

Fall 2001

Funded by a grant from the Helen F. Graham Foundation

DELAWARE



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

ABOUT THIS ISSUE

Welcome to our annual update edition that brings you information about what is happening at the Center for Disabilities Studies (the Center) and the Developmental Disabilities Council (the Council). Both organizations have new leadership, so we are taking this opportunity to introduce you to these new directors, to learn a little about them and the paths they are pursuing for these organizations. Annual updates also bring information about changes and accomplishments over the year. This issue will offer opportunities for involvement as well.

The Council is looking for new members. Council membership offers a wonderful way for individuals with disabilities and their family members to become involved with advocacy and policy setting at the state level and to meet great people who are passionately involved with disabilities issues across the state. We'll let you know how to do that.

The Council's major program, Partners in Policymaking, is beginning its tenth year, and we want to share with you what we

know about the impact of this program in Delaware and its continuing efforts to improve what it has to offer.

This spring, some of you may have noticed an issue of *delAware* that is shorter and more specific. This new publication, called *delAware: A Research Brief*, has been started by the Center to bring more information to the community in easy to understand and accessible formats.

Finally, the Center is working hard to expand our services and supports in Delaware. We have spent the past six months developing project applications to enhance prevention, systems change, and collaboration of disabilities services across the state. This issue will highlight our newly funded projects as a result of this effort.

I hope you enjoy this annual update issue, and please continue to contact me with your questions and concerns.

Sincerely,

Theda M. Ellis
Editor

delAware is sponsored by the University of Delaware's Center for Disabilities Studies and the Developmental Disabilities Council and funded by the Helen F. Graham Foundation. Comments may be made by calling (302) 831-6974 or TDD at (302) 831-4689, faxing (302) 831-4690, or writing to Ms. Theda M. Ellis, University of Delaware, Center for Disabilities Studies, 166 Graham Hall, Newark DE 19716-3301.

Editor: Theda M. Ellis, Associate Director, Center for Disabilities Studies; Copy editor: Nina Leech; Reporters: Theda M. Ellis, Carla Koss; Design & Production: Cindy Dolan

Change in leadership sees expanded commitment

The year 2001 has seen changes in leadership for both the Center for Disabilities Studies (the Center) and Delaware's Developmental Disabilities Council (the Council). With these changes has come an expanded commitment to improving the system of supports and services for Delawareans with disabilities and their families.

The Center's new leadership

Looking to expand the connections made by his predecessor, Michael Gamel-McCormick took over as director of the Center for Disabilities Studies on January 1, 2001. "We need to continue to foster and expand the connections made by Don Peters and Theda Ellis (the Center's current associate director)," says Gamel-McCormick. "Services need to be expanded, and the Center can help in several ways: be proactive, assess need, pull together, give consumers a voice."



Michael Gamel-McCormick,
Director of the Center for
Disabilities Studies

The Center's agenda

The Center lists five items on its 2001 agenda. First is adult services, the supports needed for adult family members with disabilities to live independently and well in the community. Over the summer, the Center applied for a grant to fund a family support initiative. With a range of disabilities to consider, the Center scheduled about 18-months worth of work to define the supports and services needed by Delaware's families.

"We are really focusing on this issue," stresses Gamel-McCormick, "getting it out to the legislature and the general public. We want to put the subject of adult services at the top of the state's agenda."

Items two, three, and four on the Center's agenda look at

- early intervention, the process of serving the needs of young children with disabilities.
- school inclusion, the process for mainstreaming students with disabilities into Delaware's public school system.
- ongoing program evaluation, the process in which the Center evaluates the continuing work done by the state's various departments.

Because of the direct connection to the community, education and training stand at number five on the Center's agenda. "Over the last six months," explains Gamel-McCormick, "the community education folks have received training that allows them to train others in turn. This (continuity) illustrates the ways that we are connected."

"There's also a lot of expertise on (the University of Delaware) campus that we'd like to tap into," adds Gamel-McCormick. "For example, the Ag college (UD's College of Agriculture and Natural Resources) currently has a landscape architect on staff who's promoting accessible gardening. Carol Krawczyk, A.S.L.A., uses therapeutic gardening to work with people with physical disabilities and is reaching out to include people with mental illness and developmental disabilities."

"And the folks at Health & Exercise Sciences are doing some interesting work in adaptive physical therapy," continues Gamel-McCormick. "We're reaching out and supporting their work and seeing what they can contribute to ours."

Finally, the Center's discussions on education and training include the currently required courses for a minor in Disabilities Studies. As a special-interest focus, the minor provides a unique opportunity for undergraduate students to pursue an understanding of the needs and challenges of individuals with disabilities.

For the first time last fall, an introductory course was offered to all of UD's first-year students. Taught by Gamel-McCormick and two parents with children with disabilities, the course exposed general-population undergraduates to the issues faced by people with disabilities. Through this interdisciplinary course, the Center for Disabilities Studies continues to foster and expand future connections in the community.

Continued on next page

Upper right photo: Amy Larsen of Ken-Crest Services, has completed three CDS certificate programs.

Commitment... (Continued)

The Council's new leadership

On July 16, 2001, the Council's new senior administrator began a hectic schedule of meeting new people and learning new protocols—a pace Pat Maichle takes in great stride. The Council chose Maichle (pronounced as "Michael") because of her ability to lead in a busy arena. Maichle's experience includes 20 years of advocacy on behalf of her daughter with disabilities and 12 years of work with the Delaware Division of Developmental Disabilities Services (formerly known as

the Division of Mental Retardation).

"This experience was a plus for Pat," notes Council member Theda Ellis. "Her years of advocacy at DMR and as a parent make Pat uniquely qualified for this position."

The Council's agenda

Given the Council's support, Maichle believes her three-item agenda fits well with the organization's goals for 2001. Her commitment to expanding awareness and aid, ultimately, will result in a



Pat Maichle, Senior Administrator of the Council

better quality of life for every Delawarean with a disability.

Number one—appreciating the hard work done by the Council's members. Not only is appreciation gratefully accepted, but it also stands as incentive for anyone thinking about joining the

Council. "The Council has always had very strong advocates for kids and adults," says Maichle, "and we need to honor them. We also need to increase the number of consumers and family members on the Council."

Number two—focusing on the Council's strategic plan for supporting Delawareans with developmental disabilities. The current areas of priority list education, employment, and housing. For funding reasons, these areas need to reflect federal and state priorities. As a result, the Council considers all often-heard complaints from the disabilities community and works to address each complaint with the government's help.

"The Council's objectives and activities need to meet the federal and state goals," explains Maichle. "Recently, the federal government extended the time frame for our strategic plan from three years to five, so we needed to

rework our effort to meet the need. We submitted the final draft in August."

Number three—working on the Youth Leadership Project. Obviously close to her heart, this advocacy program is a potential project for the Developmental Disabilities Council. "The goal," smiles the Council's new senior administrator, "is to teach kids how to advocate for themselves within the disabilities field and the community at large.

"I like working," adds Maichle, "to increase the state's awareness of the need for a better quality of life for all its people with disabilities."

Enhancing Community Education



These are exciting times in the Community Education program at the Center. Successfully training more than 400 professionals and paraprofessionals over the past six years to work with adults with disabilities, the Center has added new staff and new capacity to its training agenda. Mark Bernstein joined the Center in the fall of 2000, bringing more than 20 years of experience in the field. At the same time, staff assistant Carol Bernard took on new responsibilities as a trainer. The addition of their training, experience, and skills has propelled Community Education into new arenas and has allowed the Center to develop training outside the traditional certificates for support and management professionals.

Quality improvement and a systems change initiated by the Division of Vocational Rehabilitation (DVR) in the spring of 2001 spurred a great deal of this new effort. Working with Center staff, DVR identified training needs and requested training support for change management and team building. Participants learned communication and problem-solving skills as well as techniques for managing transition and building trust within the agency. "To support their needs," training coordinator Bev Stapleford states, "we established a learning environment that encouraged problem solving, team building, and self reflection using innovative and interactive training techniques. The great thing about the training was that we worked with entire teams of DVR staff, ranging from the director to the receptionist. We looked at people's strengths and abilities and how they can use their capacities in the quality improvement process." The entire training initiative lasted 11 days across the state.

During the spring and summer, there were other efforts as well. "Although we typically train those who work with adults, we expanded into the area of young children by developing training for parents in the Birth to Three Program," Stapleford added. "We also have new programs in supported employment, and we have worked with several agencies to meet their specific training needs, including Easter Seal, Brain Injury Board of Delaware, Goodwill Industries of Delaware, and Northern Delaware Early Head Start."

A new program for the fall is the Neighborhood Home Managers Certificate. This program is for both first-time and experienced managers of community homes. "Both the Division of Developmental Disabilities Services and group home provider agencies have been asking for a program for group home managers and supervisors. The neighborhood home manager has a unique opportunity to shape the quality of life in the home," says Stapleford.

And last, but by no means least, the Center is sponsoring an Executive Seminar Series: Management issues for leaders of agencies serving people with disabilities. Targeting leadership staff in agencies serving people with disabilities, the Executive Seminar Series will provide opportunities for top managers to meet together to look at best practices and to share ideas in a casual yet stimulating environment.

For more information about certificate programs, contact Carol Bernard at (302) 831-2305. If interested in contracting with the Center for specific training, contact Beverly Stapleford at (302) 831-4688.

The Council recognizes a few good folks and looks for more



"The most powerful advocates are always the folks who have personal experiences to share," according to Tess delTufo, chair of the Membership Committee of the Developmental Disabilities Council. "The feds recognize this. That is one reason the DD Act (Disabilities Assistance and Bill of Rights Act of 2000) has increased the membership on councils to be at least 60% consumers, parents, and guardians. It's also the reason that councils across the country have become leading advocates for policies and systems change."

"We are looking for a few good folks to help us meet this membership goal of 60% consumer or family. We would like to recruit people from around the state who represent a broader range of disabilities, ages, gender, and ethnic groups. To do this, we are developing a brochure in Spanish, and we'll be sending mailings to a wide number of organizations to get the word out. We also plan to get the word out on radio, so be listening to your local radio stations," says delTufo.

As part of the effort to expand membership, Pat Maichle, director of the Council, has spoken with representatives from DuPont and MBNA. According to Maichle, "Both organizations are offering wonderful support. They are giving employees release time from work to attend meetings during the day. Service on the Council is a community service, which these companies strongly endorse."

"Public recognition of contribution is also important," according to Maichle. To this end, the membership committee sponsored a fall picnic, inviting individuals, families, and businesses from around Delaware to participate. Again, Tess delTufo, membership chair advises, "We are recognizing community partners who have really helped move the system in Delaware. Our first honored recipient is MBNA." MBNA not only supports the Council by funding Partners in Policymaking, they also support a wide variety of other disability related activities across agencies. "At my agency, the Division of Vocational Rehabilitation, MBNA has supported job clubs for students with disabilities who are transitioning from school to work. We are seeing a significant increase in the number of students with disabilities who stay in school and graduate with a job. This transition effort has been due in part to MBNA's willingness to provide materials and supplies to students." (Editor's note: MBNA funds this newsletter as well.)

What do you need to know to be a Council Member?

The Council meets six times per year, the second Wednesday of every other month. There are also four program committees that meet monthly, and on occasion, ad-hoc committees. "The Council also encourages individuals to become involved at the committee level" says Maichle, "particularly if they are new to advocacy. Committees are smaller, and offer good opportunities to participate. We can pay for childcare and transportation. We don't expect individuals to have to pay in order to volunteer." Current committees focus on children and families, adult issues, rights and public policy, and membership. If you are interested in becoming a Council or committee member, you can contact Pat Maichle, telephone (302) 739-3333, fax (302) 739-2015, TDD (302) 739-4894, or e-mail, pmaichle@state.de.us.

The Center explores new directions



Keep your eyes open this fall as the Center

expands its current projects and goes off in some new directions. All the hard work spent developing projects during the spring is beginning to bear fruit.

Early Head Start Expansion

The Administration on Children, Youth and Families of the federal Department of Health and Human Services awarded funding for a major expansion of the Center's Northern Delaware Early Head Start (NDEHS) project. NDEHS serves pregnant women and children of low-income families from birth-to-three either in childcare centers or at home. Until now, this Early Head Start program has been located only in New Castle County. The expansion will move into Kent County.

"There are two parts to the expansion," explains Dr. Martha Buell, director of the NDEHS project. "We are going to add two new classrooms at Easter Seals Society of Del-Mar, Inc in New Castle County. These classrooms will serve 12 children, half of whom will have special needs. We anticipate these children will have severe disabilities because, typically, it's hard to detect milder disabilities at such a young age."

The second part of the expansion will be in the Dover and Smyrna area. Different from the expansion at Easter Seals, this will offer a classroom for eight children and a home-based service. "In the home-based option, Head Start services are provided in the home, including educating the parent or caregiver on nutrition, health, physical, social, emotional, cognitive and language development," Buell reports. There will be opportunities for 28 families to participate in the home-based service.

"The intent is to increase parental effectiveness and capacity because the parent is the child's first and most important teacher," says Buell. "Head Start is about supporting self sufficiency. We try to empower a pregnant woman or a family to get what they need to be independent. Some families have so many challenges they have a hard time getting back on track.

Early Head Start home visitors can locate resources such as job training, assistance with transportation to get there, and childcare. When we concentrate services in selected geographic areas, we promote community building by devel-



Allison Miller of NDEHS during a home visit in New Castle.

oping a network of families who can get to know, learn from, and support each other. When we support the community, it can support the family."

Who can use Early Head Start?

Families living at or under the poverty level with a child under the age of three are eligible for Early Head Start services. The income levels range from \$11,250 for a family of two, to \$28,650 for a family of eight. Once the income is established, priority is given as other factors that enhance eligibility emerge, for example: a child with a disability, parental incarceration, evidence of substance or physical abuse, or a non English-speaking family. Participation in any Head Start or Early Head Start program is strictly voluntary. If interested in more information, contact Michelle Cornwall by phone (302) 831-0472, e-mail Cornwall@udel.edu, by fax (302) 831-0474, or by TDD (302) 831-4689.

Foster Care Partnerships

The training partnership between the Division of Developmental Disabilities Services and the Center is growing to include INTERgeneration LINKS, Inc. (IgL), of Alexandria, VA and the Helen Graham Foundation. This project will develop a distance learning videotape course for Delaware adult foster caregivers and natural families. The Center's Bev Stapleford says, "Most foster parents work outside the home, so it's hard for them to take training. Using

distance learning, foster parents can get the information and skills they need to support adults with developmental disabilities in their home. We'll develop videos, provide memberships in Caregiver Connections (a national newsletter for caregivers), membership dues in the National Adult Family Care Organization (NAFCO), and telephone support to caregivers who participate.

"We are partnering with IgL because they specialize in adult caregiver concerns. They work with foster caregivers, natural family caregivers, and agencies all over the nation. We know they offer the experience and knowledge we need to make this our first distance learning project."

Family Support

A second federal award from the Administration on Developmental Disabilities provides funds to the Center to improve family support services for families of individuals with disabilities. Using the same tenets of family empowerment as Head Start, the family support project will emphasize improving supports to families of individuals with disabilities across Delaware. Neither age nor type of disability will be a limiting factor for this project.

The Center's Associate Director, Theda Ellis, describes three goals. "Currently, our systems are driven by disability label and age. Too often, children with disabilities grow up and lose the supports they need to live productive lives in the community as adults. Others are caught between agencies because they have multiple disabilities. Most adults with disabilities live at home with their family, and we have an increasing number of aging caregivers. We want to work collaboratively across state and community agencies to review policies and procedures and make recommendations for a more holistic approach to supporting families of individuals with disabilities. This will be done through a policy council of family members who have the experience and know what's needed to keep families together."

A second goal is to reach out to families, offering technical assistance to help them find resources and supports they need. Ms. Ellis continues,

"We plan to offer services similar to the Early Head Start project [described above] to any family with a child with a disability, whatever the age, or if Mom or Dad have a disability and need a little extra support." The two projects will work closely together to reach the widest number of families possible so that they may learn from each other's experiences.

"We plan to focus our outreach effort on minority families who don't always know what's available," says Ellis. "To do this, we will have a home visitor worker in Wilmington and another one in Southern Delaware. Their job will be to work closely with local families, communities, and organizations to provide information, training,

support, and connections."

The third goal, which Ellis finds particularly exciting, is to work with the Division of Developmental Services (DDDS) to try different funding possibilities. "By using Policy Council input and recommendations, we will work with families who are currently receiving family support services and try voucher systems or other means to give families direct control of the resources they use. Our ultimate goal is to have a system that is family-driven, easy to use, flexible, and culturally sensitive. While we don't expect to change the world in 18 months, we can develop a clear picture of what Delaware services and supports could be and what will be needed to make it happen."

After reading about the Northern Delaware Early Head Start program, we thought you might like to know more about what NDEHS does. Using a composite of several people enrolled in the program, this story illustrates what NDEHS has to offer.

Samantha's Family

Samantha J. enrolled in NDEHS's home-based program. Pregnant with her third child, her eligibility was based on her income, her pregnancy, and her 18-month old son, James, who enrolled at the same time. Then a caseworker began to visit for 90 minutes every week. During their first meeting, Leah, the caseworker, explained that the program is designed to meet family needs by offering information on early childhood education, health, nutrition, childhood safety, and other needs as they arise. Leah also explained that she would support Samantha as her children's first and best teacher.

Leah encouraged Samantha to go to prenatal appointments and follow her doctor's recommendations. During the following weeks, Leah provided information and education on what Samantha wanted to know. NDEHS offers education on topics including coping with stress, weight gain, smoking and drugs, sexually transmitted diseases, and pregnancy related information such as good prenatal care, what to expect at doctor's visits, pre-term labor, labor and delivery, childbirth preparation and getting ready for the hospital, breastfeeding, as well as general life skills such as budgeting and tips for fathers.

Over time, Samantha and Leah developed a trusting relationship. Together, they developed a Family Partnership Agreement (FPA) which set goals for the family and shared responsibilities in meeting those goals. Subsequently, Samantha delivered a healthy baby girl, Joanne. The family continues to receive weekly 90-minute home visits from Leah.

Samantha's newly acquired understanding of child development prompted her to express a concern that James might have a speech delay. Leah referred James to Child Development Watch (CDW) for screening and evaluation, and the evaluation confirmed Samantha's suspicion and identified some other issues as well. As a result, James is now getting speech therapy and other early intervention services from Easter Seals.

In eight short months, Samantha's family has come a long way. Samantha understands early childhood development a little better and makes sure that her children are up to date on their immunizations and physical examinations. Leah has helped Samantha to find a job and resolve some issues with her landlord. Samantha is going to parties and social events with other Head Start families and recently attended her first parent committee meeting. This family is now setting goals, and with support from their NDEHS family worker, they are getting the support they need to reach their goals.

The Partners in Policymaking program

A look at the value and accomplishments

When the graduates of the 2001 Partners in Policymaking (the Partners) program received their diplomas in September, each graduate had more than a diploma to show for his or her effort. These grads carried a newfound confidence, an ability to lead as well as to advocate for themselves and others.

A few past grads

Since its first graduating class in 1993, the Partners program has been instilling confidence and drive in consumer-advocates. Past graduates can boast accomplishments in many arenas, and a list of just a few of their names is impressive:

John Jefferson—an instrumental figure in forming a transportation coalition, bringing the people who rely on Delaware's paratransit services together with the members of the transportation system

Denise McMullin-Powell—a strong advocate for community-based services

Jamie Wolfe—an activist out of Delaware's chapter of ADAPT

Carl Kanefsky—the chief lobbyist for the Medical Society of Delaware

Phyllis Guinivan—the coordinator for the Consortium of Developmental Disabilities Councils

Dora Poppit—co-producer of One World, a cable program for people with disabilities, with Larry Henderson (executive director of Independent Resources, Inc.). A first-year Partners graduate, Poppit is now co-creating a Web site for graduates of Delaware's Partners program with her son Jason—who's graduating from the program this year!

Showing its value

"We want to show the value of the program," says Pat Maichle, senior administrator for Delaware's Developmental Disabilities Council, "and how far folks who graduate from the program can go to advocate for themselves, how they exhibit the leadership skills they are supposed to learn in the program."

With nine years of graduates working as top-notch advocates in the disabilities field, the program's funders think now is a good time for evaluating Partners in Policymaking. Taking the lead is Delaware's Developmental Disabilities Council (the Council) from getting feedback from participants, to increasing information flow.

Reviewing the program

As a national program, Partners in Policymaking has basically remained the same

since 1987, when it was founded in Minnesota. At that time, cofounders Edward Skarnulis, Ph.D., and Colleen Wieck, Ph.D., realized an essential fact: A lot of systems are built without input from the people who rely on the supports and services.

Skarnulis and Wieck believed that, for the system of supports and services to adequately support the people who used them, it needed to be consumer-driven. To this end, the Minnesota team envisioned people with disabilities as a group of well-trained advocates going up against congressional lobbyists. Creating that group became the focus of an intensive training program.

The majority of states continue to run true Partners programs, which require homework each month, one major project, and attendance during eight two-day training sessions, one session a month. Each of the sessions focuses on a different theme.

"We talk about everything a Delawarean with disabilities needs to know to advocate for systems change," says program coordinator Launay. "We try



Partners graduation 2001

to point out some pockets of excellence to inspire people to work for quality services."

To help define "quality services," each training session is held at the Dover hallmark of meeting places, the Sheraton. "If we, as advocates for people with disabilities, are going to talk about quality of life and big dreams," continues Launay, "we need to show what a 'quality life' is. Historically, we expected people with disabilities to talk to legislators about quality, but many [people with disabilities] have not had many opportunities to experience the finer things.

"The power of the program," adds Launay, "is teaching skills that many people in the

community (with and without disabilities) don't have. To be a good leader, you need to build alliances. You stand a better chance of getting systems change with others working with you.

"When I started Partners in 1992," remembers Launay of her then-new consulting contract with the Council, "there were few [people] who were sympathetic to the needs of people with disabilities. The legislators said, 'These people need to come to Legislative Hall.' Now, legislators don't say that anymore. They have strong, working relationships with people with disabilities, thanks to the Partners in Policymaking program, and that's been significant."