

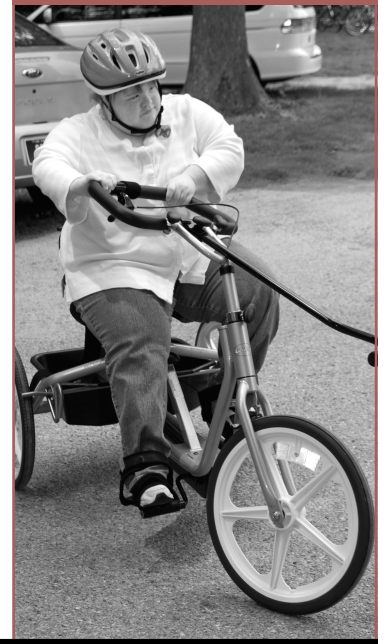
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Fall 2009

DELAWARE

A collaborative effort of the Center for Disabilities Studies & the Delaware Developmental Disabilities Council

ABOUT THIS ISSUE

Supporting the families of individuals with disabilities is an important part of our work at the Center for Disabilities Studies (CDS)—in fact, it's our mission to enhance the lives of individuals with disabilities and their families through education, prevention, service, and research related to disabilities. This issue of *delAware* focuses on some of the ways we provide families with the support they and their loved ones need to achieve independence and fully participate in the life of the community.

The **New Directions Early Head Start (NDEHS) Male Involvement Initiative** was started to encourage fathers to become more involved in the lives of their young children. It now reaches out to all males who are role models for children enrolled in NDEHS and provides the opportunity for men to share their experiences and dreams with one another, as well as learn skills for interacting with the children in their lives. To read more about the Male Involvement Initiative and how it helped one dad, see page 3.

Assistive technology not only makes life easier and more accessible for people with disabilities, it helps their families function more efficiently and effectively. In Delaware, families have been turning to the **Delaware Assistive Technology Initiative (DATI)** since 1991 for better and easier access to assistive technology. See page 2 to learn more about DATI, which is now part of CDS, and how it is helping three families.

Parents, siblings, and others who are responsible for the care and well-being of a family member with a disability may find it difficult to take a break from the full-time commitment it requires. While some caregivers do not realize there are other care options, others may be aware of these services but not have the ability to pay for them. With the creation of the **Delaware Lifespan Respite Care Network**, finding temporary relief from caregiving has become more feasible for these families. See page 4 for information about respite care and how easy it is to connect with the network.

Credit is due to parents and other family members for many of the supports that help all Delawareans with disabilities. By ardently advocating for loved ones, providing leadership, serving on committees, and meeting with legislators, these constituents

act as a catalyst for change and better services. In the most recent legislative session, which concluded June 30, 2009, they influenced at least two pieces of legislation passed by the 145th Delaware General Assembly. House Concurrent Resolution 19 proclaims the month of October "Disability History and Awareness Month" and encourages all Delaware schools to annually provide instruction and events focusing on disability history, people with disabilities, and the disability rights movement. The Governor's Advisory Council for Exceptional Citizens and parents of children with disabilities worked with Representative Quinton Johnson, himself the parent of a child with a disability, to initiate this resolution. The other piece of legislation, Senate Bill 65, was amended to allow parents with private dental insurance to secure **dental care for a child with a severe disability** irrespective of "in-network" restrictions (see page 4).

Families of children with special health needs or disabilities help other families who have children with similar needs through the **Delaware Voices® Family to Family Health Information Center (F2F)**. In *delAware's* Spring 2009 Health Issue, we introduced you to F2F. In this issue, we meet a family who is benefiting from the services of this "families helping families" program (this page).

CDS shared an exciting experience with individuals with disabilities, their families, and several state agencies and community organizations in June when an **adaptive tricycle**, donated by the Rifton Company, was presented to Bellevue State Park. Tara Bustard's photo at the top of this page says it all—at age 28, she was thrilled to have her first bike ride, and she looks forward to more rides with her family at the park.

My thanks to graduate students Liz Bozzo, Natalie Bizzarro, and Paul Galonsky for their work on this issue of *delAware*, and to Family to Family's Ann Phillips for her guidance. I hope the articles and information are helpful to you. For information about other CDS programs and projects, as well as links to other organizations with an interest in disability-related issues, please visit our website, www.udel.edu/cds.

Sincerely,

Michele Sands, Editor

The mission of the Center for Disabilities Studies (CDS) is to enhance the lives of individuals and families in Delaware through education, prevention, service, and research related to disabilities. We promote independence and productivity so individuals and families can fully participate in the life of the community. As a research and public service center at the University of Delaware, CDS relies on public and private support from individuals, corporations, foundations and state and federal entities to operate its programs. All gifts to CDS are tax deductible to the extent provided by law. Please visit the Center's website at www.udel.edu/cds or call 302.831.6974 for more information about supporting the CDS mission.

delAware is sponsored by the University of Delaware's Center for Disabilities Studies and the Delaware Developmental Disabilities Council. If you would like to contact CDS, please call 302.831.6974 or TDD at 302.831.4689; send a fax to 302.831.4690 or an e-mail to Michele Sands at msands@udel.edu; or write to *delAware*, University of Delaware, Center for Disabilities Studies, 461 Wyoming Road, Newark, DE 19716. Editor: Michele Sands; CDS. Designer: Cindy Dolan.

F2F: Trusted Health Care Resource

Kevin Rossetti's sinus surgery at Children's Hospital of Philadelphia early this spring was just the latest in a long series of surgical procedures for this nine-year-old from Milford. Diagnosed with "failure to thrive," Kevin has experienced sinus problems all of his life. Severe stomach reflux also has contributed to delayed growth. According to Nemours' KidsHealth.org®, children who fail to thrive don't receive or are unable to take in, retain, or utilize sufficient calories to gain weight and grow as expected. To make certain that Kevin gets adequate nutrition, he has a feeding tube that directs foods into his jejunum, the center section of the small intestine where food digestion is completed.

Kevin spends most of his time at home due to swallowing and communication disorders. His mom, Laurin Rossetti, does her best to make certain that her son receives the procedures and treatments he needs, but even with private health insurance, it is a difficult struggle. However, earlier this year, it became easier for Laurin to meet Kevin's medical needs because she learned about the Delaware Family Voices® Family to Family Health Information Center (F2F) and how this program could guide her family to additional resources and support.

Achieving Family-centered Care

F2F aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. It is operated and staffed at the Center for Disabilities Studies by and for families in Delaware, and there is no charge for services. Through the resources of its national network, F2F provides families with tools to make informed decisions, advocates for improved public and private policies, builds partnerships among professionals and families, and serves as a trusted resource regarding health care.

Laurin calls Family to Family's coordinator, Ann Phillips, "a godsend," explaining, "This past January, a friend of mine put me in touch with Ann, who told us about the Health Information Center and how to get additional resources for Kevin, such as Medicaid and Emergency Assistance Services.



Kevin Rossetti and his family celebrate the three gold medals he earned in swimming events at Special Olympics Delaware's Summer Games. Standing next to Kevin is his sister Leigh Ann, and behind him are his parents, Laurin and Andrew, and sister, Megan.

She also gave us information on how to apply for a grant for Kevin's food formula through the United Healthcare Children's Foundation, an organization that provides funding for services not fully covered by our private insurance."

The family now receives funding from United Healthcare to help pay for Kevin's formula; and a request by Laurin to the manufacturer resulted in the donation of 12 cases. "We never would have known about these resources or even thought about contacting the manufacturer of Kevin's food formula without the support of Ann and the Center."

Reducing Stress

Although Kevin's special health needs are an ongoing concern for the Rossetti family, which also includes his dad, Andrew, and sisters Megan and Leigh Ann, their association with F2F has alleviated considerable stress. Families striving to maintain the best health for their children can count on the Delaware Family Voices® Family to Family Health Information Center to help them navigate through the web of local and national special health care services.

For more information, visit www.delawarefamilytofamily.org or call 302.831.1705 or 877.235.3588 (toll-free from outside New Castle County).

DATI Facilitates and Improves Access to Assistive Technology

Gary Warren's favorite assistive technology device is a talking atomic watch that automatically identifies the correct time by reading radio signals in the air. Gary received his watch through the Delaware Assistive Technology Initiative (DATI) Borrow to Own Low-Vision Devices (BOLD) program. BOLD enables Gary to borrow assistive technology (AT) devices, try them out, and then request the device that works best. DATI will provide up to \$100 worth of free AT per individual each year.

Since it was founded in 1991, DATI has been working to help facilitate and improve access to AT for all Delawareans with disabilities. "I wish that I had known about the program sooner," said Gary, who has a vision disability called retinitis pigmentosis. In the past year, he has received a variety of AT devices that have improved his everyday life, from a talking tire gauge to a voice-controlled remote control for the television. Gary has been so satisfied with his experience that he has been telling everyone he knows about the BOLD program and DATI.

Mabel Warren, Gary's mother, has the same vision disability as her son and is equally satisfied with DATI. "They've really helped us very much, and I've been very impressed with how professional the staff is and how they make you feel so welcome," she said. Mabel raved about many of the products she has received from DATI, particularly a pedometer and talking keychain that help her on the treadmill. The pedometer tracks the distance she has walked or run and the talking keychain tells her the length of time she has been exercising. "These devices give me the freedom and independence to exercise and keep in shape," said Mabel, adding, "It's the little things that really mean a lot."

Free services and financial loans

The Warrens' experience is not unique. DATI provides most of its services without a fee and can help not only individuals with disabilities but also their families. DATI's financial loan program provides loans to customers who need financial assistance to buy often expensive AT equipment.

Janice Maxey-Douglas and her family are typical program beneficiaries. Janice's mother, Nancy, recent-

ly started using a wheelchair, and for Janice and her family, assisting Nancy in and out of the family's minivan was difficult. DATI information and outreach coordinator Eileen Mapes helped the family apply for and obtain a loan for the purchase of an accessible van with an electronic lift. According to Janice, "Eileen was so helpful with the process. The new van saves a lot of work and makes it much easier to take my mom to medical appointments or to other places where she needs to go." Like Gary Warren, Janice has been telling friends with disabilities about DATI so more people can benefit from the services it provides.

DATI also provides an equipment exchange program or AT "want ads." Through this program, people can list devices to sell or give away as well as post requests for items they wish to acquire. By using the AT exchange, people with disabilities can help others by sharing devices or technologies they no longer need. Consumers can search the listings for products at a much lower price than if bought new or directly from the provider. The AT exchange can be found online at DATI's website, www.dati.org, or in its newsletter, *The AT Messenger*.

Finding the right adaptive device

DATI has an Assistive Technology Resource Center (ATRC) in each of Delaware's three counties. Assistive technology specialists meet with customers at the centers to demonstrate devices and assess which technology will work best for them. As with the BOLD program, any AT device is available for a free, short-term loan, enabling customers to "try before they buy."

The ATRC in New Castle County has been particularly helpful to Haley Shiber and her family. Haley, who is 12 years old, uses an assistive technology device called the Vanguard II Plus that enables her to communicate by choosing buttons on a visual screen attached to her wheelchair. The Shiber family has been working with DATI since Haley was one year old to adapt devices and toys in their home. Haley's mom, Debbie, said that DATI has been extremely helpful every time she has purchased a new device for Haley. She and Haley visit the ATRC to view and test new communication devices because it's important to try



Haley Shiber rides her Rifton adaptive tricycle as she helps her mom, Debbie, pick out a Christmas tree at a local Christmas tree farm.

out such an item before buying it.

Because of their many features, communication devices "not only help Haley speak, but they help her to live as well," Debbie points out. "The Vanguard really empowers Haley and helps her to achieve greater independence." Soon, Haley will have a new communication device called an ECO-14. According to Debbie, it is the one of the most sophisticated devices available with half of the screen working as a computer monitor. Although it will take time to learn about and adjust to the new device, Haley and her family are looking forward to using the ECO-14.

To learn more about services offered by Delaware Assistive Technology Initiative and how your family might benefit, visit its fully accessible website at www.dati.org or call 302.651.6790 in New Castle County, 302.739.6885 in Kent County, or 302.856.7946 in Sussex County.

Haley Shiber Rocks

In many ways, Haley Shiber is the typical "tween." She loves Hannah Montana and playing games on her Wii. Although Haley's disability affects her ability to communicate with her own voice, Haley and her Vanguard can do almost anything. Not only does the Vanguard help her speak, but Haley also uses it



Haley Shiber and her friends enjoyed making cupcakes, putting together baskets, and dyeing eggs on Easter Sunday.

to listen to mp3s, navigate the computer, and change channels on the television, sometimes even playing jokes on her family and changing the channel when someone is watching TV.

In her free time, Haley is very active and loves to go swimming or ride her adaptive bike. Her family has made every effort to bring all areas of a typical 12-year-old girl's life into Haley's reach. Haley attends her fifth grade class daily and participates in 4-H every week. At 4-H, Haley and her friends hang out, engage in fun activities, and learn how to do interesting things such as taking photographs and planting gardens.

Family Support Resources



The following list is a sampling of helpful resources for families. For a more extensive list, visit the Delaware Voices Family® to Family Health Information Center website at www.delawarefamilytofamily.org/resources.html.

Practice Without Pressure

302.832.2800

Practice Without Pressure (PWP) is an organization dedicated to helping children and adults with disabilities receive quality medical, dental, and personal care with dignity and respect. PWP offers practice modules for families, direct care staff, and people with disabilities to help make medical appointments less threatening and fearful and to maintain a positive environment with respect and dignity for all involved.

NDEHS Initiative Supports Male Involvement with Children

When Troy Husser was a participant in the Male Involvement Initiative of New Directions Early Head Start (NDEHS), he learned how to listen to and play with his twins. He also became more aware of the importance of a male figure in a child's life. Troy liked being part of the group because it gave him the chance to get together with other men and share the joys of being a father. Although Troy stopped attending the monthly meetings last year due to a busy schedule, he would like to come back to the group because he enjoyed it so much.

"I joined because I thought I could learn some things from the other men in the group, and I knew it's important for fathers to learn how to interact with their kids," Troy recently recalled. "The program helped me connect with and become close to my own children."

NDEHS staff member Keith Boger, who leads the Male Involvement Initiative, said the program, which began in 2002, emphasizes the importance of a positive male figure in the lives of children, families, and communities. The initiative was started, Keith noted, because many family service agencies were not including fathers. Consequently, some men felt excluded and failed to get involved in their children's education. Originally called the Fatherhood Initiative, the name of the program was changed to reflect its focus on all male figures who might be involved in a child's life, not just the biological father.

Involved Fathers Make a Difference

The program supports and empowers fathers by educating both men and women about the benefits of active male involvement in the growth and development of children. Parents are a child's first teachers and knowledgeable parents are able to support and guide their children's education. This assertion echoes the findings of numerous research studies that indicate that "boys and girls who

grow up with an involved father, as well as an involved mother, have stronger cognitive and motor skills, enjoy elevated levels of physical and mental health, become better problem-solvers, and are more confident, curious, and empathetic."¹

The Male Involvement Initiative offers parenting resources, networking with other men, workshops and seminars, leadership training, referral services, and other information. Keith attempts to meet with each male figure initially to establish a relationship and a comfort level with him and the program. The men have the option of meeting with Keith individually to discuss their dreams and goals and/or participating in group activities.

Monthly meetings at partnering centers feature speakers who are chosen to address some of the men's primary concerns. In the past, speakers have been from the Pardon Project, Probation and Parole, HIV agencies, domestic violence agencies, and the Small Business Administration. The Male Involvement Initiative also offers possible solutions to other problems. When there are barriers to employment, the program will help the men access job training. The men also can come together at a YMCA to get to know one another, network with others who share common problems, and use the fitness center.

Activities Draw in Male Figures

At every meeting, Keith emphasizes to the dads the importance of being involved in their children's lives. To support this involvement, the program participants and their children participate in an annual Fall outing to the Brandywine Zoo in Wilmington, and periodically throughout the year activities are sent home for the male figure to complete with his child. For those who do not live with the child, activities are also available at the centers. A recent activity involved having each man and his child or children decorate a foam mitten picture frame. If a father is incarcerated and cannot participate in the group's events,



Troy Husser enjoys an outing at the playground with his twins.

NDEHS mails updates regularly about his child's progress.

Currently the program is recruiting men to read to groups of children who attend centers such as the Early Learning Center (ELC) in Wilmington. Children who do not have a significant male in their lives benefit from interactions with these positive male figures.. Keith regularly reads to children at the ELC, and based on his own experience, believes the men will be "hooked" immediately when they see the children's excitement during the readings.

For more information about the Male Involvement Initiative, contact Keith Boger at 302.831.3492 or boger@udel.edu.

¹ Appreciating how fathers give children a head start: U.S. Department of Health and Human Services, Administration for Children and Families. (2004), www.eclkc.ohs.acf.hhs.gov/hslc.

New Directions Early Head Start is an interagency program that provides care and support to pregnant women, children birth to three, and their families who fall below the federal poverty guidelines. The program's mission is to promote children's success and families' self-sufficiency through community collaboration and partnerships. Founded in 1998, NDEHS has served more than 1,500 children and pregnant women in their homes and through center-based partnership programs. Those served include 150 children with disabilities, 19 of whom are currently being helped by the program.

For more information about New Directions Early Head Start, contact Heidi Beck at 302.831.0584 or earlyheadstart@udel.edu.

Child Development Watch

www.dhss.delaware.gov/dph/chs/chscdw.html
800.671.0500 (New Castle County), 800.752.9393
(Kent and Sussex Counties)

Child Development Watch (CDW) is the statewide early intervention program for children ages birth through three. The program's mission is to enhance the development of infants and toddlers with disabilities or developmental delays and to enhance the capacity of their families to meet the needs of their young children. CDW provides comprehensive information for parents and professionals, as well as providing services such as health and nursing, family counseling, occupational and physical therapy, psychological services, and speech and language therapy.

Connecting the Dots

www.udel.edu/cds/brochures.html

Connecting the Dots (CTD) is a publication developed in 2006 as a guide to finding services for people with disabilities in Delaware. It is meant to help people with newly diagnosed disabilities find the supports

and services they and their families may need. The booklet includes medical, financial, assistive technology, legal, education, caregiving, and advocacy resources as well as a glossary of terms and a list of common abbreviations. The list of agencies was updated in February 2009 as a separate document. A limited number of published copies of CTD are available; call 302.831.3038.

SNAP—Special Needs Alert Program

www.dhss.delaware.gov/dph/ems/emscsnap.html

If you have a child with special emergency care needs, such as a tracheotomy or feeding tube, enrolling in the SNAP program, at no cost to you, may benefit your family. Emergency Medical Services staff will meet with you in your home and review your child's special health information. If you need to call 911 for any reason, the emergency services units will be notified that your child is in SNAP and they will review your child's information before arriving at your home. To enroll your child or for more information, call Delaware Emergency Medical Services for Children at 302.744.5415.

Family Education and Support Website

www.udel.edu/cds/familyeducation

This website was designed to provide practical and useful information for families coping with children's behavioral health issues. The resources available on this site can help families, counselors, physicians, and school professionals learn more about these issues and how best to support children's emotional wellness.

Family Support Center on Disabilities: Knowledge & Involvement Network (KIN)

www.familysupportclearinghouse.org

Funded by the Administration on Developmental Disabilities, this website provides a comprehensive, easy-to-access database of organizations and agencies that provide resources for people with disabilities. Families can sign up for the monthly newsletter, join the forums to discuss topics with other families, or join a State Action Team.

Lifespan Respite Care Network Gives Caregivers A Break



Approximately 160,000 adults in Delaware are providing support and care for a relative or friend. These unpaid caregivers may be responsible for bathing, feeding, dressing, transporting, administering medical care, grocery shopping, and performing household chores for an average of 65

hours per week for 18 years¹. Numerous studies and surveys conducted in Delaware have found that caregivers often deal with emotional strain, financial stress, and conflict with employment.

Respite care provides temporary relief for caregivers and families who are caring for those with disabilities, chronic or terminal illnesses, or the elderly. Such support can make a big difference in a caregiver's life, but, unfortunately, many caregivers are unaware of respite care because so little information about it has been available in Delaware.

The Delaware Lifespan Respite Care Network was developed by the Delaware Caregivers Support Coalition to help people identify and secure the appropriate form of respite care. CDS disabilities specialist Tim Brooks is a member of the coalition, which is a partnership of consumers, service providers, and advocates. Tim points out, "With the respite care network,

the public can access information about what respite care is and what is available to them."

Network Provides New Services

First offering services in July 2009, the Delaware Lifespan Respite Care Network is managed by Easter Seals Delaware & Maryland's Eastern Shore. It provides caregivers and consumers with access to information through a case manager, website, and toll-free phone number. Case managers of individuals and families already receiving services from a state agency or nonprofit organization can help match their clients' needs with existing respite services either through their agency's resources or by accessing the network's RespiteOnline database. The database, which is hosted by Children & Families First, is free and can be accessed from the Delaware Lifespan Respite Network website, www.delrespite.org.

The toll-free phone line provides caregivers and consumers with access to a dependent-care specialist. The specialist offers the caller referrals for respite providers, determines if there is a financial need, suggests potential sources of financial help, follows up with the caller within one week to determine if needs were met, and provides ongoing assistance until the needs are met. Through the support of several local foundations, the network is able to provide families



Easter Seals Saturday Respite Program participant Gerald (right) plays his winning piece defeating the Activity Leader Kristi Hughes.

with grants of up to \$500 to fund respite care. The grants will provide support for care for individuals of all ages and with any type of disability or special need. Priority for the grants will be given to families who have financial need and are not eligible for or receiving respite services from another organization or agency.

In addition to CDS, Easter Seals, and Children & Families First, a number of agencies, including Delaware's Division of Services for Aging and Adults with Physical Disabilities and the Division for Developmental Disabilities Services, are helping to implement the plan for the network and ensure it addresses all age groups. The network has been funded for three years by generous grants from the Delaware Community Foundation, Longwood Foundation, and Welfare Foundation. The Delaware Lifespan Respite Care Network is now engaged in an effort to obtain sustained funding to assure that Delaware families will continue to have the respite care services they need far into the future.

Contact the Delaware Lifespan Respite Care Network for:

Information & Referral: assistance in finding providers of respite care

Financial Assistance: help in funding care for families currently not eligible for assistance through other programs

Toll-free line:
888.610.5572 from Kent and Sussex Counties
302.479.1690 from New Castle County

Website:
www.delrespite.org

Dental Insurance for Children with Disabilities

No "In-network" Restrictions

The 145th Delaware General Assembly, which concluded its first session on June 30, 2009, passed Senate Bill 65, an act to amend Title 18 of the Delaware code relating to dental insurance and children with severe disabilities. Senate Bill 65 applies only to insurers that include dental services in their benefits package. It allows parents with such private dental insurance to secure dental care for a child with a severe disability irrespective of "in-network" restrictions. It also promotes the availability of in-network practitioners willing and able to treat such children.

State Senator Stephanie Hall-Long introduced Senate Bill 65 because parents of children with severe disabilities experience difficulty in identifying practitioners willing and able to provide effective dental care. Strict application of "in-network" insurance restrictions exacerbates the parents' dilemma because there may be no nearby in-network dentist willing and able to treat their child. In addition, parents whose child's secondary insurance is Medicaid file a claim with Medicaid when they are unable to utilize private dental insurance, resulting in an increase in Medicaid claims that should have been paid by private insurance.

For further information about Senate Bill 65 and a link to the full text of the legislation, visit www.legis.delaware.gov and click on "Bill Tracking."

¹ Center for Disabilities Studies. (2005) Delaware Caregivers Coalition Report. Newark, DE.