

A special effort for special kids

Network of advocacy and support organizations eases the path for parents of children with disabilities

By KELLY BOTHUM • The News Journal • February 23, 2010

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Samtra Devard reads to her children (from left), Sam, 7, Lauren, 9, and Solomon, 6. Two years ago, the Bear mother founded the Hope Center Network for Families to help parents of children with special needs. Her daughter has Down syndrome. (The News Journal/GINGER WALL)

When Samtra Devard's daughter, Lauren, was diagnosed with Down syndrome a week after her birth, Devard listened as doctors explained how the disability would limit her child's physical, emotional and cognitive development.

It was important information, but only half the story. No one talked about the joys they would experience as her parents. No mention was made of the organizations they could turn to for assistance and support or the possibilities that lay ahead in planning Lauren's future.

"We were never plugged into anything that gave us encouragement," said Devard, of Bear. "It seemed as if there was a lack of hope in interfacing with children who have disabilities."

The experience prompted Devard to create a more supportive, empowering atmosphere for parents of children with special needs. Two years ago, she founded the Hope Center Network for Families, an advocacy organization that works with parents, educators and other professionals to promote positive expectations for children with special needs.

Devard is part of a growing effort to help families raising children with disabilities find the resources they need. In Delaware, almost 18 percent of children -- an estimated 34,522 children -- have been identified as having special health needs, according to the 2006 National Survey of Children with Special Health Care Needs, a project of the Child and Adolescent Health Measurement Initiative. Of those, 20 percent have an illness or condition that greatly affects their daily activities, according to the survey.

While new parents initially may be devastated by a disability diagnosis, it can be even more of a struggle for them to find information, support or understanding of their children's complex health needs. In many cases, it can be the equivalent of a full-time job just to keep up with the paperwork and authorizations needed for specialty therapy or individual education plans, said Ann Phillips, director of the Delaware Family Voices Family to Family Health Information Center, which helps parents and loved ones navigate medical issues.

The experience can be simultaneously frustrating, chaotic and alienating, just the opposite of what

these parents need if they are going to effectively advocate for their families. "They need to be encouraged so they can be proactive and advocate and seek out opportunities for their children," Devard said.

'One-stop shop'

A new umbrella organization slated to open next month may help smooth the path for these families. The state Division of Public Health has awarded a grant to the University of Delaware's Center for Disabilities Studies for the development of a "one-stop shop" that will connect all the entities serving children with special needs, said Beth Mineo, director of UD's Center for Disabilities Studies.

The organization, the Family Support Initiative, aims to work with small organizations so they can maximize resources and share them in a less fragmented and more user-friendly way, said Alisa Olshefsky, chief of the family health and systems management section of the Delaware Division of Public Health. The model is based on a program developed in Rhode Island.

"Part of what the umbrella hopes to do is centralize information and referrals so that it's easier for parents to connect to a single source of information," Olshefsky said. "Imagine getting a diagnosis and not knowing where to start."

Mineo said many parents are so used to navigating a fragmented system they don't realize they could be missing out on a needed connection. As it is, parents often have to hope they get the right person on the phone who can help them with referrals, medical equipment or intervening on their child's behalf on an education-related matter.

"Everybody is busy these days. Families who have a child with a special health care need are even busier," Mineo said. "Bath time can take two hours, dinner can take two hours. They don't need to be on the phone for two hours trying to speak with somebody."

Another goal is to strengthen those organizations already working with families. Many of those organizations, like Devard's, are run by passionate, caring parents who are trying to help people just like them, Olshefsky said. As veteran parents, they know the importance of services, like respite or assistive technology, that a new parent might not consider. Rather than supplant those valued parents, the Family Service Initiative hopes to help them so these grassroots organizations can expand their reach.

"I think as a whole, we are now thinking about children more holistically," Mineo said. "It's not just that they're a student, a patient, or a kid in the daycare center. We're trying to think about them as one child with multiple needs. We're trying to blend those issues together."

Early intervention

That's not to say resources aren't already available in the state for parents of children with special needs. One of the best-known is Child Development Watch, an early intervention program that provides services for children through age 3 who have disabilities or developmental delays.

The state-run program, which has been around for more than a decade, takes referrals from parents or physicians who have concerns about how a child is developing. If an evaluation shows the child is eligible for speech, physical or another kind of therapy, Child Development Watch contracts with an appropriate agency to offer those services, said Barbara Akenhead, clinic manager for the northern Delaware site of Child Development Watch. Parents also can get assistance with transportation or psychological help or speak with a social worker about other needs.

Because the program is voluntary, parents also can decide which, if any, services they want to use. After age 3, the responsibility for administering these services is transitioned from Child Development Watch to local school districts.

Many of the children identified through Child Development Watch get services from Easter Seals, whose biggest program focuses on early intervention. Almost 700 children under the age of 3 received speech, physical and occupational therapy last year, said Pam Reucher, vice president of programs for the nonprofit, community-based health agency. Easter Seals works with children who have Down Syndrome, autism and cerebral palsy, among other disabilities.

"There's a big push during those first 1,000 days of life. That's where biggest gains can be made for a child with a delay," Reucher said. "Any services that a child may receive can help get them on target to catch up on any development delays."

A long learning curve

In addition to early intervention programs, Delaware also has community-based organizations, like the Parent Information Center, which helps parents with education-related issues, and the Family to Family Health Information Center, which offers assistance with navigating health concerns.

But the learning curve for understanding disability services keeps many parents from seeking out those needed services, particularly those related to early intervention and individual education plans, said Phillips, who had led the Family to Family Health Information Center for 1 1/2 years. The program is federally funded and run by families who have experience with the special healthcare needs of those with disabilities.

That's why other parent-run organizations can be such a valuable resource -- staffers typically have been through the process themselves and they know the questions to ask. Since the Family to Family Health Information Center opened nearly two years ago, about 125 families have been helped, said Phillips, who got involved with the disability community after her son suffered a brain injury in a car accident when he was 18 years old and was paralyzed from the chest down.

"The first thing we try to tell parents is that they're not alone and they're not dumb for asking the questions they're asking," she said. "How do you find out the stuff you don't know?"

Because the family liaisons who work with parents know first-hand the challenges, they can help guide parents when it comes to issues such as getting a communication device for a nonverbal child through the Delaware Assistive Technology Initiative. Specialist Eddie Jory said he often receives phone calls from parents who have heard from another family about assistive technology devices and want more information.

Assistive technology devices are used to help someone in their everyday life. DATI has an assistive technology resource center in each county that offers demos and equipment loans for patients who are considering a purchase.

As more children with special needs are being educated in general classrooms, their parents also have more questions about educational interventions and differentiated instruction, said Marie-Anne Aghazadian, executive director of the Parent Information Center, which offers advice, workshops and mentoring for parents on matters related to education.

To help empower parents, the nonprofit used a \$50,000 grant to open parent resource centers in 10 New Castle County schools. The resource centers are open to anyone -- not just parents whose children who have special needs -- and they provide a place for networking, educational programming and idea-sharing among parents and educators.

When Bancroft Elementary School in Wilmington opened its resource center last year, it also added a washer and dryer in an effort to attract parents. It worked, Aghazadian said, noting that Bancroft has one of the most successful and active resource centers of the grant recipients.

"Schools want to have a good rapport with parents. They just don't have the time to develop them," she said.

GETTING HELP

Here are some resources for parents who have children with special needs:

Delaware Assistive Technology Initiative

www.dati.org

(800) 870-DATI (Delaware residents only) or 651-6790

Delaware Family Voices Health Information Center

www.delawarefamilytofamily.org

(877) 235-3588

Delaware Division of Developmental Disabilities Services

www.dhss.delaware.gov/dhss/ddds

(866) 552-5758

Easter Seals Delaware & Maryland's Eastern Shore

www.de.easterseals.com

(800) 677-3800

Hope Center Network for Families

www.hopecenterofde.com

834-5735

Parent Information Center of Delaware

www.picofdel.org

(888) 547-4412

Practice Without Pressure

www.pwpde.org

832-2800

UD Center for Disabilities Studies

www.udel.edu/cds

831-6974

Variety -- The Children's Charity

www.varietyphila.org

397-0017 (Delaware division)

Photos



A touch tablet is among the items available for loan from the Delaware Assistive Technology Initiative. (The News Journal/FRED COMEGYS)

Eddie Jory, a specialist with the Delaware Assistive Technology Initiative, demonstrates a touch-screen computer monitor at the organization's Dover center. (The News Journal/FRED COMEGYS)



Amber Fosty, an occupational therapist for Easter Seals, works with Aaron Thompson, 2. (The News Journal/JENNIFER CORBETT)



The Delaware Assistive Technology Initiative loans devices to parents of special needs kids. (The News Journal/JENNIFER CORBETT)