

STATE FACT SHEET

DELAWARE CAREGIVERS SUPPORT COALITION

Start-Up Process

In Fall, 2003, The Center for Disabilities Studies at the University of Delaware (UD) published a report documenting the work of the Respite Care Task Force in a report, "Respite Care in Delaware: A Critical Need for Change." Building on the momentum of the report, Easter Seals Delaware & Maryland's Eastern Shore called together a group of interested stakeholders to form a coalition to continue discussion and work around the issue of respite care in Delaware.

The group began meeting formally in January, 2004 and developed a team charter which defined its goal, mission, and objectives.

Structure

Until January, 2009, the group structure was informal and mostly volunteer. The work of the group from 2004 to 2006 included surveying both caregivers and providers to better define the need, and understand the strengths and needs of the respite care service delivery system. From 2006 to 2008, the group developed a three-year operational plan for a statewide system to address needs defined by the surveys—caregivers' need for easy access to information, concern for affordability of services, and limitations of qualified and quality providers.

When the coalition received funding from foundations in 2009 which allowed part-time staff to be hired, the decision was made not to incorporate as a separate entity, but to allow one of the coalition's members, Easter Seals, to become the Lead Agency, and act as the fiscal agent for the group. The coalition has also operated under the principle of using existing resources in the community through contracting for services rather than developing new systems and services.

The Coalition continues to function, serving as an Advisory Committee to the funded project, the Delaware Lifespan Respite Care Network. Subcommittees have been established to address issues raised by the Advisory Committee such as Outreach, Sustainability, and Financial Assistance.

Staff

Funding from grants currently pays for two part-time positions: a project manager and project coordinator both located at Easter Seals.

Funding

UD's Center for Disabilities Studies received a \$50,000 grant from the Governor's Commission for Community-Based Alternatives for Individuals with Disabilities to work with the Delaware Caregivers Support Coalition to develop a three-year operational plan for a statewide lifespan respite system.

Another member of the Coalition, Children & Families First, Delaware's Information & Referral agency, received a two-year \$15,000 grant from Delaware's Developmental Disabilities Council to develop a web-based database of respite care services in Delaware. Currently, the database lists agencies that serve children and adults either in home or at another location.

In fall, 2008, the Coalition approached three local foundations to fund the three-year operational plan to develop a statewide lifespan respite program. All three foundations funded the project for a total of about \$500,000. The foundations include Delaware Community Foundation, Longwood Foundation, and Welfare Foundation. The grants provide funding from January, 2009 through December, 2011. The funding pays for administration as well as vouchers.

The Coalition has established a Sustainability Subcommittee which has developed a plan for ongoing fundraising activities.

Membership

Members of the Coalition represent a broad spectrum of stakeholders interested in the issue of respite care including caregivers and consumers, service providers, and state agencies. The members provide representation that is statewide, and across ages and disabilities. A list of the membership can be found at www.delrespite.org. There is no membership fee.

A recent Respite Summit held in March, 2010 provided impetus for inclusion of additional interested parties who have been invited to participate in subcommittees.

Meetings and Communication

The Advisory Committee meets quarterly, face-to-face, to provide input and guidance for the Network. Meetings are typically held at Easter Seals' Delaware corporate office building in New Castle. Attendees choose to either attend in person or by phone via a toll-free conference call phone line. Subcommittees meet face-to-face several times a year, with the option of attending by phone. Between meetings, emails are sent to the Advisory Committee, Coalition members, subcommittees, and other interested parties to keep them updated on activities, issues, and general information.

Major Activities/Services Provided

The Delaware Lifespan Respite Care Network has been operational since July, 2009. It provides two major services: 1) Information & Referral services through an online searchable database (*RespiteOnline*) and through telephone consultation via a toll-free number, and 2) help with paying for respite care services through grants to families of up to \$500 per year per care recipient.

In March, 2010, thanks to funding from the ARCH National Respite Network (through an agreement with the US Administration on Aging), the Delaware Lifespan Respite Care Summit was held with over 80 people in attendance. Keynote speaker was Jill Kagan, Program Director of ARCH National Respite Network and Resource Center.

Documents Available

Information about the Coalition and Network can be found at www.delrespice.org. The website contains a history of the Coalition, which includes reports documenting various stages of the Coalition and its work. In addition, the website provides information on the services that are available to caregivers, and access to the online database, *RespiteOnline*.

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