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.

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

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 Edelsohn 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 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 sparked nationwide desinstitutionalization. Along with desinstitutionalization 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.

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

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.

In preparation for this issue and the recent National Summit in Delaware for Leadership and Advocacy, Professor Eidelman said, “We need leaders on the policy side, as well as 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 to the workplace when I entered 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 last fall as the first Robert Edelsohn 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 development 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 Parren in Policymaking courses sponsored by the Developmental Disabilities Council. Self-advocates organize to promote viable options 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
University Welcomes Steve Eidelman

Steve Eidelman joined the University of Delaware as the first Robert Edelsohn Chair in Developmental Disabilities in September. The Robert Edelsohn Chair, endowed by Lanny and Micki Edelsohn 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, 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 developmental disabilities from the nation’s public institutions into the community. Professor Eidelman has spent his career considering the intersection between research, policy, and service provision. Describing his experience working with a community-based program, Professor Eidelman said, “I saw what was possible for people with developmental disabilities and became hooked on public policy.”

“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.”

Professor Eidelman expects to use these 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 engage students in critical thinking and research, and to help prepare them as leaders in the field.

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 its 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 for University Centers on Disabilities (AUCD), the National Association of Councils on Disability (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, Mosiac, Ride-Away Corporation, Ability Magazine, The Network, Verland Foundation, and J. Mague Memorial. For more information on the Alliance for Full Participation, visit www.AllianceForFullParticipation.org.
Community Members Learn Advocacy Skills

Individuals with disabilities are often overlooked 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. By providing information and up-to-date education, participants learn about legislation at the local, state, and national levels 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 session 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 for people with disabilities, and Ms. Coulston became motivated to continue advocating for her son and the disability community.

The University of Delaware undergraduate minor in disabilities studies introduces students 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, special education, and service delivery methods. The disabilities studies minor includes an introduction to the biological, social, and political aspects of disabilities, which creates insight into the lives of individuals with disabilities. The disabilities studies minor has broadened my horizons and given me the tools 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 including 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 the lives of people with disabilities. I also wanted to understand the cultures and communities that include people with disabilities. Additionally, I know that having 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 know it would complement my family and community services training and raise my awareness about the abilities 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 special relationship between people with disabilities and their families. The next course, Introduction to Exceptional Children (EDUC 250), offered insight and better comprehension of the experiences of schoolchildren with disabilities. The Senior Seminar in Disabilities Studies (HEPP 465) melded 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 the Individuals with Disabilities Education Act (IDEA). 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 focused on the transition planning and support a student receives 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 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 promoting 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, knowledgeable, and accepting professional with all of my students.
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 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 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.

Judy (l) assists Ken at a REAL project fine arts class. Summer Leadership Institute in Developmental Disabilities July 9-15, 2006 • University of Delaware Contact 302-831-6974 for more information. www.udel.edu/cds/leadership

SPONSORED BY • • •

Nonprofit Organization
U.S. Postage
PAID
Newark, DE
Permit No. 26