Supplementing the work of the Delaware Caregivers Support Coalition, a database of respite care providers in Delaware has been developed with grant support from Delaware's Developmental Disabilities Council. The database can be accessed on The Family & Workplace Connection's website ([www.familyandworkplace.org](http://www.familyandworkplace.org)).

Family caregiving is at the core of what sustains the majority of frail elders and adults with disabilities. Unpaid family and friends (known as informal caregivers) are a vital component of this country's health and long-term care system, but the significance of their role, and their own burdens and compromised health, are often overlooked. Unrelieved caregiver burden, exhaustion, financial concerns, and other care-related strains are major contributing factors to the institutionalization of frail elders and adults with disabilities, often resulting in higher public expenditures for nursing home costs (Feinberg, 2006).

## **Introduction**

Respite care is defined as:

The temporary relief for caregivers and families who are caring for those with disabilities, chronic or terminal illnesses, or the elderly ([www.archrespite.org](http://www.archrespite.org)).

Approximately 130,000 adults in Delaware provide unpaid support and care for a relative or friend. The average caregiver is 52-year old woman who has been caring for her family member for over 20 years (Center for Disabilities Studies, 2003). This care was valued at almost a billion dollars in Delaware alone (National Family Caregivers Association, 2006). Respite is a key component of child care, elder care, comprehensive family support, family caregiver health and long-term care, and family violence or child abuse prevention strategies. Yet respite services remain in critically short supply for all age groups, for all families in crisis, and for caregivers of the elderly and individuals with disabilities. Caregivers also face lower wages, reduced job security and loss of benefits, including health insurance, retirement savings and Social Security earnings, and are more likely than non-caregivers to suffer chronic health conditions (MetLife, 2006).

This report examines available research about the need for respite care in the country as a whole and Delaware specifically. This research provides a foundation for the development of the *Delaware Lifespan Respite Information Network*. Throughout the report are personal stories from families in Delaware about their respite care needs to help illustrate the needs that families have expressed throughout this project. The stories are based on multiple interviews with families throughout the state.

### **History of the Delaware Caregivers Support Coalition**

In the fall of 2003, the Center for Disabilities Studies at the University of Delaware published a report, *Respite Care in Delaware: A Critical Need for Change* (CDS, 2003). One of the key recommendations of this report was to coordinate respite services throughout the state. Soon after the report was released representatives from the Center for Disabilities Studies and Easter Seals Delaware & Maryland's Eastern Shore established the Delaware Caregivers Support Coalition (DCSC) to address the need for coordinated respite care services in the state.

The DCSC consisted of more than 25 members representing consumers, service providers, and state entities (see Appendix B for a list of members). The group began meeting in January 2004

and defined the scope of the need for respite care through discussion and surveys of respite providers and caregivers. A final report with the results of the surveys and recommendations was issued in October 2005. A major recommendation of the group was to develop a plan for a statewide system of respite care.

In October 2005 a conference sponsored by the Coordinating Council for Children with Disabilities was held at A.I. DuPont Hospital. “Exploring Respite Care in Delaware,” included presentations from caregivers living with the daily stress of caregiving, medical professionals seeing the health impact of caregiving, and a state representative from Nebraska who described the state’s legislation that supports lifespan respite.

The Governor’s Commission on Community-Based Alternatives for Individuals with Disabilities contracted with the Center for Disabilities Studies in 2005 to design a pilot Respite Delivery System, using examples and experiences of other states, including Nebraska and Oregon. CDS staff and members of the coalition met regularly to examine existing respite care, identify lapses in current systems and explore alternatives. A task force of representatives from state agencies, non-profit organizations, and CDS drafted a plan incorporating the suggestions and desires of the entire coalition (see Appendix B for a list of task force members). The members of the task force met monthly to create a system and present an operational plan, including a budget, to the entire Coalition (See Appendix C for final plan). This draft plan was presented to the DCSC in September 2007. A period of public comment included two public meetings and opportunities for comment by mail, email, phone, and fax. With revisions and suggestions received during the public comment period, the final *Delaware Lifespan Respite Information Network* proposal was presented to the Governor’s Commission on December 5, 2007.

Parallel to the DCSC development of the *Delaware Lifespan Respite Information Network*, a \$15,000 grant from the Developmental Disabilities Council in 2006 allowed The Family & Workplace Connection (FWC), a member of DCSC, to develop a database of respite care providers, building on its existing knowledge of

### ***Personal Experience with Respite***

*Janice Sanders and Louise White*

Janice cares for her 88-year old mother, Louise White. Mrs. White has had both legs amputated due to complications from diabetes. As a result of several strokes, Mrs. White requires twenty-four hours of personal support. Janice’s brother lives in Botswana, but he uses his vacation to care for his mother so his sister can take vacation with her husband. This is the only time of the year she is able to leave her home for more than a few hours at a time.

Although she has regular in-home paid supports, Janice has found that this care is not always reliable. “I have a very supportive supervisor who allows flexibility in my schedule. However, I constantly worry whether my help will show up. I have to get behind them constantly. You have to have a back-up.”

“Training is inconsistent, and some aides are good, some are not. Planning for weekends and holidays needs to be begin well in advance, and even then this care is unreliable – calls to the agencies and supervisors are not always helpful.”

Because she works near her home and has an understanding employer Janice is able to come at lunchtime to visit and feed her mother. ✂

and expertise with child and elder care. This database is available to the public via the website [www.familyandworkplace.org](http://www.familyandworkplace.org). Currently, there are nearly 100 providers listed on the site and over 200 searches were completed using the site as of September 2007.

## **Public Comment**

The draft of the *Delaware Lifespan Respite Information Network* was presented to the public via two public meetings and disseminated widely through members of the Commission, the University of Delaware, and the disability community. The public meetings were held at the Center for Disabilities Studies offices in Newark and at The Arc of Delaware Mid-Del office in Dover. Comments were taken at the meetings, and through the mail, e-mail and telephone.

The meetings attracted parents, professionals, and people with disabilities. The November 6<sup>th</sup> meeting held at The Arc of Delaware attracted five professionals, five family members, and one person with a disability. The meeting at the Center for Disabilities Studies attracted four professionals, one parent and one person with a disability. In addition, four comments were received by email and four by telephone.

Comments were generally supportive of the draft *Delaware Lifespan Respite Information Network* proposal, with particular emphasis on the need for a centralized system with an increased number of providers, particularly providers who will come to a client's home.

One caregiver spoke about the financial implications of respite care for her child. "Surely it would be more cost-effective to provide respite care for our disabled loved ones than it would be for the State to burden the cost of caring for an entire family. My son intends to stay with me even after he transitions into the work force. I would love to be able to care for him as long as I am able to. His disability should not be a life sentence of poverty for us."

The comments and suggestions were included in the final version of the *Delaware Lifespan Respite Information Network* proposal.

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

Several organizations in Delaware have examined the issue of respite care services within the past three years. They include the Delaware Caregivers Support Coalition, the Delaware chapter of the American Association of Retired Persons (AARP), and the Center for Disabilities Studies at the University of Delaware. Each of these organizations conducted policy analysis and surveys of families. All organizations found that, while there are some good sources of respite support in the state, there is a need for expanded respite services, a centralized database, and a way to link respite providers to caregivers in need of services. Other findings from these groups include the following:

- Approximately 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).

While there are a number of excellent respite providers in the state, and families develop networks of neighbors, friends and volunteers who provide informal caregiving, the need is far greater than is currently being met. A study of caregivers by the Delaware Regional Office of the Alzheimer’s Association identified the number one need as “affordable and reliable respite care, especially overnight and weekend” (Kingsberry, 2007).

The *Delaware Health Status Report for Adults with Disabilities*, published in 2007, reports that nearly 40% of the 66 caregivers surveyed reported the number one challenge was having time for themselves, followed by financial burdens.

Key concerns for caregivers in Delaware from these reports include:

- a lack of information about available respite services,
- the need for a centralized source of information about all respite services in the state,
- an inadequate supply of respite services,
- concerns about the quality and safety of the respite care available, and
- a lack of resources to fund respite care.

### ***Personal Experience with Respite***

#### *Vicky Marino and her brother Philip*

Vicky Marino’s younger brother Philip spent most of his life in a 65-bed facility for people with disabilities. When rising costs made it difficult for him to stay, Philip left the institution and moved in with his sister. Over the years Vicky has made her house accessible so that Philip could spend weekends and holidays with her, and she welcomed him moving into her home.

Although they have neighbors they could call on in an emergency, Vicky and Philip have no immediate family to help with their respite needs. If Vicky needs to be absent from the home for an extended period of time, Philip can stay at the institution he left, but otherwise it is difficult for her to be away for even short periods of time. Philip is involved in many activities in the community, and his sister supports his activities. They share concerns about the lack of emergency, long-term respite supports. ✕

## **Funding constraints**

The funds for respite supports are limited and services are fragmented, inadequate and uncoordinated. Despite the availability of respite services in Delaware, including volunteer respite care, the lack of a centralized, organized delivery system makes it difficult for individuals with disabilities and their families to access needed services. High out-of-pocket costs and complicated application processes, as well as the possibility of failing to meet criteria to receive services, discourage already stressed caregivers. A significant barrier is the lack of information about respite as a support service at all. For providers, a lack of funding and the difficulty of collecting fees present a significant deterrent to providing these services.

## **Lack of respite service providers**

A common thread in the surveys, focus groups, and literature on respite care is the insufficient number of competent respite care providers. In some cases, agencies do not share information about respite because the shortage of providers prevents them from helping families take advantage of respite allowed by policy. Respite care is similar to child care as it is generally low-paid and undervalued by funding agencies. It is difficult to find individuals who are willing to do this work for little compensation provided, and families are sometimes uncomfortable with a lack of quality services. When trained medical care is needed to serve children with complex medical, behavioral, or emotional needs, it is even more difficult to find a provider with the training necessary to provide appropriate care (Dougherty, 2001).

## **Family Supports and Respite Care**

Respite care is best delivered within a network of family supports where respite is one of an array of options families may choose to meet their needs. Family supports are flexible, individualized, and designed to meet diverse needs (*Family Support, 2006*). Respite is the family support service most frequently requested by family caregivers to help them continue to provide care at home. Respite has also been shown to be cost-effective. The Met-Life Caregiver Study estimates that U.S. businesses lose between \$11 and \$30 billion per year due to caregiving duties by employees. Respite has proven to help reduce or delay more costly out-of-home placements, improve the health and well-being of the caregiver, prevent abuse or neglect, and help sustain marriages (MetLife, 1999).

Family support programs make use of structured services and supports, as well as informal or natural supports to ensure that people with disabilities can live as much like other families as possible. The supports that a family receives should be determined based on that family's culture, values, preferences, and specific needs at any given time. Providing useful support can involve any number or types of services and/or support. These supports might be aimed not only at the person with a disability, but at other family members as well. As previously stated, respite care is an important aspect of family stability.



### ***Personal Experience with Respite***

*Nicole Maynard and her granddaughters*

“The summer is *long* for a grandparent,” stated Nicole Maynard. She is caring for two grandchildren, a six-year-old and a 12-year-old, one of whom has a learning disability. Nicole’s daughter has had problems with drug addiction and has very little contact with her family. The children’s fathers are also not in a position to contribute to their care.

Like many grandparents caring for their grandchildren, Nicole Maynard is on a fixed income and was not prepared for this caregiving challenge. Through her experiences, Nicole has become an advocate for grandparents’ rights and started a support group for other grandparents. “We are raising the next generation. You make so many choices and hope they are right.”

About her need for respite and other family supports, Nicole said, “It’s often that I’m tired and they’re still rarin’ to go. It is hard for me to keep up, so I need all the help I can get, but it is just as hard to ask for help *and* to know if any help exists.” ✨

Upon completion of a review of the research, the DCSC concluded that any statewide system should provide *centralized* access to *comprehensive lifespan* respite services that are *easy to access* and provide supports for individuals with *all types of disabilities, chronic health concerns, and aging needs*. Respite care should be one of many options provided in the family support service system.

### **Current programs in Delaware**

There are a number of respite programs currently offered in Delaware. The Division of Developmental Disabilities Services provides respite care to a significant portion of its 3000 clients who still live at home or in the community; the Delaware Autism Program provides respite care statewide for families who have children in the program; the Division of Services for Aging and Adults with Physical Disabilities has respite programs that serve groups stipulated by the Older Americans Act; and there are other state agencies that have some limited respite offerings for qualified families. Finally, there are private providers who offer respite care on a private pay basis or when it is covered by health insurance.

Programs are targeted at a specific population, limited by diagnosis or age, and/or are not widely publicized because of lack of providers and limited funding. The systems are difficult to navigate and families who want to hire their own providers often cannot find them. The draft *Delaware Lifespan Respite Information Network* was created to address this fragmentation of available resources by giving families direct access to respite services.

### **Cost of Caregiving**

The lack of services to support caregivers and families costs employers, families, and society a great deal. A recent report from MetLife and the National Alliance for Caregiving estimates productivity losses to businesses related to absenteeism, care crises, work interruptions, unpaid leave and other work interruptions related to caring for an individual as more than 17 billion dollars a year (MetLife, 2006). The same report suggests programs to provide respite care for caregivers as a tool to reduce these costs.

## Key Findings from Met Life Study

- The total estimated cost to employers for full-time employees with intense caregiving responsibilities is \$17.1 billion.
- The average cost per employee for those with intense caregiving responsibilities is \$2,441.
- The total estimated cost to employers for all full-time, employed caregivers is \$33.6 billion.
- The average cost per employee for all fulltime, employed caregivers is \$2,110 (MetLife 2006).

The AARP Public Policy Institute found the contributions of unpaid caregivers “not only the foundation of the nation’s long-term care system, but an important component of the U.S. economy, with an estimated economic value of about \$350 billion in 2006.” In Delaware, the economic value is estimated at over one million dollars (Feinberg, AARP). “Public policies to alleviate stress on caregivers” and their employers “could be implemented at a small fraction of the value of their contributions,” the report concludes.

Caregivers are themselves in need of care and support. Caregivers who receive supports that reduce their stress, such as respite care, are able to delay or avoid institutionalizing their loved one. Caregivers are a higher risk for stress-related health concerns such as high blood pressure, heart problems and depression. Many cannot find time for preventive health care (Family Caregiving Alliance, 2006).

While saving the government funds, caregivers’ responsibilities often interfere with their working lives, which in turn compromises the care they are able to give. Among those with the heaviest caregiving responsibilities, 92 percent report major changes in working patterns. The AARP in a survey conducted with the National Alliance for Caregiving found that 83 percent arrive late, leave early or take time off during the day; 37 percent go from full-time to part-time; and 41 percent take a leave of absence.

Many caregivers have either quit work or reduced their hours to care for a family member. Caregivers and employers are often not aware of the availability of respite services, and may not be aware of how much they need it, until someone offers. A major role of the *Delaware Lifespan Respite Information Network* will be raising awareness for both the need for respite and for the services offered by the State Network.

## Public Policy and Legislative Responses

There is an increasing recognition of the role for the public sector in supporting and sustaining caregivers. In the absence of federal legislation, state policy makers have been trendsetters in identifying and implementing successful strategies to help families. Several states have developed Lifespan Respite Programs. These programs are defined as “a coordinated accessible, community-based system of respite services for family caregivers and individuals regardless of age, race, ethnicity, or disability or need” (MetLife, 1999).

The first state respite programs, along with the movement towards family oriented supports, began in the 1970s (Silberberg, 2001). These supports were often grassroots organizations funded by grants and other private funds. In the 1990s several states enacted Lifespan Respite programs, and many more have developed centralized Respite Care Networks with private funds and effort. The National Lifespan Respite Care Act of 2006 (Public Law 109-442) was signed into law by President George W. Bush on December 21, 2006. The law had universal support, passing unanimously in both the Senate and the House of Representatives, but has yet to be funded.

## **Descriptions of Other State Networks**

A recent report by the Arch National Respite Center concluded after studying four established state systems (Nebraska, Oregon, Oklahoma and Wisconsin) that these systems:

- are welcomed by state and local agencies and improve access to services by previously underserved populations,
- save states money by reducing administrative costs and duplication of services,
- benefit all families through a centralized information and referral service,
- encompass collaborative efforts that allow states to maximize existing services and leverage new funds from a variety of sources,
- are more able to respond to specific shortages and gaps, and
- can address a critical shortage of respite care providers (Baker, 2004).

Below are brief summaries of respite care programs in other states. Oregon, Nebraska, Wisconsin, and Oklahoma developed their programs through legislation. A number of other states have developed centralized respite networks without legislation, including Michigan (which passed but never implemented a Lifespan Respite Act), Florida, and New Jersey. Respite is often offered within a larger system of family supports, of which respite is one of multiple options for services.

### ***Personal Experience with Respite***

*Doreen Marks and Richard Marks*

Doreen's now 16-year old son Richard was diagnosed with developmental disabilities as an infant. At age four he was diagnosed with autism when he suddenly lost his verbal abilities. His behavior challenges his mother, and he requires constant attention. Although significant progress has been made through the efforts of his parents and the Delaware Autism Program, his needs have often strained the family's bonds.

Doreen was financially able to quit her job to care for Richard. In the process of advocating for her family's needs, she has become a champion for respite care. The Marks live in a semi-rural area, and finding respite care can be a challenge. She is lucky to have neighbors with teenage children who include Richard in some of their activities.

She finds the stress of caregiving on the family often goes unmentioned. "The stress on the spouse, who is not the primary caregiver, shouldn't be ignored. You get tired of hearing no. Families need supported to be able to care for their children." ✨

## **Oregon**

In 1997, Oregon was the first state to pass Lifespan Respite legislation and implement a Lifespan Respite Program. The Oregon Lifespan Respite Program, funded through the state general fund, is administered by a State agency, the Oregon Department of Human Services. Funding is distributed through contracts to local sponsoring agencies or local networks in order to maintain their infrastructure. Although there are 36 counties in Oregon, some counties were consolidated, leaving 28 contractors or local networks. Each local network has an advisory committee made up of community partners and consumers. Local networks have their own registries of providers and often share recruitment and training activities with other programs such as Medicaid (Baker, 2004).

## **Nebraska**

The Nebraska Lifespan Respite Program, *Respite Subsidy Plan Across the Lifespan*, was created by legislation in 1999 and is administered by Health and Human Services (HHS). The program has been called a “model respite care system” by the National Center for State Legislatures. Funding for the state program and the respite subsidy component for caregivers who do not have access to other funding comes from tobacco settlement funds. The purpose of the Nebraska program is to establish a statewide system for the coordination of respite resources that serve the lifespan. Contracts are in place between HHS and six local entities (networks), one in each region, which are responsible for information and referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public’s awareness of respite, coordinating training opportunities for providers and consumers, and quality assurance and program evaluation. The subsidy program is administered through the state’s Health and Human Services Central Office (Baker, 2004).

## **Wisconsin**

In 1999, Wisconsin became the third state in the nation to adopt Lifespan Respite Care legislation. The legislation authorized the Wisconsin Department of Health and Family Services (DHFS) to contract with the Respite Care Association of Wisconsin (RCAW) to administer the program. Funding to support the program comes from state general funds. A portion of the funds are used by the RCAW to provide information and referral, maintain a website, provide training and technical assistance, conduct outcome-based evaluation, and manage grants. The remaining funds are distributed to Lifespan Respite Networks in five counties. The “networks” are community-based respite programs, typically housed in a larger provider agency. The networks are strongly collaborative and are required to provide services across the lifespan and range of disabilities (Baker, 2004).

## **Oklahoma**

The Oklahoma Respite Resource Network (ORRN) began offering statewide respite services in 2000. ORRN is a statewide partnership of public and private agencies whose goal is to support families and caregivers by increasing the availability of respite care. State agencies, including developmental disabilities, mental health, aging, maternal and child health and others, have come

together voluntarily with private agencies and foundations to pool resources through three-year contracts for respite. Funds are disbursed to family caregivers through voucher program managed by OASIS, the statewide information and referral agency (Baker, 2004).

### **New Jersey**

The New Jersey Statewide Respite Program was started in 1988 and is administered through the New Jersey Office of Health and Senior Services, Division of Senior Affairs. The state uses casino revenues and Medicaid funds to support a \$5.75 million respite program. Although administered by county offices of the New Jersey Health and Senior Services Department, respite is not limited to the elderly, but is provided to families and caregivers of any adult with physical or mental disabilities. The program's goals are to assist families in need of routine and crisis respite care and to help families avoid unnecessary or premature institutionalization of the person needing care. New Jersey's program also provides caregiver education and training, and funds educational courses, in-home training, and caregiver skills training (National MS Society).

### **Florida**

The Florida Respite Coalition is a nonprofit organization formed in the fall of 1997 to address the needs of families in the state for respite care. During its first four years the Coalition expanded its base to 300 members; it contracted with the Department of Children and Families in 2001 to develop a statewide lifespan community-based respite care system. The mission of the Coalition is to "ensure that each caregiver in need of respite will have access to available, affordable, and quality respite care services." The Florida Respite Coalition has a centralized information and referral website, and is actively involved in advocating for lifespan respite legislation at the state and national level. One of their stated goals is to build capacity and support providers of respite care (<http://www.floridarespite.org/>).

## **Recommendations from the Coalition**

The DCSC identified three key recommendations that are included in the *Delaware Lifespan Respite Information Network*. First, the need for a **centralized information and referral source is critical**; without it families will continue to flounder and miss valuable services available to them. Second, without a **major outreach and awareness campaign** families in need of respite care services will not get them. Families often feel isolated and ashamed of feeling overwhelmed; they need to know that they are not alone and help is available. Finally, the Coalition feels that **developing and training competent respite care providers** is vital and that the Network must work with other organizations in the state to develop this pool. These recommendations are included in the *Delaware Lifespan Respite Information Network* described in detail in Appendix A.

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## **Appendix A**

### **Delaware Lifespan Respite Information Network Proposal**

**Mission: To assure that people with disabilities and their families will have easy access to quality, affordable respite care.**

The proposed Delaware plan addresses the most pressing needs of caregivers in the state, including the:

- lack of information about respite care;
- lack of qualified, dependable providers of respite care;
- difficulty accessing available funds; and
- shortage of funds for respite care.

The *Delaware Lifespan Respite Information Network* will be a 24-hour service delivery system dedicated to helping people identify and secure the appropriate form of respite care from the broad spectrum of options available. Caregivers will be able to make arrangements through system support staff or directly with respite care providers. They will make their own choices from a range of options regardless of disability type or financial status. These options could include such choices as: selecting long-term or short-term; in-home or in a center; certified nurses, trained family friends, or anything in between. The system will recognize the value of respite care providers and support staff by providing training and supports to assure a qualified pool of respite options. The cornerstone of the Network will be the respite provider database website currently being developed by The Family and Workplace Connection.

Administration of the system will be through a central office. The major functions of the system are:

- **Information and Referral (I&R)** – The website and database currently run by Family and Workplace Connection is the centerpiece of the I&R function. In addition to this database, the system will have trained personnel/counselors to assist caregivers with appropriate information about providers and funding sources.
- **Caregiver Training and Support** – Giving families the tools to make decisions about appropriate respite care, and helping families find appropriate funding sources is integral to the system. Training for people with disabilities, mentors, and volunteers will also be targeted.
- **Public Relations and Advocacy**– Raising awareness of respite care among the general public, families needing care, potential providers, and lawmakers and other influential persons in the state is a primary function. The *Delaware Lifespan Respite Information Network* and its board will actively advocate for more support and resources for respite and family support.
- **Provider Services** - Increasing the pool of agencies, organizations and individuals who provide respite care across all ages/disabilities and providing training, and technical assistance as needed to improve the quality of care will allow services to be provided.



- **Administration** – This function includes coordinating traditional administrative functions such as planning, program evaluation, quality assurance, budget and finance and recordkeeping.

## **Operational Plan**

After careful consideration of the available funding options, including state general funds, Medicaid funds and federal funds from the National Lifespan Respite Care Act, the Coalition decided that initially the *Delaware Lifespan Respite Information Network* should be contracted through an existing non-profit agency. The urgency and depth of the need requires an immediate solution, which makes private fund-raising the most expedient way to obtain funding at this time. Ongoing efforts to influence state legislation and policies that recognize the value of family supports, including respite care, will not be limited by this grass-roots effort, and may in fact prove to be more persuasive by providing an existing program to the state.

### *Board of Directors*

The Board of Directors will be representative of all stakeholders, and geographically and culturally inclusive. The board will consist of no more than 15 members, with an even distribution of family members and consumers of respite care, local non-profit agencies and providers, and state agencies. The board should have some representation from major corporate interests in the state. In addition, a member of the *Delaware Lifespan Respite Information Network* board will be on the board of the host agency.

### *Central Administrative Office*

The need for respite care is diverse and represents every age, ethnic group and income. Providers of respite care can be friends, neighbors, other family members, volunteers or paid professionals. Respite needs differ among geographic areas, cultures and disabilities or special needs. Existing programs are dispersed throughout the community. The coalition recognizes the inherent interconnectedness of respite as only one aspect of family support. In order to fully take advantage of this synergy, the *Delaware Lifespan Respite Information Network* will be contracted through a private, non-profit organization selected by the Board of Directors. Housing the network in an existing agency will provide the most efficient and effective service to families in Delaware. The *Delaware Lifespan Respite Information Network* will gather and disseminate information as it serves as a resource for families, agencies and providers, rather than replace existing systems. The central administrative unit will be responsible for oversight of the five functions as discussed earlier, although some of these functions could be delivered by subcontracting with other agencies. Services provided by the *Delaware Lifespan Respite Information Network* will not duplicate services that already exist, but build on existing organizations and expertise.

### *Staffing*

The central office will be staffed by a project director, outreach worker and clerical staff person. The project director will oversee planning, policy development, implementation of operational

plans, and monitoring of contracts and quality of the system. The outreach worker will work with community-based groups to help with public awareness of the system, recruitment of providers, advocacy, and funding initiatives. The clerical staff person will support the central office with all clerical and administrative duties.

The functions of information and referral and public relations will be contracted to outside vendors. The scope of service provision will be detailed in service contracts. Every effort will be made to coordinate the work of the central administrative office and that of contractors so that duplication is avoided, and efforts are streamlined and effective.

### *Focus of Activities*

The first year of operation will be focused primarily on developing the system and will include hiring staff, setting up the office, developing policies and procedures, and contracting with vendors. There will also be a strong emphasis on community outreach to service providers and caregivers to raise awareness. It is anticipated that actual information and referral services, in addition to the currently operating website at The Family and Workplace Connection, would be operational by mid-year, and would be provided from 8 a.m. to 5 p.m. for non-emergency care.

The second year will begin a focus on building capacity by developing systems to recruit and support respite care providers primarily in the areas of typical respite and drop-in respite. Data from use of the respite website and other requests for respite services will be used to identify areas of most need for respite (kind, geographic area, etc.). Information and referral will continue to be provided from 8 a.m. to 5 p.m. for non-emergency respite.

In the third year, the focus will be on developing capacity and processes to respond to emergency respite care needs, and will transition to a 24-hour system. Also, all aspects of financing respite care will be explored, including Medicaid, vouchers, and private pay. A mentoring system of volunteers will also be developed to guide families through the system and provide links to existing volunteer pools who currently provide respite care or would like to be trained to provide in-home respite care.

### **Funding**

*Administrative System:* Operational aspects of a statewide system can be supported through a variety of funding streams. During the start-up phase, possible sources are local foundations and corporate contributions. On an ongoing basis, support may include money from the DHSS, Federal Lifespan Respite Care Act and Delaware's Health Fund (tobacco funds). A small contribution from state agencies currently providing respite care could be solicited to supplement and support their efforts.

*Payment for Respite Care:* Currently, a variety of state and non-profit associations provide support for respite, including Delaware's Division of Developmental Disabilities Services, various organizations that support services for people with autism, and disability specific organizations such as the Delaware Chapter of the National Multiple Sclerosis Society. The system could also accommodate those who are interested only in information and can purchase

respite as self-pay. Efforts would need to be made to identify other ongoing sources. Most states that currently have statewide respite systems depend heavily on Medicaid as a source of funding.

### *Sustainability of the System*

In 2007, the federal Lifespan Respite Act (P.L. 109-442) was passed (for a copy of the act see <http://www.archrespite.org/PublicLaw.pdf>). As passed, the act authorized grants totaling \$289 million for fiscal years 2007-2011. However, a financial appropriation was never passed to support the law and subsequent efforts have not been successful.

Future funding for the act would provide proportional support to each state to develop statewide systems of respite care and other respite care activities, such as training and recruiting respite workers, providing information to caregivers, and assisting caregivers in gaining access to such services. States with an established respite network will be the earliest recipients of these funds. With a functioning network in place, the state of Delaware will be much more likely to receive these funds than states that have not take this action.

In the meantime, the DCSC is seeking private funds from foundations and corporations to help in the development of the administrative structure over a three-year period. During this time, the DCSC expects to work with key state agencies/stakeholders to win their support for appropriating a portion of their Division budgets toward ongoing funding for this activity. These agencies include the Department of Education; Department of Children, Youth, and Families; and Department of Health and Social Services, including the Divisions of Developmental Disabilities Services, Aging and Adults with Physical Disabilities, and Substance Abuse and Mental Health. Some of these agencies already allocate funding toward respite activities.

Medicaid is the primary source envisioned for ongoing payment for respite care services. In other states that have developed statewide systems, Medicaid is their primary funding source. Concerted advocacy will be required to assure the inclusion of respite services as part of the current Medicaid Waiver system and to assure that respite is included in state policies for use of money through the “Money Follows the Person” initiative.

If state agencies commit to funding the administrative structure required to coordinate services, and if Medicaid money is made more widely available for use in paying for actual care, an ongoing system that provides a centralized source of quality care that is affordable to caregivers is assured.

### *Budget*

A three-year budget can be found in Appendix D. It reflects changing priorities and increasing capacity for providing services over this time period.

Compensation: As described in the operational plan, the system would be staffed by three positions. The total FTE’s would increase to reflect increases in service as follows: Year 1 = .7 FTE; Year 2 = .95 FTE; and Year 3 = 1.3 FTE.

Consultants/Contractors: Two functions that would be provided through contracts are Information & Referral (I&R) and Public Relations (PR). I&R would include maintenance of a database of respite service providers as well as several methods for obtaining information (online information, phone consultation). In addition, this point of contact would be responsible for providing consumer information so that individuals can make informed choices when looking for services.

Public Relations would include development of a message and materials to promote understanding and awareness of respite need and services for consumers, providers and the general public.

Indirect Costs: Indirect costs include items such as liability insurance and support services such as Human Resources and Financial Services.

Other lines:

Other lines are budgeted at a constant rate except for first year start up (equipment, etc.).

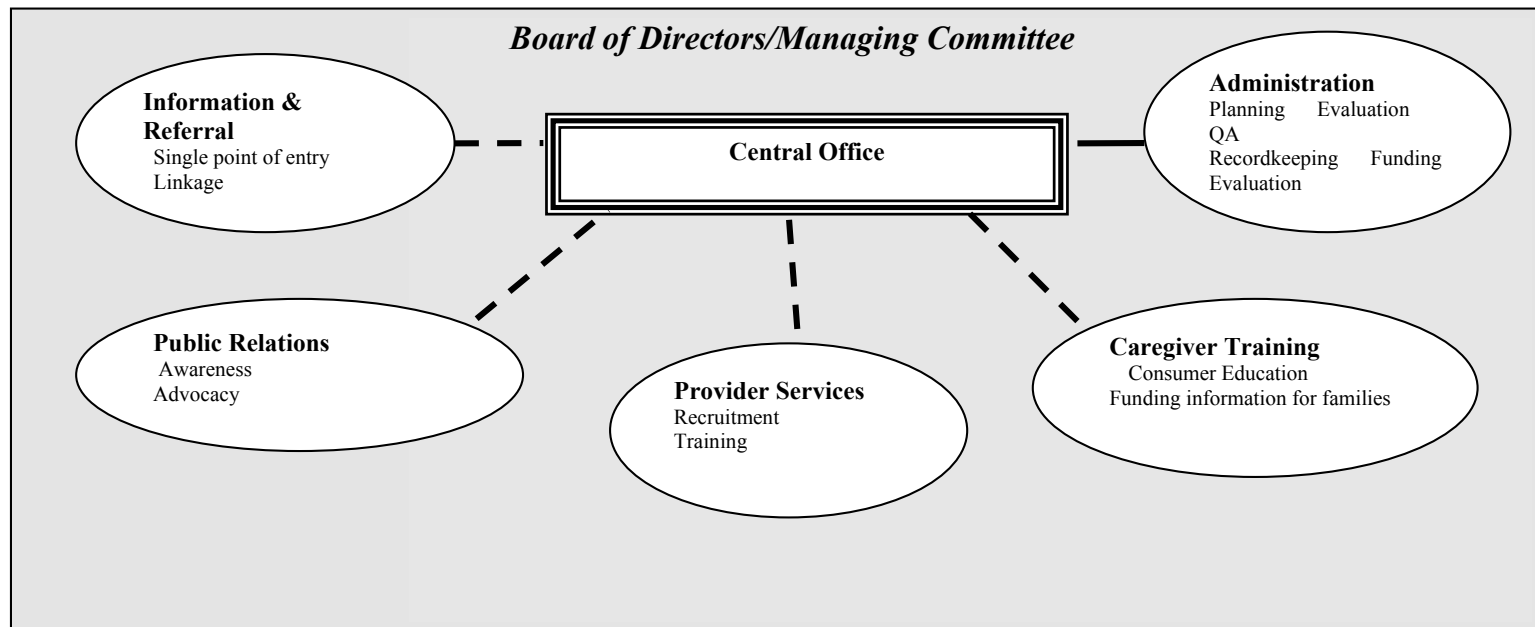
**Appendix B**  
**Delaware Caregivers Support Coalition/Respite Care Members**  
**\*Respite Care Plan Development Task Force**

Name	Organization
Carol Barnett	Division of Services for Aging and Adults with Physical Disabilities/Family Member
Lisa Becker *	Center for Disabilities Studies
Don Bilyew	Chimes
Tim Brooks *	Center for Disabilities Studies
Peter Doehring	Christiana School District
Theda Ellis	Autism Society of Delaware
Kathy Goldsmith	Delaware Department of Education
Carla Guzzie	Parent
Robert Hall	Delaware Ecumenical Council
Helen Diskau	Department of Health and Social Services/Division of Developmental Disabilities Services
Kathy Hyde *	Family & Workplace Connection
Roy Lafontaine	Division of Developmental Disabilities Services
Lora Lewis	Dept. of Public Health
Tracy Mann	Center for Disabilities Studies
Meghan Morgan *	Division of Developmental Disabilities Services
Penny Orndorff *	Division of Developmental Disabilities Services
Ann Phillips	Center for Disabilities Studies/Parent
Angie Sipple	Parent/Lower Delaware Autism Foundation
Barbara Snyder *	Easter Seals
Ginger Stein *	National Multiple Sclerosis Society
Donna Stowell	Elwyn, Inc.
Allan Zaback	Division of Services for Aging and Adults with Physical Disabilities

## Appendix C Delaware Lifespan Respite Information Network Structure

*Mission*

To assure that children and adults with disabilities or special needs and their caregivers will have easy access to quality, affordable respite care.



The Delaware Lifespan Respite Information Network will consist of a Central Administrative Office that oversees five major functions. Four of these function, Public Relations, Information and Referral, Provider Services and Caregiver Training could be subcontracted – indicated by dotted lines in the diagram. Major administrative functions such as recordkeeping, quality assurance, funding and evaluation, are performed directly by the Central Administration unit. The entire network will be overseen by a Board of Directors/Managing Committee with representatives from all stakeholders and impacted groups.

**Appendix D**  
**Delaware Lifespan Respite Information Network Budget**

	Year 1	Year 2	Year 3	Total
<b>REVENUE</b>				
Fees for Service	\$ -	\$ 10,000	\$ 30,000	
State and Federal Contracts	\$ -	\$ 50,000	\$ 50,000	
Fundraising	\$ 140,659	\$ 101,888	\$ 125,142	\$ 367,689
<b>TOTAL</b>	<b>\$ 140,659</b>	<b>\$ 161,888</b>	<b>\$ 205,142</b>	<b>\$ 507,689</b>
<b>EXPENSES</b>				
<b>Compensation</b>				
<b>Salaries</b>				
Project Director \$50,000	25% \$ 12,500	25% \$ 12,875	25% \$ 13,261	
Outreach Worker \$35,000	50% \$ 17,500	50% \$ 18,025	75% \$ 27,578	
Clerical \$25,000	25% \$ 6,250	25% \$ 6,438	25% \$ 13,068	
Total	\$ 36,250	\$ 37,338	\$ 53,908	
<b>Benefit Package</b>	25% \$ 9,063	\$ 9,334	\$ 13,477	
<b>Total Compensation</b>	<b>\$ 45,313</b>	<b>\$ 46,672</b>	<b>\$ 67,385</b>	
<b>Other Expenses</b>				
<b>Outside Consultants/Contracts</b>				
Information & Referral	\$ 17,000	\$ 25,000	\$ 26,000	
Public Relations/Marketing	\$ 2,000	\$ 2,000	\$ 2,000	
Sub-Total Consultants	<b>\$ 19,000</b>	<b>\$ 27,000</b>	<b>\$ 28,000</b>	
<b>Marketing Efforts</b>				
Production Costs & advertising	\$ 10,000	\$ 10,000	\$ 10,000	
<b>Training</b>	\$ 10,000	\$ 10,000	\$ 10,000	
<b>Travel</b> (5,000 @\$.40/mi)	\$ 2,000	\$ 2,000	\$ 2,000	
<b>Equipment</b>	\$ 3,000	\$ 1,000	\$ 1,000	
<b>Occupancy</b>	\$ 3,000	\$ 3,500	\$ 4,000	
<b>Other Direct Costs</b>				
Phone	\$ 1,500	\$ 1,800	\$ 2,000	
Postage	\$ 1,500	\$ 1,800	\$ 2,000	
Supplies	\$ 2,000	\$ 2,000	\$ 2,000	
Total	\$ 5,000	\$ 5,600	\$ 6,000	
<b>Vouchers for Respite Care</b>	<b>\$ 25,000</b>	<b>\$ 35,000</b>	<b>\$ 50,000</b>	\$ 110,000
<b>TOTAL DIRECT COSTS</b>	<b>\$ 122,313</b>	<b>\$ 140,772</b>	<b>\$ 178,385</b>	
<b>INDIRECT COSTS (15%)</b>	<b>\$ 18,347</b>	<b>\$ 21,116</b>	<b>\$ 26,758</b>	
<b>GRAND TOTAL</b>	<b>\$ 140,659</b>	<b>\$ 161,888</b>	<b>\$ 205,142</b>	<b>\$ 507,689</b>