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.”

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 Krouczek, 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 us.”

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.

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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
Enhancing Community Education

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 programs 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 Seals, 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. "That is why we recognize this. That is why 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, age, 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) 739-3131, fax (302) 739-2255, TDD (302) 739-4996, or e-mail, pmaichle@state.de.us.
The Center explores new directions

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 and organizations 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 knowledge of 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 (DDS) 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 to identify systems or other means to give families better 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 look like and we can start to change that.”

By Lisa Ellsworth and the Center’s Policy Council.
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 graduates 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 Jefferon—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

Doris McMillin-Powell—a strong advocate for community-based services

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

Phyllis Guinan—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 Muschle, 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, co-founders Edward Skarnulis, Ph.D., and Colleen Week, 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 Week 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 home-work 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 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 excellence to inspire people to work for quality services.”

Partners in Policymaking program, and that’s been significant.”

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.”

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Address correction requested.