

# DELAWARE

Information for people with disabilities, their families and the professionals who support them.

## Self-advocacy



## ABOUT THIS ISSUE

**“W**hat does self-advocacy mean to you?” If you’re like the people who were interviewed for this issue of *delAware*, your answer is probably one of the following, whether or not you have a disability: standing up for what I believe in; making my own choices and decisions for what’s best for me; being able to speak up for myself in order to live the way I choose.

The importance of advocating on one’s behalf is the root of all social activist movements, according to a definition of self-advocacy on the website of the Research and Training Center on Community Living in Minnesota (<http://rtc.umn.edu/self/sadefinition.asp>). It states, “The self-advocacy movement was started by and for people with developmental disabilities because they wanted to be their own advocates rather than having others, such as professionals, parents and other family members, and advocates with or without other disabilities, speak about their needs and desires.”

In this issue of *delAware*, we look at the federal mandate to support the involvement of self-advocates; we explain how Delaware’s developmental disabilities network and other organizations support self-advocacy in the state; we review the experiences of Delaware’s delegation to the regional self-advocacy summit in March 2012; we explore some of the ways in which Delawareans, including two University of Delaware students, are involved in self-advocacy; and we include information about some of the programs that provide training and opportunities for self-advocacy.

The self-advocacy summit provided the inspiration to focus on self-advocacy as the theme of this issue of *delAware*. We appreciate the time that members of the Delaware delegation took to share their thoughts with us. Because of the wealth of valuable information provided, we are publishing a larger-than-usual newsletter and posting some “extras,” including an interview with Jamie Wolfe, on the Center for Disabilities Studies’ *delAware* website page, [www.udel.edu/cds/delaware.html](http://www.udel.edu/cds/delaware.html).

My special thanks to Meredith Cooke, graduate assistant with the CDS Dissemination and Advocacy unit, for conducting many of the interviews and writing some of the articles for this issue. Meredith is a school psychology major in the School of Education who is completing her second year at CDS. She will be serving as an intern in the Colonial School District during the 2012-2013 school year.

*Michele Sands*

Michele Sands, Editor

The Center for Disabilities Studies (CDS) at the University of Delaware supports the well-being, inclusion and empowerment of people with disabilities and their families. Our mission is to enhance the lives of individuals and families through education, prevention, service and research related to disabilities. We promote independence and productivity so individuals and families can fully participate in the life of their communities in Delaware and beyond.

CDS, the Delaware Developmental Disabilities Council and the Disabilities Law Program of Community Legal Aid Society, Inc. are partners in Delaware’s developmental disabilities network. Each partner receives a portion of its funding from the Administration on Intellectual and Developmental Disabilities, which is the U.S. Government organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. CDS also relies on public and private support from individuals, corporations, foundations and state and federal entities to operate its programs.

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*delAware* is published by Center for Disabilities Studies. Editor: Michele Sands. Designer: Cindy Dolan. CDS contact information: 302-831-6974 (phone), 302-831-4689 (TDD), 302-831-4690 (fax), [ud-cds@udel.edu](mailto:ud-cds@udel.edu) (email), [www.udel.edu/cds](http://www.udel.edu/cds) (website), 461 Wyoming Road, Newark, DE 19716 (mailing address).

## Developmental Disabilities Act Provides a Mandate for Self-advocacy

**“S**elf-advocacy has been a cornerstone of the Developmental Disabilities movement in the United States, starting over 35 years ago with the original People First organizing efforts.”

With this statement, Sharon Lewis, Commissioner of the Administration on Intellectual and Developmental Disabilities (AIDD), began a letter proposing a series of regional self-advocacy summits.

According to Commissioner Lewis, “The Developmental Disabilities Act (DD Act) makes clear the importance of the voice, influence and power of people with intellectual and developmental disabilities.” This legislation authorized a network of agencies for each state—the State Developmental Disabilities Councils (SDDCs), the University Centers for Excellence in Developmental Disabilities (UCEDDs) and the Protection and Advocacy agencies (P&As). These agencies “are expected to encourage and support the involvement of self-advocates,” the commissioner wrote.

Delaware’s network includes the Delaware Developmental Disabilities Council, the Center for Disabilities Studies and the Disabilities Law Program of Community Legal Aid Society, Inc. They are funded, in part, by the Administration on Intellectual and Developmental Disabilities (AIDD), which was known as the Administration on Developmental Disabilities (ADD) until mid-April 2012. Network partners use the funding to achieve AIDD’s major goal: to partner with state governments, local communities and the private sector to help people with intellectual and developmental disabilities reach their maximum potential through increased independence, productivity and integration within the community.

### Ensuring self-advocacy

Empowering individuals with developmental disabilities to become self-advocates aligns with the AIDD mission of “ensuring that individuals with developmental disabilities and their families participate in the design of and have access to culturally-competent needed community services, individualized supports and other forms of assistance that promote self-determination, independence, productivity and integration and inclusion in all facets of community life.”

When Commissioner Lewis proposed the self-advocacy summits, she noted, “Throughout the country, thousands of self-advocates are working at the local, state and national level to improve the lives of people with disabilities.

Collectively, we have accomplished a great deal, but we still have much further to go.”

As a result of the commissioner’s proposal, regional self-advocacy summits were held in 2011 and 2012. Each state’s delegation included representatives of its developmental disability network and self-advocates. Delaware was part of the regional summit that took place in Baltimore in March 2012 (see page 4).

### Community living initiative

The change in ADD’s name, to include intellectual as well as developmental disabilities, followed the creation of a new federal agency, the

Administration for Community Living (ACL), within the U.S. Department of Health and Human Services (HHS). The goal of the new agency is to increase access to community supports and full participation while focusing attention and resources on the unique needs of older Americans and people with disabilities. The ACL includes the efforts and achievements of the Administration on

Aging, the Office on Disability and AIDD in a single agency.

In her announcement about the ACL on April 16, 2012, HHS Secretary Kathleen Sebelius said, “All Americans—including people with disabilities and seniors—should be able to live at home with the supports they need, participating in communities that value their contributions.” She noted that, building on President Barack Obama’s Year of Community Living Initiative, “the ACL will pursue improved opportunities for older Americans and people with disabilities to enjoy the fullest inclusion in the life of our nation.”

There has been favorable reaction to the new agency from many of Delaware’s advocates for the rights of individuals with disabilities. Lisa Furber, senior paralegal with the Disabilities Law Program, said that additional focus placed on community living will help ensure that people are living in the least restrictive and most independent environment.

Jane Gallivan, director of the Division of Developmental Disabilities Services, said the new structure will reinforce changes in community living initiatives she is working to implement in Delaware. “It will support people to get jobs and live as independently as possible in their communities. It takes the focus away from institutional living. I am looking forward to innovative federal policy to support diverse choices for programs and funding for individuals and their families to live in their communities.”



Through membership in Delaware People First, adults with disabilities have many opportunities to become better self-advocates. Paula (right), who has received training as a “navigator,” helps Debbie develop an emergency readiness plan.



## UD Student Stands Up for What He Believes In to Bring About Change

**"P**rior to my accident, I was an advocate for people with disabilities. Since my accident, I advocate for myself and others [with disabilities] through legislative activism, raising awareness about disability issues and empowering youth to become leaders now. It's important to work individually and collectively to bring about change."  
—Clement Coulston

At age 11, Clem Coulston became a volunteer at the Mary Campbell Center, a Wilmington-area residence for people with a wide range of disabilities. He was motivated to work with people with disabilities because of the injustices he perceived when people view individuals with disabilities as having limited abilities.

When Clem was a junior at Salesianum High School in Wilmington, he gave a speech as part of the Spread the Word to End the Word campaign, a program supported by Special Olympics and Best Buddies. He recalls that there were "mixed reactions" when he encouraged fellow students to refrain from using the words *retard* and *retarded*. However, when Special Olympics Delaware staff members heard about Clem's talk, they invited him to get involved with Project Unify.

The goal of Project Unify is to educate, motivate and activate young people to develop school communities where all students are agents of change—fostering respect, dignity and advocacy for people with disabilities. Before long, Clem progressed from being a Unified Partner to serving as a coach. He is now one of 20 members on the National Youth Activation Committee.

### Becoming a self-advocate

Clem had just started his senior year of high school when a serious accident resulted in a brain injury. It was then that he realized the importance of becoming a self-advocate. "No one is going to do things for me—I need to advocate for things to be a success," he explained.

For Clem, self-advocacy is "standing up for what you believe in, voicing your beliefs, desires and what you know is right, and not being afraid to stand up to others—in a respectful way—especially when they react negatively."

Clem believes that change cannot take place if you do not raise awareness of "diffability" issues, a term Clem borrows from Tim Shriver of Special Olympics.

"We all have different abilities and that's a good thing," says Clem. "My goal is to break down stereotypes about people with disabilities, to change the low expectations most people have of our community. You can bring about change when you stand up for what you believe in and work as a group."

Through his efforts with one group, Delaware Kids Inspiring Kids, Clem is helping to empower elementary, middle and high school youth to become self-advocates. This group, which is sponsored by the Brandywine Special Needs PTA (BSNPTA), has conducted two programs for students with disabilities, their parents and the school personnel who work with them. The first program was a youth-led transition conference held in November 2011. Clem and three other students presented a program about being proactive self-advocates and shared the best approaches to help students with disabilities learn. According to Clem, this presentation "opened the eyes of teachers, parents and students" to the reality that students with disabilities can access higher education and be successful.

Clem has issues with memory and attention because of his brain injury. Now a student at the University of Delaware, Clem not only is raising awareness of his own needs, but more broadly of the need for the inclusion and acceptance of all people with disabilities. He meets with his professors at the beginning of each semester to let them know the ways in which he can be successful and what's hard for him. He is trying to make them aware that "I learn a different way, but I can learn" and to give them the chance to express their concerns and ask him questions.

Clem's experiences, however, led him to conclude that many teachers "don't get it." When one professor referred to his accommodations as "privileges," Clem realized how important it is for all students with disabilities to advocate for themselves and, in so doing, to pave the way for other students.

### Teaching self-advocacy and self-determination

This thought led to the development of a second Delaware Kids Inspiring Kids program, involving 12 hours of self-determination training for eight students in grades five through nine. Clem teamed up with Kathie Herel to develop curricula based on the skills, resources

and supports one needs to be self-determined. Both Clem and Kathie, coordinator of the Educational Surrogate Parent Program at the Parent Information Center of Delaware, volunteered their time.

"I loved it—it was a lot of work—but amazing to see them grow," Clem said of his experience with the eight students. The process and results of the training were demonstrated in a student-led BSNPTA Delaware Kids Inspiring Kids program on March 8, 2012.

To encourage greater self-advocacy and self-determination in people with disabilities, Clem would like to implement a program like Delaware Kids Inspiring Kids with more students. He also wants to provide training and awareness to teachers so they can use this self-determination approach with their students. Clem believes that learning self-determination is a step in the right direction for students to eventually lead their own IEP meetings and work towards independence.

Before his accident, Clem received advocacy training in the 2009 Junior Partners in Policymaking (JPIP) program. He has since put that training to use, meeting with state legislators and presenting testimony to the General Assembly about disabilities issues. Clem returned to JPIP in 2011 as a presenter for a session called "Teamwork, Advocacy and Leadership." His message to students with and without disabilities: "You're all leaders—find your skills and talents and learn how to contribute to society."

Through his advocacy efforts, Clem Coulston is certain to continue to make a contribution to society as an agent of change benefiting people with disabilities. Changing mindsets about what he calls diffabilities, empowering youth to take the lead, and raising awareness that all people have value are just a few of the short-term goals of this self-determined coach, mentor and UD elementary teacher education major.



Clem Coulston

## CDS Promotes Self-advocacy with Person-centered Programs

Person-centered planning is a flexible and creative process to assist an individual with or without disabilities in achieving positive and possible goals in their lives, often through self-advocacy. Many programs at the Center for Disabilities Studies that involve person-centered planning are part of the Transition, Education and Employment Model (TEEM) unit. The model offers people with disabilities a comprehensive set of services, supports and opportunities that will enable them to develop the skills needed to increase their independence, lead productive lives and participate in the community as adults. They focus on the person's needs and build upon the idea of self-determination—putting the person in charge of defining the direction for his or her life. Visit the CDS website at [www.udel.edu/cds](http://www.udel.edu/cds) for more information about the following programs.

The **Career and Life Studies Certificate (CLSC) Program** is a two-year, non-residential certificate program for students with intellectual disabilities (ID) providing academic, career/technical and independent living instruction in preparation for gainful employment or further postsecondary education. CLSC students attend classes, participate in internships and work experiences and engage in many campus activities. CLSC is a model demonstration program designed to deliver a high-quality, inclusive and comprehensive postsecondary transition program that assists students with ID to reach their employment, education and independent living goals.

**TEEM Employment Services** is a research-based program that utilizes person-centered planning in order to develop and execute an individualized plan for employment. This process promotes independence, productivity and job retention, creating opportunities for individuals to fully participate in the life of their community. CDS provides assessments, supports and other services that aid individuals in finding and maintaining meaningful positions that are a match for their skills and interests.

**Community Connectors** is a program for young adults with disabilities who want to build leadership skills, network and socialize in an environment independent of their families and caregivers. The program helps participants enhance their social interaction and communication skills and enjoy the success that results. Members set goals, receive individualized coaching and participate in personalized training sessions. They take part in recreational events, community service projects and fundraisers, often partnering with the University of Delaware fraternity and sorority community and other campus student organizations. Meetings are facilitated by coaches who work with the members to plan and implement the events.

### Self-determination

Programs that encourage self-determination for people with disabilities may lead to a change in the decision-making roles of family members. While the individual with a disability is learning to assume more responsibility for the path his or her life will take, parents who previously made decisions for their children, even as they grew into adulthood, may need to adapt to new roles in their (adult) children's lives.

To address this issue, CDS hosted a workshop in October 2011 that explored self-determination from the perspectives of parents and self-advocates. Sue Swenson, deputy assistant secretary for Special Education and Rehabilitative Services, U.S. Department of Education, addressed how parents and self-advocates can use the idea of self-determination to strengthen their families and build stronger relationships in their communities. Liz Weintraub, self-advocacy project specialist with the Association of University Centers on Disabilities and a member of the President's Committee for People with Intellectual Disabilities, shared her story and provided tools to help participants encourage others to become self-advocates. The event concluded with a panel discussion featuring the guest speakers and local parents, professionals and self-advocates. They presented their views about various scenarios relating to self-determination.



## Delaware Leadership Programs Create Advocates and Self-advocates

**O**n February 9, 2012, 23-year-old Gregory Gouge stood before members of the Joint Finance Committee in Delaware to speak about Partners in Policymaking (Partners), a program that transformed his life.

"I needed to find a way to not only fill the empty life I had but to make friends as well," he reported to members of the committee. "Now I have a chance to be great. Partners did that."

In 2010, Greg participated in Partners, a leadership training program of the Delaware Developmental Disabilities Council (DD Council). It offers education, training and the tools needed to enact change in one's own life and in the disability community as a whole. The program is designed for parents raising young or school-aged children with a developmental disability and for young adults with developmental disabilities.

"I now attend classes at Delaware Technical Community College, where I am studying to become an art therapist. I also do volunteer work at my local library as well as a local art gallery," Greg said in his testimony. "None of this would have even begun to be a possibility without Partners."

Partners in Policymaking was first developed by the Minnesota Governor's Planning Council on Developmental Disabilities in 1987. It is currently offered in 40 states, as well as other locations worldwide. Delaware's DD Council began its program in 1993. More than 200 Delawareans have completed the program, developing skills to teach policymakers a new way of thinking about people with disabilities.

### Partners trains future leaders

Partners provides current information, education and skill-building activities about the legislative process and local, state and national issues that affect individuals with disabilities. Participants attend two-day sessions once a month for a total of eight months; the program is conducted in even-numbered years.

Topics presented during the training sessions 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.

Pat Maichle, director of the DD Council, said that as a self-advocacy education program, Partners helps to create leaders. "Most of the leaders of the disability community in Delaware are Partners graduates," she said. "It is where we get DD Council members and other individuals committed to self-advocacy."

Several staff members at the Center for Disabilities Studies are Partners graduates, including Phyllis Guinivan and Gary Mears of the Health and Wellness unit. Although Phyllis has a Ph.D. in the biological sciences, she turned her attention to disability rights and advocacy after her youngest son was born with a developmental disability and she found it difficult to locate and access services for her family. After graduating from Partners, Phyllis joined the DD Council and became its chairperson. She then worked as member services manager at the National Association of Councils on Developmental Disabilities for 13 years before joining the staff of CDS.

Gary previously worked in mental health and health care settings before turning his interest to health-related research. Before coming to CDS, he worked on a variety of health science-related projects, including projects with the Health Resources and Services Administration and the Centers for Disease Control and Prevention. In recent years, he has focused his career on disability-related issues. Gary is the parent of a young woman with a developmental disability.

Jamie Wolfe, the Center's disabilities specialist, attended Partners as a self-advocate. In addition to her responsibilities at CDS, Jamie serves on many state committees as an advocate for people with disabilities.



Rep. Michael Barbieri of Newark met with 2011 JPIP participants during their visit to Legislative Hall.

### Junior Partners in Policymaking

To create a larger community of disability advocates and support the efforts of self-advocates, the DD Council designed an innovative program for youth and young adults in 2005. Junior Partners in Policymaking (JPIP) is held for one week during odd-numbered years at the University of Delaware. Individuals aged 15 to 22, with and without disabilities, learn the importance of self-determination and how to advocate for the issues most important to them.

Participants learn about the history of disabilities in the United States, including the development of the self-advocacy movement, the choices that need to be made when someone is trying to advocate for themselves, the tools to assist someone who wants to self-advocate, and how to campaign for initiatives that support self-advocacy or disability rights. Megan Pell, a UD doctoral candidate in the College of Education and Human Development and a graduate assistant at CDS, coordinated the program in 2009 and 2011.

"In addition to the formal curriculum, Junior Partners also offers interactive, on-campus living experiences, where personal self-advocacy kicks in," Megan said. "Our participants learn to self-advocate in social settings, as program staff facilitate activities for participants to get to know each other after class."

JPIP participants stay in dorms, eat in the dining hall and attend classes at UD. On the last day of the program, they use the advocacy skills they learned throughout the week during a visit to Legislative Hall. Here, they have the opportunity to meet with legislators. Megan explained the importance of this concluding experience: "The participants are not just learning the how-to's of self-advocacy, but also where to go and who they need to talk to when advocating for themselves or others."

Later on, as self-advocates, students who participated in Junior Partners

sometimes enroll in the senior Partners in Policymaking program, become DD Council members or find employment in the disabilities field, according to Pat Maichle. "The program has been an overwhelming success for people with disabilities," she said. "They get involved, get in touch with their own disability and become self-advocates."

CDS staff member Blake Bossert is a graduate of the first Junior Partners class. As a young man with a disability, Blake learned the skills needed to speak up and act on behalf of himself and others. He later completed Partners and served as a mentor in a CDS program that teaches people with disabilities how to avoid becoming a victim of violence. As someone who completed both JPIP and Partners, Blake said that both programs "teach you that you have a voice." According to Blake, JPIP is a great way to "get your feet wet so that if you wanted to participate in the senior Partners program next, you could use the knowledge and experience you already gained to be one step ahead."

"Junior Partners in Policymaking has created a network of young adults who can speak more clearly about their needs and the needs of people with disabilities, as well as their strengths," Megan said. "Information is power, and we have over 30 young adults in the community who—through Junior Partners—now have a language that allows them to more directly speak to their needs and the needs of others."

Funding for the Partners and Junior Partners programs originates from the Administration on Intellectual and Developmental Disabilities through a grant to the Delaware Developmental Disabilities Council. Other sponsors include the Delaware General Assembly, Interagency Coordinating Council and Delaware Department of Education.

Visit [www.ddc.delaware.gov/policymaking](http://www.ddc.delaware.gov/policymaking) for more information about Partners in Policymaking. Visit [www.udel.edu/cds/initiatives-adults-jrpartners](http://www.udel.edu/cds/initiatives-adults-jrpartners) for more information about Junior Partners in Policymaking.



Ashley Curran (center), 2011 JPIP co-coordinator, and two program participants enjoy working together on an activity.



## Delawareans Develop Self-advocacy Plan and Goals at Summit

A two-day summit in Baltimore, Maryland attended by self-advocates and professionals from Delaware has energized and empowered the self-advocates to make their voices heard by policymakers in their home state—and to encourage all self-advocates to do the same.

The March 2012 summit was one of four regional workshops organized by the Administration on Intellectual and Developmental Disabilities (AIDD) this year. A strong message emerging from the summit, according to CDS Director Beth Mineo, was the importance of engaging young people in self-advocacy. CDS Disabilities Specialist and self-advocate Jamie Wolfe agrees. She noted the emphasis on tapping into self-advocates who are 18 through 30 years of age.

Jamie attended the summit as a graduate of Partners in Policymaking, a program of the Delaware Developmental Disabilities Council. Since completing Partners, Jamie often conducts sessions on self-advocacy for the program. She summarized two of AIDD's goals for the summit: to hear comments from self-advocates about the direction and priorities of this federal agency and to provide direction to the representatives on building a strong disability agenda for each of their states.

Other self-advocates representing Delaware were Brigitte Hancharick, Bill and Barbie Monaghan, Drew Netta and Nancy Teel. In addition to Beth Mineo, professionals attending were Susannah Eaton-Ryan, manager of employment and outreach for The Arc of Delaware; Lisa Furber, senior paralegal for the Disabilities Law Program at Community Legal Aid Society, Inc.; Jane Gallivan, director of the Division of Developmental Disabilities Services; Carol Reid Hall, outreach coordinator for The Arc of Delaware;



*A facilitator works with Delaware's self-advocacy summit delegation to develop national-level advocacy recommendations.*

and Pat Maichle, director of the Developmental Disabilities Council.

Drew Netta said that by participating in the summit he helped contribute to the disability field “on a level beyond” what he ever thought possible. Drew has participated in Junior Partners in Policymaking and is a student in the Career and Life Studies Certificate (CLSC) program at the University of Delaware. He said he used to be shy and quiet—until he became involved in the self-advocacy movement.

“Becoming a self-advocate has helped me step up and become a leader, become a role model for other people,” he said. “I want to show people with disabilities how to have confidence and motivation to speak their mind and not be afraid to be judged.”

### Self-advocates take the lead

The summit was structured to ensure that self-advocates would take the lead in developing plans and making decisions for their states, Lisa Furber explained. AIDD Commissioner Sharon Lewis (who convened the summit) wasn't expecting the professionals to do everything, Pat Maichle observed, but instead just be a support for the self-advocates. “We were supposed to let the self-advocates take the reins: be in control of the discussion, presentation, decisions and recommendations. When the summit facilitators met with the Delaware group, they only called on the self-advocates. This approach was successful,” Pat said.

Jane Gallivan noted that it was “challenging” to let

## Empowering Delawareans to Advocate for Themselves

Delaware's delegation to the 2012 self-advocacy summit in Baltimore came home with a better sense of where Delaware stands in regard to self-advocacy for individuals with disabilities. “Delaware has work to do,” said Lisa Furber of the Disabilities Law Program (DLP) at Community Legal Aid Society, Inc., summing up the opinion of the entire group. “The people from Delaware can capitalize on their experience at the summit, continue their momentum and grow self-advocacy efforts,” she concluded.

The Disabilities Law Program is one of many organizations and agencies in Delaware providing services to individuals with disabilities while striving to empower their clients to advocate for themselves. “We provide self-advocacy materials, instruction and assistance to empower people to be able to advocate for themselves—this is important for people with and without disabilities. We give them tools to help them become better self-advocates,” Lisa explained. “We receive more requests for services than we can provide, so it helps everyone if we can help people advocate for themselves,” she said.

Lisa described DLP as being a law firm that protects the rights of people with disabilities, making sure they have equal access to housing, education, assistive technology and other services. For people with disabilities who live in an institutional setting, DLP works to ensure they are not abused or neglected.

As outreach coordinator for The Arc of Delaware in Kent County, Carol Reid Hall works with people with intellectual disabilities who live in the community to help them become as independent as possible. She thinks of herself as an “interpreter,” making sure that each of her clients understands what the system is asking of him or her, then assisting in conveying what the person needs, whether at a medical appointment or in court.

Carol also is the advisor to the People First program in Kent County, a group Nancy Teel has belonged to for more than ten years. Both women agree that the monthly meetings are creating better self-advocates, with programs about fire safety, financial issues, tips for organizing one's home, self-esteem, decision-making and goal-setting. Membership in People First has helped Nancy become more independent and advocate for herself, she said.

One of the goals of the Developmental Disabilities Council is to provide financial support to a self-advocacy organization in Delaware each year,

according to Council Director Pat Maichle. Through this goal, the Council promotes self-advocacy by helping to enable an organization to conduct meetings, provide its members with leadership training and opportunities, discuss current disabilities issues and participate in recreational opportunities.

Pat reported that the Council is researching a service called “PowerUP” that helps organizations reach their self-advocacy goals. It is offered by the Human Services Research Institute (HSRI) and includes three parts: assessment of how well a group is working; recommendations for actions the group can take to make it stronger; and making a plan with the group so it can grow stronger. See [www.theriotrocks.org/power-up](http://www.theriotrocks.org/power-up) for more information.

### Creating a strong self-advocacy voice in Delaware

Jane Gallivan, Director of the Division of Developmental Disabilities Services (DDDS), who was part of the self-advocacy summit delegation, hopes the plan that came out of the summit will help coalesce the state's efforts. Although three or four groups were named in the plan as self-advocacy organizations, Jane said she hopes “they will come together with one loud strong voice—in that way, they can make a bigger difference.”

Since becoming director of DDDS in October 2011, Jane has been concerned that self-advocacy in Delaware needs to be stronger. She pointed out that “there are pockets, but it's not well-coordinated.” Her main goal is to have a self-advocacy program with staying power.

“I'd like to be able to work with our partners to build a system, to make it more organized as a self-advocacy organization, not a social organization,” Jane said. She noted that self-advocates need to work with their peers on an agenda that includes such issues as exercising the right to vote, planning for disasters, achieving a healthy life style and other topics that are of concern to them.

“Some of the best training has been done by self-advocates regarding rights, because they are living these rights and recognize that rights come with responsibilities and consequences. That is a powerful message” Jane observed. “Self-advocates need to make themselves known to local legislators in order to keep the focus on the need for services, so the legislators will understand how these services support people to live meaningful lives in their communities.”



the self-advocates take the lead. “It takes time and a trained facilitator to get this process to work, but at the end, everyone benefits.” Because of her experience in state government, she was able to answer the self-advocates’ questions about the role of government and Medicaid and Medicare.

Carol Reid Hall agreed that the most important part of the summit was the people running it. “They deferred to the self-advocates always—they wanted to hear from the self-advocates first [then the professionals].”

Nancy Teel liked that the self-advocates sometimes met in one room, the professionals in another. “It was a good way to pick our brains,” she said.

Delaware’s self-advocates made all of the presentations on behalf of the state’s delegation, which was not the case for all of the states, Lisa pointed out. Beth Mineo said she was very happy with the group’s dynamics; the self-advocates assumed the leadership role with ease and everyone else supported them. “The team from Delaware was very cohesive.”

### The summit’s importance to Delaware

Before attending the summit, Delaware state team members met to outline the successes and challenges of the self-advocacy movement in the state. Self-advocates in Delaware have a history of advocating at the state level for services and supports, often under the leadership of graduates of the Partners in Policymaking program. Self-advocates serve on various boards, state councils and committees, act as teachers and mentors, and influence state legislation and budgets.

Nancy found it “really, really fantastic” to meet people from different states and compare their situations to Delaware’s. She and other delegates agreed that, despite many successes, Delawareans continue to face a number of obstacles to improving self-advocacy efforts. The lack of transportation is one of the biggest barriers for people with disabilities, according to Bill and Barbie Monaghan. As president of the People First program in New Castle County, Bill tries to help members with transportation and other issues so they can participate in this self-advocacy organization.

On the first day of the summit, Bill and Jamie reported on the plan the delegates had developed for Delaware. Transportation was the focus of two of their goals: (1) to establish Sunday and evening accessible bus service and (2) to assure that a self-advocate is at the transportation decision-making table whenever changes are made that affect the disability community. Other goals involved self-determination, the Employment First initiative and the Money Follows the Person program for all people with disabilities.

After hearing from members of each state team, the Delaware delegation met to define state and national goals for the future. The first state-level goal is to establish individualized self-directed community-based services and supports for people with all types of disabilities. Terri Hancharick, who attended the conference with her daughter Brigitte, a self-advocate, explained that self-directed support means that instead of funding flowing to an agency or to a building, it would be given directly to the person with a disability to choose his or her own supports.

“Brigitte, who has multiple disabilities, uses a wheelchair and is nonverbal, could use that money to attend conferences and travel to increase her self-advocacy,” Terri said. “She could also use it for tuition for classes where she’s matriculated with typical college students. We’re hoping that this summit will push us farther in the direction of self-directed supports and give self-advocates more leadership roles in the community.”

The second state-level goal is to survey people with disabilities to determine what they “want, need and are willing to do with regard to self-advocacy.” Drew and Jamie were selected to begin reviewing resources



Bill Monaghan and Jamie Wolfe present Delaware’s self-advocacy plan to summit participants in Baltimore.

that already exist in Delaware and identify whose voices are missing.

### Perspective on the national agenda

On the second day of the summit, Drew and Barbie presented the Delaware team’s recommendations for advocacy and action on a national level. The first recommendation is for AIDD to develop a national anti-stigma campaign that is culturally, linguistically and ethnically sensitive—a recommendation that struck home for many members of the team.

Barbie said she is “so happy they put in the law for the R-word.” She was referring to “Rosa’s law,” signed by President Barack Obama in 2010. It mandates that federal statutes will no longer use the term *mental retardation*—the replacement phrase is *intellectual disability*. Barbie shared her own experiences of having been labeled by a reporter with the R-word and needing to explain the nature of her disability.

The second policy recommendation requires agencies in the developmental disabilities network to work together on a plan to strengthen self-advocacy by improving accessibility and using respectable language, as well as supporting the hiring of individuals with disabilities by the network partners.

### Moving forward

Although there is much work left to be done to accomplish these goals at the state and national levels, both the self-advocates and professionals on Delaware’s team believe that the summit was a game-changer in the conversation about self-advocacy. “Sharon Lewis made us realize the power of self-advocates,” Pat Maichle stated. Jane Gallivan said she thought the summit made us begin to take a look at what we’re doing in the state.

Carol Reid Hall, who serves as the advisor for the Kent County People First program, agrees that Delaware needs more emphasis on self-advocacy. She noted that some state governments include a self-advocacy position held by a person with a disability. While Carol would like to see a push for such a position or department in Delaware, she also suggested the formation of a self-advocacy group that legislators can consult for their expertise on disability issues.

The summit reinforced the importance of self-advocacy for Bill, who said he learned to become a stronger self-advocate. He hopes to use what he learned at the summit to train more advocates to be stronger through participation in People First.

Terri said that being able to attend such meetings is Brigitte’s way of contributing. “Just seeing her at the table, her presence, is advocating for her. People see Brigitte and know that individuals like her can be part of the community and enrich the community.”

The summit also helped Drew think more about his future in the field of self-advocacy. “When people usually think about what ‘disability’ means, they think of something that holds you back. I see it as a gift, something I was blessed with, that really motivates me. I’ve become so independent, with the support of my advisors and student coaches. They’ve helped me gain so much confidence. Now I want to set an example and inspire others to do things they may never have thought possible for them.”

## Resources Suggested by Summit Participants

### Delaware People First

Delaware People First provides a forum for adult self-advocates to network, discuss issues of importance and enjoy social interactions. Members meet on a regular basis to learn about policies and developments in housing, transportation and employment, and to determine the impact of these issues on their lives. The groups in Kent and New Castle counties are affiliated with The Arc of Delaware ([www.thearcofdelaware.org/support/empowerment](http://www.thearcofdelaware.org/support/empowerment)). The Sussex County group is sponsored by Independent Resources, Inc. ([www.iri-de.org](http://www.iri-de.org)).

### Delaware Aspergers Support and Advocacy Group

Delaware Aspergers is a support and advocacy group for individuals with Aspergers and their parents. It is led by these individuals, as well as those with similar diagnoses, such as Autism Spectrum Disorder, Pervasive Development Disorder (Not Otherwise Specified) and high functioning autism. Monthly meetings are held in New Castle County at Nemours/A.I. DuPont Hospital for Children. To learn more about this organization, contact Bill Doolittle at [delawareaspergers@verizon.net](mailto:delawareaspergers@verizon.net).

### Turners Syndrome Society

Delaware has a chapter of this national organization, thanks to the efforts of Tina Fields, a Wilmington-area resident. The Turner Syndrome Society of the United States (TSSUS) provides health-related resources to patients, families and physicians for the diagnosis and treatment of Turner syndrome. TSSUS holds an annual conference that provides an opportunity to exchange information on many topics of interest to individuals of all ages with Turner Syndrome. There are chapters and support groups located throughout the country. See [www.turnersyndrome.org](http://www.turnersyndrome.org). To learn more about the Delaware Chapter, contact Tina at [tsangels1@verizon.net](mailto:tsangels1@verizon.net) or 302-292-6810. (See Tina’s photo at the top of page 1.)

### Self-Advocates Becoming Empowered

Self Advocates Becoming Empowered (SABE) is a national self-advocacy organization dedicated to achieving full inclusion of people with developmental disabilities in the community in this country and the world. It is run by a board of self-advocates representing nine regions of the United States. To learn about SABE’s missions, beliefs and goals, and for information on joining, see [www.sabeusa.org](http://www.sabeusa.org).

# Best Buddy Billie Jobson Believes in Self-advocacy for Everyone

When Billie Jobson was in elementary school, she struggled to read and write. Yet she was able to overcome these difficulties with the appropriate resources and support, including a teacher who “stepped back” to help her. At the time, she didn’t realize that not everyone “outgrows” these kinds of problems.

“I want to do that for someone,” said Billie, recalling the teacher who helped her. Billie’s degree in elementary teacher education with a concentration in special education—her minor was in disabilities studies—is bringing the 2012 University of Delaware graduate closer to realizing this goal. Shortly after graduation, she was hired as a second grade teacher in Lancaster, Pennsylvania. Billie believes her special education background will make her a better classroom teacher, and she plans to encourage her students to make the choices she knows they are capable of making.

Just as Billie knows what’s right for her—and she wouldn’t want others making decisions for her—she feels the same way about individuals with intellectual disabilities and differences: They need to learn self-advocacy so they can have the same rights as people without disabilities, so they can stand up for themselves, take ownership and make their own choices and decisions about what’s best for them.

## “I’m big on advocating for people with intellectual disabilities.”

From a young age, Billie knew she wanted to be a teacher, but not in a typical classroom setting. When she learned about special education, she thought, “That’s something I think I could be passionate about.”

As a student at Southern Regional High School in Ocean County, New Jersey, Billie began to pursue that passion. She took time from study hall to help students with disabilities who were assigned to a self-contained classroom. When she learned that these students wouldn’t be attending the junior prom, she helped them organize a prom.

Billie continued her efforts to advocate on behalf of students and others with disabilities when she enrolled at UD. She became involved in Best Buddies, an organization that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities. She also worked on the annual Spread the Word to End the Word campaign. This program, supported by Special Olympics and Best Buddies to encourage people to refrain from using the words *retard* and *retarded*, has been a been “a huge part of my college career,” said Billie.

Through her work with Best Buddies (she was president when the UD chapter received an Outstanding Chapter award), Billie was able to give people with developmental disabilities the opportunity to become more independent. Although she modeled behaviors for her buddy—like others in the UD Best Buddies group—



Billie Jobson staffed tables at Trabant University Center and Perkins Student Center to encourage UD students to pledge not to use the R-word.

she and her buddy worked together to build a friendship. Each UD buddy established an individual plan with his or her buddy, all of whom were from the Career and Life Studies Certificate (CLSC) program during the 2011-2012 academic year. They decided on a place to meet and often just “hung out” at the UD student’s dorm; this gave the CLSC buddy a better idea of what college life is like, Billie said.

UD students also have off-campus buddies who are residents at the Mary Campbell Center, where they enjoy weekly individual visits and a group activity once a month. “Some residents only see staff and other people with disabilities, so they enjoy having the buddies come,” Billie explained. “When we come in, they choose what they want to do.”

The segregation of people with disabilities (by others) is of concern to Billie, who notes that some people with disabilities choose to segregate themselves. To involve more people with disabilities in advocating for themselves, “We need to break down the barriers and get everyone to advocate. It needs to be a community effort, based on need, not ability,” asserts Billie.

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Center for Disabilities Studies  
College of Education and Human Development  
University of Delaware  
461 Wyoming Road  
Newark, DE 19716  
Return service requested.