

Acknowledgements

The Coordinating Council for Children with Disabilities thanks all those who supported the symposium, especially A.I. duPont Hospital for Children. Their efforts on behalf of the symposium were invaluable.

The Council also thanks the planning committee for the symposium and representatives from Easter Seals of Delmarva, the Delaware Division of Public Health, the University of Delaware Center for Disabilities Studies, and the Delaware Chapter of AARP.

The Coordinating Council for Children with Disabilities invites all symposium attendees as well as the families with persons with disabilities and the general public to share suggestions about Delaware's respite resources with the Council.

References

- ¹ National Alliance for Caregiving and the AARP. (2004). Caregiving in the U.S. Washington, DC: NAC & AARP.
- ² Center for Disabilities Studies. (2005) Delaware Caregivers Coalition Report. Newark, DE.
- ³ Schultz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. The Journal of the American Medical Association, 282(23), 2215-2219.
- ⁴ Oklahoma Department of Health. (2000). Maternal and Child Health Block Grant Annual Report. Oklahoma City, OK.
- ⁵ Abelson, A. G. (1999). "Economic consequences and lack of respite care," Psychological Reports, 85(3), 880-882.

The Coordinating Council For
Children With Disabilities
c/o Genetics
A.I. duPont Hospital for
Children
1600 Rockland Rd
Wilmington, DE 19803

Get Involved

To share your ideas about respite care with the Council, contact Tim Brooks at 302-831-4612 or tbrooks@udel.edu.

Respite Care in Delaware

A Report from the Coordinating Council For Children with Disabilities

June 2006

Dear Friends,

Last fall the Coordinating Council for Children with Disabilities held a conference on "Exploring Respite Care in Delaware" at the A.I. duPont Hospital for Children. The conference covered a number of topics including: caregiver concerns, caregiver stress, the Nebraska Lifespan Respite care Act and the current state of respite care in Delaware.

Dennis Byars, a senator from Nebraska, gave the keynote address on how his state developed a centralized, comprehensive plan for the delivery of lifespan respite services. The Nebraska plan could be a model for other states including Delaware. Currently Delaware has a variety of excellent respite programs but they are not always well coordinated and families sometimes have a difficult time accessing appropriate care. The attached document is a summary of sessions that were held during the conference. Since the conference, the Coordinating Council for Children with Disabilities and the Center for Disabilities Studies (CDS) at the University of Delaware have continued to examine ways to improve respite care in Delaware. Recently, the Commission for Community-Based Alternatives for Individuals with Disabilities awarded a significant grant to the CDS for the development of a draft of a centralized plan for the delivery of respite care in the state. CDS will work with the Delaware Caregivers Support Coalition to develop this draft plan for distribution throughout the state.

The Coordinating Council for Children with Disabilities thanks all of the attendees at the fall conference and looks forward to continuing its efforts to find ways to improve upon the current delivery system of lifespan respite care in the state.

Sincerely,



Louis E. Bartoshesky, MD. MPH
Chair, Coordinating Council for Children with Disabilities

Conference Information

Exploring Respite Care in
Delaware: A Symposium

October 7, 2005

Alfred I. duPont Hospital
for Children

Conference sponsored by:

The Coordinating Council for
Children with Disabilities

A.I. duPont Hospital for
Children

Exploring Respite Care in Delaware

On October 7, 2005, the Coordinating Council for Children with Disabilities (CCCD) sponsored a symposium about respite care titled, "Exploring Respite Care in Delaware." The purpose of this day long conference was to share the current state of respite care in Delaware and to begin to plan for improvements to the respite care network. The symposium was planned, organized and sponsored by the CCCD with significant support from A.I duPont Hospital for Children. The symposium was held at A.I. duPont for Children with approximately 95 individuals in attendance. Participants included state legislators, agency and program representatives from organizations providing services to persons with disabilities, physicians and health care providers, family members, and policymakers.

The symposium speakers included the following distinguished presenters:

Dr. Lou Bartoshesky from A.I. duPont Hospital for Children, who lead the organization for the symposium and introduced the day's events;

Dr. Steven Bachrach from A.I. duPont Hospital for Children, who discussed caregiver stress;

Dr. Tim Brooks from the Center for Disabilities Studies at the University of Delaware, who discussed the current state of respite care in Delaware; and

Senator Dennis Byars of Nebraska who presented the keynote address about Nebraska's approach to lifespan respite care.

In addition to the four speakers above, a panel of five parents of children with disabilities shared their experiences with the respite care system in Delaware. The panel included: **Sharri Cuffee, Cheryl Kelly, Brenda Kramer, Ann Phillips** and **Cynthia Slater**.

Symposium Topics

The speakers at the symposium covered a wide range of topics, including: the current status of respite in Delaware, caregiver concerns about respite, caregiver stress, and the structure and funding of a lifespan respite network.

Goal of the Symposium

The CCCD decided to hold this symposium because of the concerns that family members, physicians, and providers have communicated about the lack of respite services and supports throughout Delaware. The CCCD established a number of goals for the symposium:

- 1) to present to a group of advocates and policymakers, the current state of respite services in Delaware;
- 2) to form a coalition of advocates and organizations interested in creating a comprehensive and centralized approach to the delivery of respite care services in Delaware; and
- 3) to assist in creating a lifespan respite care program in Delaware that will provide affordable, safe and reliable respite care to all caregivers of persons with disabilities and/or chronic health care needs.

Nebraska Survey Results *(continued from previous page)*

Senator Byars also reported on the evaluation of the Nebraska Lifespan Respite Care System after one year of implementation. The evaluation was conducted by the Munroe-Meyer Institute of the University of Nebraska Medical Center. A total of 163 caregivers and families were surveyed. The finding included the following:

- families indicated that respite services delayed the need for out of home residential placements, therefore reducing costs to the state,
- caregivers reported that access to respite services reduced their stress and feelings of isolation,
- caregivers reported that having respite services available helped to improve their relationships with spouses and other family members, and
- 58% of caregivers from families with children under the age of 21 and 65% of family members over the age of 21 reported decreased isolation once respite services were available.

Recommendations & Next Steps

Based on the information presented at the symposium as well as the studies and reports conducted by the Delaware Chapter of the AARP, Easter Seals of Delmarva, and the University of Delaware Center for Disabilities Studies, the Coordinating Council for Children with Disabilities will support the development of a comprehensive, statewide approach to providing respite care services for families with members with disabilities, chronic health needs, and terminal illnesses. The Council will take the following action steps over the next 18 months:

- remind the legislature and governmental officials that the provision of respite care reduces the need for out of home placements which cost significantly more than in home supports;
- endorse the design and implementation of a statewide pilot program for the delivery of respite services with the goal of the pilot being a model for a centralized respite system;
- support efforts to develop Lifespan Respite Care legislation in Delaware, if appropriate, using the Nebraska system as a model;
- educate legislators on the benefits of a single point of entry, and a centralized, statewide system of respite care; and
- work with the Governor's Commission on Community-Based Alternatives for Persons with Disabilities to bring the issue of respite care to the attention of state officials and urge them to make appropriate changes.

Caregiver Stress

Dr. Steven Bachrach, Director of the Cerebral Palsy Clinic at the A. I. duPont Hospital for Children, addressed the symposium participants about the issue of caregiver stress. He made the following key points:

- caregivers of close family members are among those with the highest levels of stress;
- chronic stress can lead to impaired immunity, cardiovascular disease and emotional exhaustion;
- caregivers need to care for themselves if they are to continue to care for others;
- chronically stressed populations, such as spousal caregivers of patients with Alzheimer's disease have been found to have poorer cellular and humoral immune responses than well matched controls to viruses and other contagious agents;
- Caregivers with more diverse social networks have greater resistance to upper respiratory illness; those caregivers with more and a great variety of types of social ties are less susceptible to common colds; and
- strategies to relieve the stress of caregivers should include increasing social ties, increasing community support, and introducing or increasing relaxation activities for caregivers.

The Nebraska Lifespan Respite Network

The keynote speaker for the symposium was Senator Dennis Byars of Nebraska. Senator Byars spoke about the implementation of legislation for a lifespan respite network. Senator Byars made the following points about the implementation of the legislation that authorized the creation of the Nebraska Lifespan Respite Network.

The Nebraska Respite Network was created with the passage of Legislative Bill 148 and the follow-up of a number of additional bills. The bills specifically:

- enacted the Nebraska Respite Network administered by the Nebraska Health and Human Services System; this state agency serves as the central point of coordination for respite care in the six service regions in the state;
- the network established a statewide respite system and coordinated respite resources that provide lifespan respite services;
- these services are paid for from existing Medicaid funds, Child Care Block Grant funds, and Part C Early Intervention funds with an additional \$228,000 of state general funds; and
- a follow-up piece of legislation (Legislative Bill 692) established a respite subsidy program for families in need of financial assistance.



Major Accomplishments of the Nebraska Lifespan Respite Care Act

Senator Byars reported on the major accomplishments of the legislation and creation of the Lifespan Respite Network. These accomplishments included:

- the development of a statewide database that includes,
- a comprehensive database of licensed and approved providers,
- optional training, by the state, for all providers,
- completed background checks on all providers,
- family interviews to select the provider of their choice,
- the ability to track caregiver requests for services in order to assess family needs for respite, and
- the ability to communicate respite demands and use for each region statewide.
- a system that emphasizes ease of access, including:
- one statewide phone number for caregivers to access respite services,
- a single point of contact for each of the six regions, and
- coordination with Medicaid to pay for respite services for families who are eligible.



Current Status 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 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;¹
- 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;²
- the type of care provided by caregivers includes bathing, feeding, dressing, transportation, medical care, grocery shopping and household chores;² and
- caregivers identify their greatest concerns to be emotional strain, financial stress and conflict with employment.²

The organizations that conducted studies of the respite system in Delaware also found that caregivers had a number of concerns. These concerns are outlined in the next section. The key issues for caregivers in Delaware, based on the three studies, are:

- lack of information about available respite services;²
- the need for a centralized source of information about all respite services in the state;²
- an inadequate supply of respite services;²
- concerns about the quality and safety of the respite care available;² and
- lack of resources to fund respite care.²

Based on the information collected by the AARP, Delaware Caregivers Support Coalition and the Center for Disabilities Studies, there continues to be an overwhelming need for safe, available, affordable respite care for families throughout the lifespan. While there are a number of excellent respite providers in the state, the funds for respite supports are limited and services are uncoordinated. Caregivers need access to comprehensive, lifespan respite services that are coordinated, easy to access, and provide supports for individuals with all types of disabilities, chronic health concerns, and aging needs.



Definition of Respite Care

The CCCD discussed respite care and its purpose before settling on a specific definition as stated by the National Respite Network (www.archrespite.org):

Respite is defined as the temporary relief for caregivers and families who are caring for those with disabilities, chronic or terminal illnesses, or the elderly.

The CCCD will work from this definition, as it moves forward to meet the goals listed on page 2.

Caregiver Concerns

In addition to the key issues listed above, caregivers have identified a number of significant concerns about respite care. From national studies, these concerns have been identified:

- persons providing care for an elderly individual with a disability and experiencing caregiver strain had mortality risks that were 63% higher than persons not providing care;³
- for caregivers, the number of their hospitalizations, as well as the number of their medical care claims decreased as the number of respite care days available to them increased;⁴
- there is a significant relationship between the severity of a child's disability and the parents' job absenteeism;⁵
- a lack of available respite care appears to interfere with parents accepting job new opportunities.⁵



In Delaware, many families and caregivers are responsible for 24-hour a day, seven day a week care of their children with multiple disabilities. Access to respite care of any kind is usually limited. The Parent Panel members who presented at the symposium confirmed this as well as made the following comments:

- Once I figured out what respite care provides, I knew I absolutely needed it. My son needs to be flipped every two hours at night; he has seizures and needs a monitor in his bedroom. I had to quit my job to care for him, he requires twenty four hours a day, seven days a week supervision. I feel like a prisoner in my own home.
- My son is non-verbal, he hurts himself and he has no understanding of danger or of hurting someone else. I suffer from immune problems and chronic pain problems as a result of my stress levels. I need help
- Respite care has given my husband and me the chance to go out to dinner and to spend time with our other two children and give them a childhood.
- I am a new mom of a 22-month-old child. I just found out that my baby has a disability. I have no idea who to call or who can help me. I feel like I am at a dead end with nowhere to go.
- I could only sleep 45 minutes at a time for the first 18 months of my son's life because he needed constant care. My son still requires around the clock care.

- The respite that I receive is incredible. I receive twenty four hours a month and one week a year of respite. There is only a small parent co-pay that is based on my income.
- Lack of respite care has also had a negative impact on my marriage. The stress levels in our home have been quite high and have necessitated therapy for my husband and me, and require the therapist to come to conduct sessions in our house, since just to arrange one hour per week to leave the house together only added to our stress.



While the parent panel participants had significantly different family situations, they did arrive at consensus about a number of points. First and foremost, the panel members believe that the lack of available respite care is a major cause of stress in their lives and that the availability of reliable, affordable respite care would greatly reduce their stress levels. From their own experiences, the panel members also believe that there is an inadequate amount of available, affordable respite care in Delaware and, that when there is respite care available, there is an extreme lack of qualified respite providers.

The panel participants also identified the following strategies for improving the respite care services in Delaware.

Centralized Telephone Number

They agreed that a centralized telephone number is necessary. The phone number should connect families to a central database that can provide information to families about all types of respite services, information about costs and availability of services.



In-home respite

The panel also emphasized that in-home respite is the preferred model for providing respite services because it avoids disruptions to family schedules and better fits the needs of the family and the person needing respite services.

Increased number of hours

Finally, the panel participants stated that there is a great need for an increase in availability of respite hours and of qualified providers. The panel members felt that the current amount of respite hours available is inadequate and that there was no guarantee about the qualifications or training background of those providing respite services.