



Summer 2010

DELAWARE

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

ABOUT THIS ISSUE

We are pleased to present this issue of *delAware*, which focuses on a critical life passage, the transition to adulthood. This is a complex passage to navigate: young people leave the predictability of the K-12 education system for post-secondary education and/or employment; they give up the comfort of the pediatric health care system for a much more fragmented adult system; and they are expected to assume more responsibility for their daily living activities.

The Center for Disabilities Studies is committed to facilitating smooth transitions for individuals with disabilities – and their families – through its advocacy, policy initiatives, and model demonstration programs. These efforts are carried out through partnerships with other entities, including departments at the University of Delaware, schools, community organizations, state agencies, and foundations. You will learn more about our programs and partnerships in this issue of *delAware*.

One state agency we work closely with is the Delaware Developmental Disabilities Council. This agency is authorized by Public Law 106-402 to address the unmet needs of people with developmental disabilities through system-wide advocacy, planning, and demonstration projects. To learn how this agency carries out its mission of promoting and embracing inclusion, equality, and empowerment, visit www.ddc.delaware.gov.

CDS is Delaware's University Center for Excellence in Developmental Disabilities (UCEDD) and a member of the Association of University Centers for Disabilities (AUCD). We are one of 67 UCEDDs working to accomplish a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. By providing transition services, we are coming closer to achieving this vision.

Several AUCD network members have contributed to the recently published book, *Launching into Adulthood: An Integrated Response to Support Transition of Youth with Chronic Health Conditions and Disabilities*. This book makes research-based recommendations that will streamline access to services, meet young people's individual needs, and improve long-term outcomes. More information about AUCD and the book is available at www.aucd.org. Two CDS staff members are among contributors to new books that relate to transition planning; details are included in the other article on this page.

My special thanks to Natalie Bizarro for researching and writing the articles in this issue. Natalie has been a graduate assistant with the Dissemination and Advocacy unit at CDS for the past two years. She is a school psychology major in the School of Education and will be serving as an intern in the Christina School District during the 2010-2011 school year.

Michele Sands

Michele Sands, Editor

The mission of the Center for Disabilities Studies is to enhance the lives of individuals and families 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 their communities in Delaware and beyond. 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. Designer: Cindy Dolan.

A Person-centered Approach Eases Life Transitions

Life transitions don't have to be difficult for teens and young adults with disabilities – or for their families. The Center for Disabilities Studies has developed several programs that provide positive transition experiences and successful outcomes. These programs use a person-centered approach to assist each individual in making plans for the future. Person-centered planning is a flexible and creative process that assists students – with or without disabilities – to chart a course for the future using their own strengths, hopes, and dreams as a starting point.

Many of the Center's transition programs are part of the Transition Education Employment Model (TEEM) unit. This model offers individuals with disabilities a comprehensive set of services, supports, and opportunities that will enable them to develop the skills needed to increase their independence, lead productive lives, and participate in the community as adults.

They focus on the person's needs and are built upon the idea of self-determination – putting the individual in charge of defining the direction for his/her life.

TEEM provides opportunities for persons with disabilities to increase self-esteem, acquire life skills, develop effective communication, obtain vocational and job skills, enhance interpersonal relationships, enjoy social leisure activities, practice money management, and strengthen problem-solving abilities. TEEM currently has three active components: Community-based Education Alliance (CBEA), Employment Services, and Pathways for Life. This edition of *delAware* includes an article about each of these components.

Healthy Transitions

The CDS Health and Wellness unit is helping families make smoother transitions from pediatric health care to adult health care. Healthy Delawareans with Disabilities and Delaware Family Voices Family to Family Health Information Center have partnered with the Transition of Care program at the Alfred I. duPont Hospital for Children to develop a series of "Healthy Transitions" workshops (see page 4).

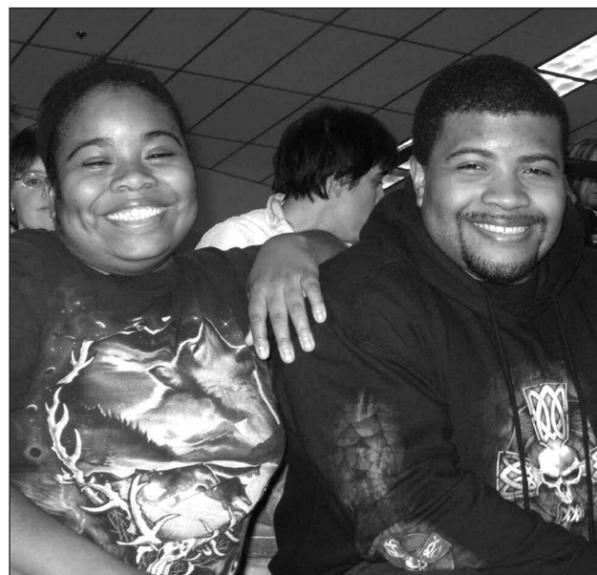
In its work with families of children with special health care needs, Family to Family recom-

mends the use of care notebooks for the documentation of information about a child's health history. Having this information is particularly valuable when it is time to develop a health transition plan for teens (see page 4).

Research

In addition to offering model transition programs, CDS is involved in research about issues relating to transition. Laura Eisenman, Ph.D., associate professor in the School of Education

and advisor for the Disabilities Studies Minor, is studying the experiences of young adults and teachers in an inclusive technical high school. Her interests include understanding how schools can foster students' self-determination, learning about the social and community experiences of young adults with significant disabilities, and exploring the meaning of disability identity in educational contexts. Along with Karen Mancini, director of the Office of Disabilities Support



The antics of the Harlem Globetrotters bring smiles to the faces of Community Connectors member David Hill and his sister, Sara. They attended the game with other Connectors and their family members.

Services, Dr. Eisenman wrote "College Perspectives and Issues," a chapter for *Think College: Post-secondary Education Options for Students with Intellectual Disabilities*. This book was published in November 2009 by Brookes.

Sarah Celestin is the project director for the Delaware Alternate Portfolio Assessment and a doctoral student in the university's Educational Leadership program. Her research interests include instruction/assessment for students with moderate to severe disabilities and transition planning. Sarah collaborated with Laura Eisenman to write "Facilitating New Social Relationships: Social Skills, Supports, and Networks for Adolescent Transitions." This chapter will be included in the *Handbook on Transition for Youth with Disabilities*, which will be published by Routledge, Taylor & Francis.

With programs that focus on the needs of each individual, ongoing evaluation of these programs, and research about the transition from youth to adulthood, the Center for Disabilities Studies is addressing a critical period in the lives of young adults with disabilities – and making life transitions smoother for youth and their families.

Skills, Desires, and Goals Guide Individualized Employment Plans

Doug Dallabrida loves his job at the Marriott Courtyard Newark-University of Delaware. His success is one example of how TEEM Employment Services is achieving its goal: ensuring that all participants work in jobs they enjoy that are of their own choosing. Employment Services, one component of the CDS Transition Education Employment Model (TEEM), uses a person-centered approach to help young adults and adults with disabilities develop an individualized plan for employment based on their skills, desires, and goals.

The program includes vocational evaluations, vocational and job skills training, real work experiences, career exploration, job site accommodations, job coaching/support, and 13-week internships. Doug, who was referred to CDS for competitive employment, was part of the Center's original CBEA (Community-based Education Alliance) program. An aspiring hotel worker, Doug and another student enrolled in and completed a 90-day training program offered by the Marriott to certify students in hotel hospitality services.

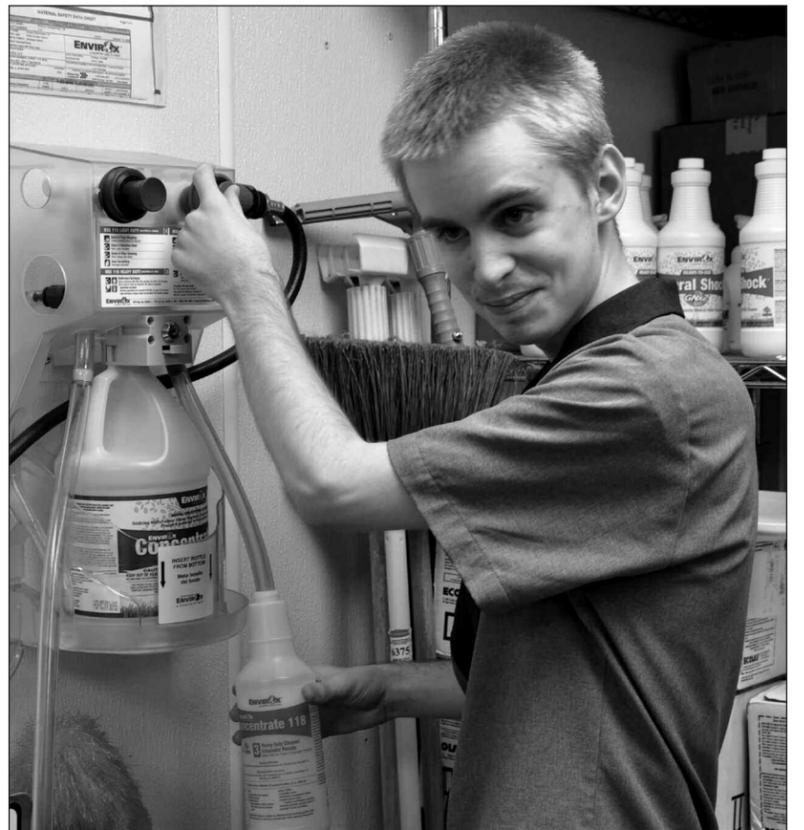
In addition to learning job skills during his internship, Doug gained independence and began to take more initiative. "I don't expect other people to do

things for me. I do things myself," he explained. Doug was subsequently hired by Marriott to work three days a week in the housekeeping department. Whether he's doing laundry, cleaning, vacuuming, or operating the machine that folds sheets, Doug likes everything about his job.

CDS served as the provider of Doug's employment services through one of the partnerships the Center has established with three Delaware state agencies: Division of Vocational Rehabilitation (DVR), Division of Developmental Disabilities Services (DDDS), and Division for the Visually Impaired (DVI). These agencies support a variety of programs for people with disabilities who qualify for services leading to employment.

One program is Early Start to Supported Employment (ESSE), which was developed by DVR, DDDS, and other state agencies to provide a more seamless transition for students who need supported employment services for job success. ESSE targets young adults – students in 18- to 21-year-old school programs – and helps them choose an adult service provider. If the student and his/her family choose CDS as their provider, TEEM Employment Services staff members immediately begin working with the student on the transition from school to work.

The young adult begins by completing three community-based work assessments, which determine the individual's interests and how his/her skills match with various occupations. TEEM Employment Services staff members also conduct vocational evaluations and job skills training and engage in career exploration with the student. When this process is completed, the next step is for the student to be hired as a paid employee before graduating or exiting from school. Once the student is hired, CDS provides a coach for 90 days to provide for a smooth transition and to help establish natural supports in the workplace. After this period of time, the coach gradually withdraws support until the employer or individual determines support is no longer necessary.



Doug Dallabrida refills a cleaning solution container for his job in the housekeeping department at the Marriott Courtyard Newark-University of Delaware.

Other DVR clients in need of competitive or supportive employment services may choose CDS as their provider, depending on their particular needs. Individuals in competitive employment are provided with job coaching and support for the first 90 days after being hired into an integrated work setting. Supported employment is for young adults and adults who need job supports in an integrated work setting for an indefinite period of time.

The foundation for the Center's employment initiative was laid in 2008 with funding from a generous three-year grant from the Howard W. Swank, Alma K. Swank, and Richard Kemper Swank Foundation. During its first year, TEEM Employment Services has supported more than 45 clients. The program has been successful in helping to employ numerous people with disabilities in meaningful jobs.

For more information about TEEM Employment Services, contact Wendy Claiser at 302.831.8103.

A Transition Guide for Parents

"Parents really struggle when their child's entitlement to formal education is coming to an end," observed Wendy Claiser, program coordinator of TEEM Employment Services. An evaluation she conducted in 2009 found that many parents of children with disabilities feel unprepared for and uneducated about the process of helping their children transition from school into employment.

To help parents navigate this process, Wendy created "A Transition Guide for Parents." The brochure includes information about providers and the roles and rights of families in the transition process; a checklist of steps for parents and students to take; and places to take notes and record information from transition coordinators and case managers. To receive a copy, contact Wendy at 302.831.8103.

Transition Resources and Programs

- The Center for Disabilities Studies website – www.udel.edu/cds – includes information about the Center's transition programs.
- CDS maintains a website related to Career and Technical Education (CTE) – www.SuccessDE.org. It was created in partnership with the Delaware Department of Education (DDOE). Included are articles and functional tools for teachers of CTE, students with disabilities who are enrolled in CTE classes, and their parents, to facilitate a successful transition from secondary education to post-secondary education, work, and adulthood.
- The University of Delaware Office of Disabilities Support Services – www.udel.edu/DSS – meets the unique educational needs of students and employees with disabilities by coordinating and providing accommodations, offering support to faculty and staff, providing textbooks and materials in alternate format, assisting with accommodations for public programs, reviewing campus facilities for accessibility, and engaging in campus outreach, programming, and research.
- Division on Career Development and Transition – www.dcdt.org/transitionresources.cfm – is an organization for parents, professionals, and students that keeps transition at the forefront of educational efforts. (Dale Matusovich, education associate for DDOE Transition Services, is president of this nationwide organization.)
- The Delaware Department of Education website – www.doe.k12.de.us – includes information about school-to-adult life transition for parents and guardians. Go to Information Suites on the bottom of the Home page, click on "Students & Family," then "Special Education," then "Transition Service."
- DDOE and the Department of Labor sponsor the Community of Practice Delaware Transition Conference in April for youth aged 14 to 21 receiving special education services, their parents, educators, and professionals.
- DDOE published the *Tri-State Transition Slide Guide* in partnership with the Departments of Education in Pennsylvania and Virginia. Contact dedoe@doe.k12.de.us to learn how you can receive a copy.
- Parent Information Center – www.picofdel.org – sponsors events to help parents prepare their children for transition from school to post-school options and also publishes a weekly e-newsletter.
- Think College! – www.thinkcollege.net – is for individuals with intellectual and other developmental disabilities of transition age and adults attending or planning for college.
- We Connect Now – weconnectnow.wordpress.com – serves college students with disabilities in an effort to connect and integrate them more as a virtual community with a voice on important issues.

CBEA Students Develop Skills to Transition to Adulthood

Students with disabilities in three New Castle County 18- to 21-year old programs are enhancing their education through real-world experience, thanks to a collaborative partnership between the Center for Disabilities Studies and three school districts. The Community-based Education Alliance (CBEA) is an integral component of the CDS Transition Education Employment Model (TEEM). It helps young adult students transition from school to adult life and work while they are still enrolled in their respective schools.

CBEA began as the Transition Partnership Project in the mid-1990s with an agreement between CDS and the Meadowood Program of the Red Clay School District. It was expanded a few years ago to include additional school districts, involve the students in University of Delaware activities, and provide job training at campus sites.

CBEA kicked off the 2009-2010 school year with a new mission and a completely revised program. Individual schools in the partner districts select students whom they believe will benefit from the opportunities offered by the CBEA program. Pathways for Life team members teach independent living skills and TEEM Employment Services staff members focus on employment skills.

During the independent living skills

track, students learn about self-determination, goal setting, decision making, problem solving, communication, navigation, money management, and safety in the home and community. Success with independent living skills is important for moving into the employment track, according to Debbie Bain, program coordinator of Pathways for Life.

Student Experiences

Andrew (Drew) Netta, an 18-year-old student from Delcastle Technical High School, was a first-year CBEA student during the 2009-2010 school year. He noted that one of the most valuable skills he learned during the fall semester independent living track was how to pay bills on his own.

At the beginning of the spring semester, Drew completed the first half of the CBEA employment track, which involves career exploration, job skills training, portfolio development, and job shadowing. He then progressed to the second half, transition into work sites that are on or near the University of Delaware (UD) campus. In this track students select three work sites, interview with department managers at each of them, and are then selected to complete their unpaid internship at one of these sites on or around campus.

Drew was helping to set up for a ban-

quet at the Marriott Courtyard Newark-University of Delaware when he was interviewed for this article. He was in his first week as an intern with the food and beverage department. Drew said he selected the Marriott because of the diverse opportunities it provides and the wonderful work environment. He will revisit his goals during the next two years of CBEA, and through hands-on experiences, he will get to know his strengths and job preferences.

Brittney Ciamaricone, a student at William Penn High School, also enrolled in CBEA in September 2009. She said she enjoyed learning such skills as how to interact with people and how to budget.

During the first phase of employment training, Brittney's interest in doing clerical work in an office setting was confirmed. She interned at UD's Cooperative Extension in the spring, helping with filing, stuffing folders, and other clerical jobs. Brittney says that the experience was "great" and she really enjoyed it.



Brittney Ciamaricone assisted with some clerical tasks at the Center for Disabilities Studies on Disability Mentoring Day in October 2009. With her are CDS Office Clerk Blake Bossert and Lauren Blakeley, a University of Delaware student who served as Brittney's mentor.

In addition to supporting individual students, CBEA staff members help support parents of students enrolled in the program. Workshops assist parents in supporting their children as they work to gain independence.

The Center for Disabilities Studies values the partnerships it has established with New Castle County school districts. Together, they are giving students the opportunity to have a productive transition into adulthood and find meaningful employment.

For more information about these partnerships or the CBEA program, contact Bev Stapleford, TEEM unit leader, at 302.831.4688.

Pathways for Life Programs Build Independence

Pathways for Life gives young adults opportunities to develop skills needed to increase their independence and capacity to successfully transition into adulthood. As a component of the Center for Disabilities Studies TEEM (Transition Education Employment Model) unit, Pathways uses a person-centered approach and provides opportunities for community inclusion, empowerment, self-determination, independence, and pursuit of personal, vocational, residential, and recreational goals.

There are four aspects to Pathways for Life – coaching, Summer Transition Education Program (STEP), Community Connectors, and workshops and seminars for students and parents. Participants in these programs are referred to as students because they are learning skills important for their lives.

Students who enter a one-on-one coaching program start by developing an individual PATH based on their goals, skills, and dreams. PATH, which stands for Planning Alternative Tomorrows with Hope, is a research-based practice that helps students build and develop a concrete plan for their future.

Coaching provides encouragement, instruction, and information. Because the emphasis is on having the coach take his/her lead from the students, the students develop greater independence and control in their lives. Each student's independence and success is measured and defined according to his/her own goals.

The annual one-week Summer Transition Education Program also involves goal setting and step-by-step planning to achieve independence. STEP trainers provide coaching support and learning opportunities as students identify personal goals in areas such as interpersonal life skills, leisure and career exploration, post-secondary education, and advocacy. This information is used to develop a blueprint for action that the students implement upon their return home.



Kim Jackson, a member of Sigma Kappa sorority (left), works with Brynn MacBride, a Community Connectors member, at the car wash that raised more than \$700 for the Connectors.

Community Connectors

Community Connectors is an ongoing program designed for young adults who want to build leadership skills, network, and socialize with peers. Originally created as a social and recreation program and funded by a variety of sources, the focus of the program was expanded a few years ago to include a leadership component. Members learn skills to help them connect with peers and take responsibility for coordinating group events. In the past, coaches led each meeting; now, meetings are member-driven and the role of the coaches is limited to helping to facilitate discussion.

When funding sources for Community Connectors ended in the summer of 2009, the group's future was uncertain. After several months, members and their families spoke up about their desire to continue the program – and they began discussing how to sustain Connectors. At "Save the Connectors" meetings, members and their families brainstormed ideas for

seeking outside funding sources and raising their own funds. Their ultimate goal is to secure long-term, diverse, and stable funding.

The first decision was to charge modest membership dues to help support the group. Then fundraising efforts began in earnest. Bob Spengler, a member of the Knights of Columbus (KofC) Coffee Run Council and father of Connectors member Robert Spengler, applied for a KofC grant. In February, the Connectors were awarded \$560 from funds the Council earmarks to support persons with intellectual disabilities.

In March, Connectors raised more than \$500 through a fundraiser at Friendly's on South College Avenue in Newark that was coordinated by members. After making presentations to Greek organizations on the University of Delaware (UD) Newark campus, Connectors, their parents, and staff members gained support from the Greeks. Sigma Pi Fraternity and Sigma Kappa Sorority members joined the Connectors for a car wash in April that raised \$725. Additional UD partnerships are being explored, working toward the future goal of integration into the campus community and more opportunities for socialization with campus peers.

Debbie Bain, program coordinator for Pathways for Life and a coach/facilitator for Connectors, notes that the funding difficulties have provided a great opportunity for growth for many of the Connectors. Some members have become more active in the group, helping to plan and organize meetings, lead meetings, and plan events.

"You see that they've made a commitment because this is important to them, something they benefit from," says Debbie, adding, "They're very impassioned about this group."

For more information about Pathways for Life and Community Connectors, contact Debbie Bain at dbain@udel.edu or 302.831.8733.

Workshops Focus on Taking Responsibility for Health Care

The ability to take greater responsibility for their own health care will help adolescents and young adults with disabilities and special health care needs transition more successfully into adult life. To help them achieve this goal, the Center for Disabilities Studies created Healthy Transitions, a series of three workshops for adolescents, young adults, and their caregivers. It was offered to New Castle County residents in 2009 through funding from DFRC (Delaware Foundation Reaching Citizens with Intellectual Disabilities).

Caregivers and young adults participated in separate classes that covered the same three topics (one per workshop): medical transition, insurance issues, and healthy lifestyles. Caregivers were taught ways in which to support their adolescent or young adult children in becoming more independent in their medical affairs.

Staff from two CDS projects – Healthy Delawareans with Disabilities and Delaware Family Voices Family to Family Health Information Center – facilitated the classes in partnership with the Transition of Care pro-

gram at the Alfred I. duPont Hospital for Children. All participants received a resource book of materials.

During the medical transition class, adolescents, young adults, and their caregivers were taught skills to help ease their health care transition. They learned how to look for a new doctor and what questions to ask when you first meet a new doctor.

The insurance issues class centered on how to navigate Supplemental Security Income (SSI) and Medicaid programs. For example, young adults learned how they can work and still receive their benefits, while parents reviewed how important it is to stay in contact with insurance companies to ensure that their child is being covered.

The healthy lifestyles portion of the series featured a panel of guests that included a dental hygienist, a



Alyssa Cowin and her mother, Cathy, review the resource book of materials they received as participants in the Healthy Transitions workshops.

Med-Peds physician (a doctor trained in both pediatric and adult care), a nutritionist, and a student in exercise physiology. After speaking about their areas of expertise, the guests interacted with the participants, practiced exercises, and demonstrated oral health care.

Benefits to Participants

“I came to the workshop series from two perspectives, as a parent that had already started asking these questions, and as a transition specialist in the Christina School District,” shared Cathy Cowin. “As a parent, I found it helpful because there were some pieces of information and programs I didn’t know about. As a professional, it gave me wonderful resources to share with parents.”

Cathy’s daughter, Alyssa, said she learned some valuable information, but also discovered that she was already on the right track: “I learned that I need to call about my appointments for the doctor, but that I already know how to set up medicine for the week, and every week I change it.”

Time for interaction before and after each class added a social dimension to the program. “It was great seeing that the young adults were making some really nice friendships with each other, and the parents were supporting each other, too,” noted Terri Hancharick, research associate at CDS and organizer of the Healthy Transitions workshops.

The Healthy Transitions workshop series will be offered in Kent and Sussex Counties in the fall of 2010, funded by the Delaware Division of Public Health. For more information, contact Terri Hancharick at 302.831.8374 or terrih@udel.edu.

The Care Notebook: A Record-keeping Tool

A care notebook is a valuable organizational tool for families of children and adolescents with disabilities and special health care needs. It is the place to keep track of – and maintain an organized record of – important information about a child’s health care, services, and providers. The care notebook is designed to help organize the information in a central place to assist both families and providers. This is a perfect complement for the medical home model, which promotes coordinated care between the health care team and the family.

Care notebooks have a variety of uses and benefits. Caregivers can share the notebook with health professionals and educational staff to provide continuity and assure the best care possible for their child. The notebook can be used to track changes in medicine or treatments, list contact information for providers and community organizations, file information about health history, and help families prepare for appointments. It serves as an easy-to-access reference for families and professionals.

For teenagers who are increasing their independence and preparing to transition out of child-centered services, the care notebook can be an additional way to understand and participate in their own care. Keeping a care notebook encourages adolescents to be more engaged in their health care, provides information about their condition and health history, and helps them prepare for emergency situations. The notebook is a valuable resource when teens are developing a care plan for the future.

Delaware Family Voices Family to Family Health Information Center periodically offers training for families and providers on how to put together a care notebook. Call Michelle Lamers at 302.831.6608 to learn about future training sessions, or visit www.delawarefamilytofamily.org.

The following websites are valuable resources for learning more about care notebooks and the steps to take to construct them; they include examples and blank forms.

- Build Your Own Care Notebook, National Center for Medical Home Implementation, American Academy of Pediatrics: http://www.medicalhomeinfo.org/tools/care_notebook.html.
- Planning and Record Keeping, The Center for Children with Special Needs, Seattle Children’s Hospital, Research and Foundation: <http://cshcn.org/planning-record-keeping>.