

Spring 2006

DELAWARE



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

Promoting Leadership in the Field



This issue of *delAware* acknowledges the efforts of people with disabilities, family members, advocates, and professionals in the disabilities field.

By identifying ways to represent all people in public policy and public discussions, mass media, and other avenues, advocates help define a more inclusive community. Many national and local programs are accessible to more people and promote independent living and self-determination because of the work of these dedicated leaders.

Even so, there is a growing need for more leadership development, according to Steve Eidelman, the University of Delaware's first Robert Edelson Chair in Developmental Disabilities. Current leaders, advocates, and organizational managers are aging and retiring, at the very time that the number of people with disabilities in the community grows. In response

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to the growing need, Professor Eidelman said, "We need leaders with a special skill set in the field today." The ability to make connections between grassroots movements, businesses, nonprofits and government officials, for example, is increasingly important today, according to Professor Eidelman.

Self-Advocacy and Family Member Advocacy

Historically, self-advocacy has been a catalyst for establishing disabilities rights. The People First Movement began in the 1960s and spurred nationwide deinstitutionalization. Along with deinstitutionalization came a demand for more appropriate services and service delivery. During this time, self-advocates had major influence on the way people with disabilities were treated in the larger community. Since then, self-advocacy and leadership training programs have helped to teach people with disabilities to become community leaders through direct action and by encouraging and mentoring future leaders.

Organizational Leadership

The most successful agency and program directors in the disabilities field meld business with an understanding of the individual needs of people with disabilities. Some current workplace topics include maximizing human capital, implementing an individualized service model rather than a medical model, and offering quality services on a limited budget.

Organizational leaders must be aware of these topics and other changes in a field that offers myriad services and also relies heavily on government funding. In light of this, innovative leaders also must continue to push for change on a systemic level using collaborative strategies that both are in line with quality services for people with disabilities and appeal to policymakers.

Professional Training

To address these issues and in recognition of the impending retirement of current national, state, and local leaders, a Summer Leadership Institute will be offered from July 9-15, 2006 at the University of Delaware. The week-long, intensive leadership development program is designed for emerging leaders in the field of developmental disabilities. The Summer Leadership Institute is co-sponsored by the ANCOR Foundation, the Council on Quality and Leadership, and the University of Delaware Center for Disabilities Studies.

Participants will get an overview of the best practices in services and supports for the individuals with disabilities and their families. Understanding human needs and government policies are both critical. The program aims to hone leadership skills and promote creativity in current and future professionals. Institute topics include public policy, leadership challenges, trends in developmental disabilities, government and nonprofit boards, and leading and inspiring people.

Institute Director Steve Eidelman expects the program to attract those with leadership potential who are passionate about the field of disabilities and who have the vision to engage people and move progressive programs forward. Participants will come from areas of management, program leadership, or senior direct support positions in organizations providing, advocating for, or funding community-based services and supports

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Successful leaders need a combination of management skills, knowledge of government policies, and creativity to offer quality, individualized services on a budget.

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for people with developmental disabilities and/or their families and communities. The Institute is designed to motivate the next generation of leadership and create a network of leaders in the field dedicated to quality services for people with disabilities and their families. The Summer Leadership Institute is a component of a larger initiative by the Center for Disabilities Studies to build a network of national disabilities leaders.

ABOUT THIS ISSUE



In preparation for this issue of *delAware*, I reflected on the people who I believe are leaders in the field. I consider it a blessing that many people come to mind because of their commitment to community inclusion and full participation of people with disabilities. I want to tell you briefly about two of them and their influence on me.

First, my cousin Blair has had the most influence on my decision to enter this field. He was beginning the process of transitioning from high school at the same time I was entering graduate school, and I researched transportation, employment, housing, and recreation for people with disabilities because I saw, firsthand, the value to our communities when all people are included. Blair and I graduated from our respective schools within weeks of each other. He now works through The Arc Northern Chesapeake Region's Supported Employment Program. He enjoys his job and values the relationships he has developed with his coworkers and others in his community. Second, Blair's mother, my Aunt Nancy, works in the field helping students with disabilities and their families navigate the transition process, and she also serves on boards and councils in Maryland. She uses the knowledge she gained as a mother to advocate for services and supports for many other families. Blair and Nancy are my leaders and my teachers and inspire the work I do.

At the University of Delaware, we are pleased that former Executive

Director of The Arc of the United States, Steve Eidelman joined the University of Delaware last fall as the first Robert Edelson Chair in Developmental Disabilities. As a Professor and Senior Policy Fellow with the Center for Disabilities Studies, Professor Eidelman will focus on elevating the quality of services and supports for people with disabilities through leadership initiatives. His vision for leadership training is truly inclusive, and he promotes leadership training opportunities for people with disabilities and their families, direct support professionals, and all levels of management and administration.

In Delaware, several organizations are addressing the need for leadership development in a number of ways, and we have highlighted a few of them in this issue. People with disabilities and their family members can become involved in advocacy through the *Partners in Policymaking* courses sponsored by the Developmental Disabilities Council. Self-advocates organize to promote for more supports for people with disabilities in the community through People First. The Center for Disabilities Studies will offer the first Summer Leadership Institute in Developmental Disabilities in July 2006 organized by Professor Eidelman. I hope this issue highlights the need for leaders in the field and profiles something you will consider getting involved in.

Sincerely,

Tracy L. Mann, Editor

delAware is sponsored by the Center for Disabilities Studies, University of Delaware and the Delaware Developmental Disabilities Council. If you would like to contact us, please call (302) 831-6974 or TDD (302) 831-4689, fax (302) 831-4690, email Tracy Mann, tlm@udel.edu, or write to *delAware*, University of Delaware, Center for Disabilities Studies, 166 Graham Hall, Newark DE 19716.

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University Welcomes Steve Eidelman



Steve Eidelman joined the University of Delaware faculty as the first Robert Edelson Chair in Developmental Disabilities in September. The Robert Edelson Chair, endowed by Lanny and Micki Edelson and named for their son, Robert, who has a cognitive disability, supports a faculty member who focuses on services and supports for adults with disabilities. With over 30 years of experience in the field of developmental disabilities, Professor Eidelman brings knowledge and prestige to Delaware. He expects to influence the quality of education about, advocacy for, and services to adults with disabilities and their families in Delaware, as well as nationally. Professor Eidelman teaches in the Department of Individual and Family Studies, is a Senior Fellow at the Center for

Disabilities Studies, and holds a joint appointment as Professor in the School of Urban Affairs and Public Policy.

Professor Eidelman began working with people with disabilities in group homes in Maryland. While pursuing his

graduate degree, he became interested in social justice issues; specifically, the deinstitutionalization movement of the 1960s which moved people with intellectual and develop-

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“We have an opportunity at the University of Delaware to teach students, practitioners, and policymakers about the intersection between research, public policy, and the lives of people with intellectual and developmental disabilities.”

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mental disabilities from the nation’s public institutions into the community. Professor Eidelman has spent his career considering the intersect between research, policy, and service provision. Describing his experience working with a community-based program,

Most recently as the Executive Director of The Arc of the United States, Mr. Eidelman developed new programs and increased the organization’s national presence. He has also served as the Pennsylvania Deputy Secretary of the Department of Public Welfare and Director of Mental Retardation Services for the Philadelphia Department of Public Health. By holding both government and nonprofit positions, Professor Eidelman has gained recognition in the field as a catalyst for change on issues of services and supports for persons with disabilities. The Robert Edelson Chair presented an opportunity for him to share this knowledge with future leaders in the field.

In his ongoing work in leadership development, Professor Eidelman has organized a weeklong seminar at the University of Delaware for the summer of 2006 to train leaders in disabilities issues. The University’s location is an



Steve Eidelman

epicenter for policy and practice providing professionals and students with the resources available to build strong leaders in the field. In his role as a University of Delaware Professor and Senior Fellow with the Center for Disabilities Studies, Professor Eidelman expects to use these resources as a basis for encouraging positive change in the field for people with disabilities and their families.

Alliance for Full Participation



The 2005 Summit of the Alliance for Full Participation (AFP) was held in Washington DC on September 22 and 23, 2005. The Alliance was founded by eleven leading agencies in the disabilities field. More than 2,000 people attended the Summit including people with disabilities, family members, and professionals and specialists in the field with a interest in providing resources to promote self-advocacy and community inclusion. Over 40 people from Delaware attended the event.

Discussion topics included ways to increase the self-direction of services; the high rate of poverty among people with disabilities, their families, and staff in the field; and Medicaid reforms. Emphasis was placed on prioritizing state initiatives for a more strategic approach to systems change. According to Jamie Wolfe, Chair of the Delaware Developmental Disabilities Council, the AFP Summit was a good opportunity to get national organizations together with their state affiliates. Ms. Wolfe stated, “People advocating in their states sometimes get state-specific about issues. This conference was a good chance to pull together and try to solve the issues we are all facing. We have to go beyond discussing the problems to look at what we are going to do to solve them together.”

Delaware priorities

State Team leaders were asked to submit a list of changes in policy or practice needed within their states to provide individuals with developmental disabilities better opportunities to become valued, contributing members of their local communities. Pat Maichle, Director of the Delaware Developmental Disabilities Council, chaired the Delaware State Team for the 2005 Summit. The State Team prioritized the need “for continuing education programs for people with disabilities, parents and caregivers, and families on self-advocacy, systems advocacy, and leadership through collaboration and creative models of training.” The Delaware priorities state, “We also need to support and champion existing advocacy training programs while growing programs across disabilities and collaboratively among multiple stakeholders.” Other priorities

listed include using community leaders to help mobilize and encourage trainers and trainees, offering leadership and professional development programs to train leaders within the system, and promoting the disabilities field among students and young professionals.

The abilities of individuals

By emphasizing the *ability* of individuals with disabilities to contribute and belong to the community, the 2005 Summit also demonstrated the need to recognize people with disabilities as active and essential members of the community.

Several groups from Delaware made their way to Washington DC for the Summit. Representatives from the Center for Disabilities Studies at the University of Delaware, the Delaware Developmental Disabilities Council, Delaware People First, the State Council for Persons with Disabilities, The Arc of Delaware, the Division of Developmental Disabilities Services, and other self-advocates represented Delaware.

The Summit attendees had the opportunity to meet people from other states and to interact and understand the common initiatives and barriers faced across the nation by people with disabilities. Speakers from states with unique programs also presented their experiences. Karen Jacobs, President of Delaware People First and a representative in Support Services at MBNA for the past five years, was a panelist during the town-hall-style meeting that closed the conference activities. Ms. Jacobs stated that her responsibilities as the President of Delaware People First include leading a group that speaks out for people with disabilities.

During the conference, Ms. Jacobs took particular interest in keynote speaker Martin Luther King III’s message that leadership means not only recognizing and achieving your own goals but also encouraging and supporting others to achieve theirs, as well. The Summit was the first time Ms. Jacobs shared her story with a large group. She reflected, “It reminded me that we need to keep trying to get people with disabilities into the community groups and continue to speak out for people with disabilities.”



Continuing Alliance for Full Participation Activities

While the Summit brought many people together to discuss policies and strategies concerning people with disabilities, the AFP continues efforts to promote a better and more fulfilling quality of life for people with developmental disabilities beyond this event. Made up of eleven leading organizations serving the developmental disabilities field, including the Association for University Centers on Disabilities of which the Center for Disabilities Studies at the University of Delaware is a member, the AFP promotes collaboration between organizations in the disabilities field. AFP’s objective is the full realization of meaningful, productive, and personally satisfying lives for people with disabilities living in their community of choice. The summit was coordinated by representatives from the American Association on Mental Retardation (AAMR), the American Network of Community Options and Resources (ANCOR), the Association of University Centers on Disabilities (AUCD), the National Association of Councils on Developmental Disabilities (NACDD), the National Alliance for Direct Support Professionals (NADSP), the National Disability Rights Network (NDRN), The Arc of United States, The National Association of State Directors of Developmental Disabilities Services (NASDDDS), United Cerebral Palsy (UCP), The Council on Quality and Leadership, and Self-Advocates Becoming Empowered (SABE). The event was sponsored by CDC, NISH, Therap Services, Amtrak, College of Direct Support/ MC Strategies, Mosaic, Ride-Away Corporation, Ability Magazine, The Mentor Network, Verland Foundation, and J. Maguire Memorial. For more information on the Alliance for Full Participation, visit www.AllianceForFullParticipation.org.

Community Members Learn Advocacy Skills



Individuals with disabilities and parents of children with disabilities are often looking for a way to become more involved, informed, and active participants in the policies affecting their lives and the lives of their families. In many cases, these individuals with disabilities and parents become community leaders and advocates. Many people have found success through their involvement in *Partners in Policymaking*. *Partners in Policymaking* is a leadership training program that offers education, training, and the tools needed for individuals to enact change in their own lives and in the disability community as a whole. Through information and up-to-date education, participants learn about legislation at the local, state, and national level and its effects on individuals with disabilities.

“Ordinary people, just like me, do extraordinary things to help our children with disabilities,” stated Ellen Coulston, a 2004 graduate of *Partners in Policymaking*. According to Ms. Coulston, she was able to learn about laws and the history of disabilities in the United States. Through learning about pioneers who advocated for groundbreaking legislation for people with disabilities, Ms. Coulston became motivated to continue advocating for her son and the disability community.

Partners in Policymaking was first developed by the Minnesota Governor’s Planning Council on Developmental Disabilities and spread nationwide to 40 states. Today, over 5,000 people have been trained through this program. In 1993, the Delaware Developmental Disabilities Council began its program and continues to offer the training today with great success. Almost 200 Delaware residents have completed *Partners in Policymaking*. According to Becky Allen, Executive Director of The Arc of Delaware, *Partners in Policymaking* is the main leadership training program of its kind in the state of Delaware.

Topics discussed during the training session include the history of the disability movement; inclusive education; community supports and supported employment; vision for the future and the planning process; assistive technology; local, state, and federal policy and legislative issues; how to meet public officials and give legislative testimony; community organizing; and working with the media.

A limited number of participants each year are selected through

an application process which seeks men and women of culturally diverse backgrounds from various regions of the state. Preference is given to adults who have developmental disabilities and to parents of young children with developmental disabilities. All sessions of the program are held in Dover, Delaware, and are conducted over eight, two-day sessions held once a month from March through October.

“My miracle is not for my disability to go away; a miracle happens when we give ability a chance,” stated Randy Chang, a 2003 graduate of *Partners in Policymaking*. According to Mr. Chang, he not only learned about social issues that affect him, but he also became motivated to share his talents with the community. Mr. Chang volunteers his time at nursing home ministries (currently serving three nursing homes), senior centers, and fund raisers for non-profit organizations. Additionally, Mr. Chang is the author of *The Rhythms of Life*, a collection of his poems and articles, and has played the piano at a variety of

charity events and functions including the Kennedy Foundation International Award Ceremony. *Partners in Policymaking* has inspired Mr. Chang to learn about disability issues and to continue serving his community. By being involved, he now feels he has reached his goal of full inclusion.

Participants in *Partners in Policymaking* gain understanding through a more in-depth examination of public policy and legislation regarding individuals with disabilities. By becoming well versed in these policies, graduates of the program are able to offer lawmakers and political figures a unique perspective that informs their voting on laws that will affect the disability community. Since graduating, Ms. Coulston has joined the executive board of the Parent Information Center of Delaware, which offers education and support to parents seeking to understand and utilize the Individuals with Disabilities Education Act (IDEA). Additionally, Ms. Coulston has co-founded the Brandywine

Special Needs PTA, the first of its kind in Delaware. The focus of the PTA is to help students with disabilities reach their full potential in academics and in their social lives.

Ms. Coulston stated that one of the most important and influential aspects of the program was developing friendships with her classmates. In addition to the speakers and classroom material, she learned a great deal from her classmates.

“*Partners* taught us about opportunities to participate on state councils and committees; and together, as classmates, we grew into disability advocates,” stated Ms. Coulston. After graduating from the program, many people with disabilities and parents become advocates for people with disabilities.

Partners in Policymaking is funded through the Delaware Developmental Disabilities Council, the Delaware General Assembly, MBNA Foundation

Helen F. Graham Grants Program, the Delaware Department of Education, and the Birth to Three Program. There is no fee charged to participate in *Partners in Policymaking*, and participants receive lodging and meals during the training. Additionally, personal attendant care, facilitator services, child care, and respite care may also be reimbursed on the basis of individual need.

Becoming involved and being active participants in the community is the main teaching and philosophy of *Partners in Policymaking* both in Delaware and nationwide. Ms. Coulston’s sons understand what disability advocates are and realize the importance of self-advocacy. They have participated in rallies and have delivered awards to legislators who have made positive differences in the disability movement. “My family and I have learned you have to be active in the process to affect the process,” said Ms. Coulston.

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University Undergraduates Learn About Disabilities

by Maggie Young, IFST '06

The University of Delaware undergraduate minor in disabilities studies introduces stu-

dents to a better understanding of individuals with disabilities and the disability community. In its ninth year, the disabilities studies minor has an enrollment of over fifty students this year.

To earn a minor in disabilities studies, students must complete three core courses and three elective courses in human development, social systems, and service delivery methods. The disabilities studies minor includes an introduction to the biological, social, and advocacy components of disabilities which creates insight into the lives of individuals with disabilities. The disabilities studies minor has broadened my horizons and given me the insight I need to be successful in my future career as a school counselor. The disabilities studies minor can benefit students in all majors and disciplines by providing a better understanding of people with disabilities and the laws, policies, and services that impact them.

Like many freshman and sophomore undergraduate students, I struggled to find my niche and the major that was right for me. I considered many different options includ-

ing special education, law, public relations, and working for a non-profit agency. I chose to pursue a degree in family and community services, and I want to pursue a career in school counseling. I credit my studies in the disabilities studies minor with helping me to clarify my career goals. I chose the minor for a number of reasons. I have someone close to me who has a disability, and I wanted to learn more about her particular disability and about the lives of people with disabilities. I also wanted to understand the cultures and communities that include people with disabilities. Additionally,



Maggie Young (l) and Christi Theron (r), a student in the Transition Partnership Project.

I knew that earning a disabilities studies minor would prepare me to be a more open-minded student who would ultimately become a more open-minded professional in my chosen career. I chose the minor because I knew it would complement my family and community services training and raise my awareness about the

ability of the community to serve all people.

The disabilities studies minor courses I have taken have affected me profoundly. Learning about the lives of people with disabilities has heightened my awareness and drive to serve all people in the community. My first course in the minor, *Families and Developmental Disabilities*, focused on the dynamic between people with disabilities and their families. The next course, *Introduction to Exceptional Children* (EDUC 230), offered insight and better comprehension of the experiences of schoolchildren with disabilities. The *Senior Seminar in Disabilities Studies* (HEPP 465) molded my outlook by building on my experiences in the minor. This course promoted hands-on experience through working with families of the Down Syndrome Association of Delaware to promote the *Buddy Walk*, an

awareness and fundraising event. I also learned about laws and regulations, including the Individuals with Disabilities Education Act (IDEA) and Individualized Education Plans (IEPs). Through these courses, I was able to learn about the impact of policies and laws on individuals with disabilities, their families, and society.

During the Fall semester of 2005, I completed *Transitions from Secondary Special Education* (EDUC 473). This course focuses on the comprehensive planning required when a student leaves special education and moves into adult life in the community. The most important and valuable aspect of this course has been my opportunity to work with a high school student through the Center for Disabilities Studies Transition Partnership Project. Through my friendship with this student, I have developed insight into this individual’s life and supported the student to self-advocate through the IEP process.

As a college senior reflecting on my experiences in the disabilities studies minor, I feel gratified by the understanding, respect, and knowledge I gained over my two years in the program. The results have far exceeded my original expectations. I have learned so much about disabilities, but more importantly, I have learned about individuals with disabilities. Completing the minor has added to my success as a student and rewarded me with the insight that has altered my perception of individuals with disabilities. I have become an interested and avid learner about the disabilities community, and I hope to continue learning and using my experience to become an advocate for inclusive communities. As a future school counselor, my disabilities studies minor will forever enable and motivate me to be an open-minded, informed, and accepting professional with all of my students.

Personal Experiences Drive Mom's Community Advocacy



Individuals often become community leaders because of a personal connection to a cause or organization. Many parents of children with disabilities advocate tirelessly for the needs of their child, and some turn that energy into community advocacy.

For 23 years, Judy Brimer has been advocating on behalf of her son, Ken, who has multiple severe physical disabilities. Her activism in the disabilities community began when



Judy (l) assists Ken at a REAL project fine arts class.

she joined a group of parents whose children attended the same school as Ken. Her involvement has developed into her current leadership role in a new organization for young adults with disabilities. The depth and breadth of Ms. Brimer's participation in advocacy activities is veiled by her humble nature and tendency to attribute credit to others, but it is clear that her commitment to her son has driven her to a larger focus on improving the lives of people with severe disabilities in Delaware.

When Ken entered John G. Leach School in New Castle, Ms. Brimer sought the company of other parents whose experiences reflected her own.

In the Colonial School District, the Leach School serves children and youth from ages 3 to 21 with physical disabilities. The warmth and inclusive nature of the curriculum at the Leach School carries over into the efforts and concerns of the parents. The atmosphere of the parents' group, focused on learning by sharing experiences with each other, inspired Ms. Brimer to explore other support systems for parents with young adult children with disabilities.

After learning advocacy skills through the Parent Information Center of Delaware (PIC/DE), Ms. Brimer joined and later became the President of the New Castle Parent Teacher Association. Ms. Brimer found that those with similar inclinations to advocate for their children with disabilities gravitate toward each other. By joining and supporting other groups and attending many conferences and information sessions offered in the area, Ms. Brimer met many other parents who were working for quality community services for their children. She describes the social interdependency that forms within the community of parents that drives them to continue their advocacy efforts.

Children with disabilities can receive services from the public education system through the age of 21. As her son grew older, Ms. Brimer and her family asked the question, "Where do we go when Ken turns 21?" With several other parents in the same situation, Ms. Brimer focused her energies on finding community services for young adults transitioning from the school system. Ms. Brimer recalls discussions with other parents also discouraged by the lack of quality, challenging day programs for their children. "These young adults have a right to continue learning," Ms. Brimer said, "and we needed to be the ones to create opportunities for that to happen."

The daunting undertaking of this task was an obstacle easily overcome by these parents. "This is where our heart is," said Ms. Brimer, referring to the children. Using their vision as a guide of what the future should look like for their children, the parents headed into uncharted territory and paved their own road. Eight years in the making, the Collaborative Effort to Reinforce Transition Success (C.E.R.T.S.) was recently founded. A collaboration of numerous community members, parents, and agency representatives met to

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begin their journey on the road to what C.E.R.T.S. has become today.

C.E.R.T.S. is currently searching for a location to house their programs, which include services for people with severe disabilities in the areas of functional academics, daily living skills, social community interaction, and recreational activities. These Resource Centers will be managed by a staff experienced in serving the needs of people with severe disabilities. Through the involvement of experienced members of the community and dedicated parents, C.E.R.T.S. will be launched in the spring of 2006. Grassroots leadership efforts, like the C.E.R.T.S. program, are typical of the ways family members create lasting impact on the community.

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