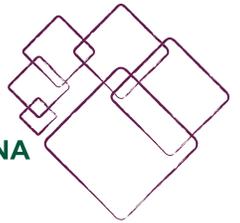


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DISABILITY RIGHTS
NORTH CAROLINA

Champions for Equality and Justice



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Support and Strong Self-Advocacy Skills Lead to Independence



Bethany Smith, left, and Kristine Sullivan, attorney with Disability Rights NC.

By all appearances, Bethany Smith is living a typical life for a young adult. The 25-year-old student at Pitt Community College shares an apartment with two young women in a pleasant community populated by other students. She hits the books, catches favorite shows with a roommate, and dyes her hair interesting colors.

But for those who have known her for a while, these ordinary details seem quite extraordinary. No one knows that better than

Continued on page 2

October 1st began a new year for Disability Rights NC. In the middle of this newsletter, you will find a separate publication that outlines our work plan and targets for 2016.

From the Director

Happy New Year! Well, it's a new year to us since our fiscal year restarts every October 1. Our new year brings new Target areas for our work



(see insert) and new laws from the General Assembly.

Among the new laws impacting people with disabilities is a framework for moving the state's entire Medicaid program from fee-for-service to a managed care

Continued on page 2

Inside This Issue

2016 Conference Keynote Speaker3

Cooper's Story.....4

Retired: Christine Trottier.....4

General Assembly Session Wrap-up6

Issue Spotlight: Higher Education.....7

Insert: 2016 Targets

From the Director

Continued from page 1

model. This means the rest of Medicaid will catch up with the Behavioral Health side of Medicaid (our MCOs). Under the new system, the state will stop reimbursing all Medicaid providers for each service and, instead, will provide a per capita payment to managed care entities for each Medicaid patient they enroll.

So in the coming year, NC DHHS and its Division of Medical Assistance will need to create rules to make sure people receiving Medicaid services continue to have access to quality care. There will be lots of organizations keeping an eye on this process. And we will be one of them. Disability Rights NC will be working hard to protect the services Medicaid beneficiaries with disabilities need to remain healthy and independent. Creation of new rules will require a good bit of patience on everyone's part but it is critical that the flow of information remain open. Policymakers need information from advocates to build a system that will ensure and enhance the well-being of Medicaid recipients. If the doors of conversation close, the people we work so hard to protect may lose.

Join us in making a new year's resolution to overcome our differences and work together with policymakers to create a Medicaid system that benefits the people who need it.



Vicki Smith, Executive Director

Support and Self-Advocacy Skills

Continued from page 1

Kristine Sullivan, an attorney with Disability Rights NC, because she and Bethany met about two years ago under very different circumstances.

As a member of the Investigations and Monitoring Unit at Disability Rights NC, Kristine visits hospitals and other facilities that treat people with disabilities, watching for abuse and neglect and advocating for appropriate remedies when patients' rights have been violated. It was on a monitoring visit to Cherry Hospital that Kristine met Bethany, who was undergoing treatment for behaviors related to childhood trauma. Bethany struggled with self-injury and an eating disorder. She had been admitted to mental health facilities several times during her adolescence, and was now at Cherry for what would be a two-year stay.

Even during those difficult years, when Bethany often needed intense therapy and a staff person by her side 24 hours a day, Kristine could sense her strength. "Bethany has a huge spirit and she's very creative," said Kristine, remembering how she watched as Bethany and her friends sang a take-off on Little Orphan Annie's "Hard Knock Life" for a patient talent show. Bethany wrote poetry and spoke to new patients at orientation sessions. For the patient newsletter, she wrote a 10-page article on changes to criteria in the DSM-5, the Diagnostic and Statistical Manual of Mental Disorders.

In her role as an advocate, Kristine served as a resource for Bethany. If Bethany was having issues with the hospital staff or rules, Kristine helped her understand her rights and sort out what she had to accept and what she might have a right to challenge.

So last year, when Bethany experienced problems at a different hospital, she knew what to do. If she hadn't known Kristine, she said, "there wouldn't have been anybody I could have called." Bethany had been improperly restrained. Federal law prohibits the use of restraint on patients in psychiatric hospitals unless their behavior puts themselves or others in danger. When Bethany told Kristine about the incident, Disability Rights NC launched an investigation.

Footage from the hospital's security cameras confirmed Bethany's description of what happened. She had been on a phone in the hallway when approached by staff to be taken to an acute ward. The video shows that she had sunk to the floor, and that she was not being aggressive in any way when hospital police officers arrived, donned gloves, and took her by her arms and legs to another part of the ward, her hospital gown dragging on the floor.

Still, it wasn't clear to Bethany that her rights had been violated. "I was upset and angry," she said, "but I didn't know they had broken the rules." She was surprised when Kristine called to

tell her the results of her investigation.

Disability Rights NC had submitted a complaint to the Division of Health Service Regulation, which found deficits in the hospital's training and procedures, particularly around the use of restraints. The agency determined that excessive force had been used in the incident involving Bethany. The Centers for Medicare and Medicaid Services notified the hospital that it must improve its policies and procedures to continue receiving federal funding.

When Bethany visited the hospital again for a medical condition, she was pleased to see improvements. She did not see anyone restrained while she was there and, on the wall by the phone she had used, was a big poster about patient rights. "It was taller than me," she laughed.

Happy to be out on her own now and engrossed in her studies, Bethany looks forward to the day she will walk across the stage for a post-secondary degree and begin a career as a patient advocate. It goes without saying that she will have a great deal of empathy for those she serves. She is driven to educate others about the experience of being institutionalized, and is writing a book.

"I'm not going to be able to get rid of all the ignorance, but one of my goals is to raise awareness and get rid of stigma," Bethany said. "That is my purpose."

Disability Rights North Carolina is a federally mandated protection and advocacy system with funding from the U.S. Department of Health and Human Services, the U.S. Department of Education, and the Social Security Administration. It is a 501(c)(3) nonprofit organization.

Disability Advocacy Conference Keynote Speaker Announced for 2016 Conference

The Honorable Kristin Booth Glen will join us as the keynote speaker for the Disability Advocacy Conference scheduled for April 20, 2016. Judge Glen will share her thoughts on how the disability rights movement has helped transform society's view of incapacity and how the law should respond to a paradigm shift from guardianship to supported decision-making.

Judge Glen is dean emerita of the CUNY School of Law. She served as a judge on a number of New York courts and retired in 2012 from her position as a judge on the New York County Surrogate's Court. Her final decision as a judge captured the attention of the autism and special needs communities when she proposed that banks and special needs trustees should take proactive steps to determine the needs of people with disabilities and to spend trust money to

improve their beneficiaries' lives. It is not enough to simply invest the trust assets; the trustee has a legal responsibility to visit the person with a disability, inquire about his condition, and apply trust income to improve his life.

Registration for the 2016 Disability Advocacy Conference will open in December. In addition to the keynote speaker, the staff of Disability Rights NC will offer a number of breakout sessions on topics such as disability law trends and updates, Medicaid law and appeals, alternatives to guardianship, special education, resources for people with disabilities, employment, and full access to community living. The popular networking lunch tables will return this year as well as your favorite exhibitors from last year along with new ones offering information on adaptive yoga and relaxing chair massages.

Young Man Builds Career Skills After Receiving Supportive Services

Sesame hummus bites, San Diego fish tacos, and Caribbean shrimp and rice salad. Cooper Johns served up a heaping table of delicacies last summer to the delight of friends, family members, supporters, and teachers alongside his fellow graduates at the Eliada School of Trade Arts (ESTA) in Asheville. While the spread demonstrated that Cooper had risen to the challenge of learning sophisticated culinary skills in his year at ESTA, the occasion also served as a celebration of Cooper's success when faced with a number of other challenges.



Cooper Johns, left, and Lisa Nesbitt, attorney with Disability Rights NC.

Cooper was 15 years old when his parents first asked Disability Rights NC to help secure the services he needed, was entitled to, and simply was not getting on a consistent basis. Cooper has a diagnosis

of autism spectrum and ADHD. His difficulty in managing the stressors of school put him at risk of institutionalization.

Disability Rights NC helped Cooper get basic support services in place. Within an improved environment, Cooper excelled in his class work, earning high grades and taking early college courses. After high school graduation, numerous holes in the service system sent him into a downward spiral that led to homelessness and joblessness with no prospect of continuing his education.

Eventually, through diligent advocacy and coordination with his case manager, Disability Rights NC helped Cooper enroll in the ESTA program at Eliada in Asheville (www.eliada.org). The program not only provided culinary training, which he now plans to continue, but gave him a safe and stable place to live, extensive life skills training, and invaluable support of caring mentors.

Cooper is now looking at the future with hope, and those of us who have come to know him could not be more proud!

Dedicated Attorney Retires



Christine Trottier, center, celebrates her retirement with longtime colleagues Lisa Rabon, left and Debbie Thome.

Christine Trottier began advocating for people with disabilities as a new attorney in the 1970s, well before passage of the Americans with Disabilities Act, before the *Olmstead* decision held that people with disabilities have a right to live in the community, and before the Individuals with Disabilities Education Act made the Individualized Education Plan commonplace for students with disabilities in public schools.

At that time, the fledgling Carolina Legal Assistance (CLA), which Christine helped launch, was advocating for clients in psychiatric hospitals who were denied basic rights, including the right to refuse treatment. For example, CLA represented a woman who was declared incompetent through the "lunacy statute," without notice or hearing, when she refused surgery as a cancer treatment.

Christine worked alongside executive director Deborah Greenblatt to achieve steady reform in those early years, including repeal of that statute. CLA filed successful class action lawsuits. One case brought services to children who were being denied appropriate education and treatment. Another brought relief for adults who were being illegally confined in psychiatric facilities.

When Deborah Greenblatt became ill, Christine helped steer CLA through a process that ended in its 2007 designation as North Carolina's Protection and Advocacy System, responsible for protecting the rights of North Carolina citizens with disabilities under the Americans with Disabilities Act and other federal laws. CLA was renamed Disability Rights North Carolina later that year.

Eight years after redesignation, Christine leaves

an agency focused on the highest priorities of North Carolinians in the area of disability rights. And she leaves a community of advocates and attorneys who she mentored with her passionate and determined leadership.

One of her signature projects was the Special Education Juvenile Justice Project (SEJJP), which advocates for students who have been caught in the school-to-prison pipeline. As Christine recently wrote, "Illiteracy and disability-related behaviors are the biggest predictors for school suspensions. Student reading problems often become behavior problems, which lead to suspensions and court referrals."

The SEJJP has achieved systemic changes that go beyond its individual cases, including robust training for teachers and administrators and less reliance

on suspensions and other disciplinary exclusion practices. The focus on systemic change has been an underlying theme throughout her career. She builds things, with an eye toward maximum impact.

Christine retired in July. As we bid her farewell, we offer gratitude for her extensive contribution. As noted by her longtime colleague John Rittelmeyer, Director of Special Litigation at Disability Rights NC, "Chris never wavered from her high standards -- always demonstrating immense skill, tact and a quiet determination in her advocacy. Chris never phoned it in."

Christine's legacy lives on in the skills and determination developed by the dozens of advocates and attorneys who she mentored. As Executive Director Vicki Smith said, "You are the model to which I think we should all aspire."

Education Team Continues to Challenge Exclusion

Christine Trottier may have retired, but Disability Rights NC continues its work to ensure students with disabilities receive the educational services required by law. Senior Attorney Virginia "Ginny" Fogg is the new Team Leader for the Education Team. Ginny graduated from Columbia Law School in 1994 and clerked for Justice John Webb at the NC Supreme Court. She has years of experience representing children in special education and discipline matters. Other members of the Education Team are Lisa Rabon (Senior Attorney), Debbie Thome (Advocate), and Lucy

Ireland (Attorney).

The Education Team focuses on reducing referrals to the juvenile justice system for students with disabilities, and preventing and addressing long-term suspensions and other exclusionary practices. While we can't represent every child who has been denied an appropriate education and services, we do take cases that will allow us to both return the student to the regular school environment with appropriate services in place, and achieve system and statewide changes to school exclusion policies.



Education Team left to right: Lisa Rabon, Virginia Fogg, Debbie Thome, and Lucy Ireland.

Policy Update: General Assembly Session Wrap-Up

The North Carolina General Assembly wrapped up an unusually long 2015 session in early October. A number of pieces of legislation impact people with disabilities.

On September 23, the governor signed a measure that will start the state on its way toward a managed care system for all of Medicaid. The legislation sets up the basic framework and infrastructure to move the state's Medicaid program from fee-for-service to a managed care model.

Under the new system, the state will stop reimbursing providers for each service or procedure and will start providing an upfront payment to managed care entities for each Medicaid patient they enroll. Those entities will include three private insurers, each operating statewide, and up to ten "provider led entities," which will be regional doctor and hospital systems.

The new system of payment will reward cost containment rather than the provision of more services, so developing rules that assure access to quality care will be a crucial part of implementation.

In another development, children with autism will benefit from a measure passed in the last hours of the session. The Autism Health Insurance Coverage Act requires insurance companies to cover screening, diagnosis, and treatments for autism in children under age 18. Insurers will be required to cover adaptive behavior treatment for up to \$40,000 of expenses per year. This was a long-sought measure that will be effective for insurance contracts that begin after July 1, 2016.

The final budget included several provisions that will impact people with disabilities:

- ◆ Lawmakers expanded supports for young adults in foster care up to the age of 21. Since many children in foster care have disabilities and need services past the age of 18 in order to transition successfully to adulthood, this provision is welcome news.
- ◆ Older adults with disabilities will benefit from a partial restoration of Home and Community Care Block Grant funds that provide important community-based services.

- ◆ Broughton Hospital received an additional \$16.6 million to fund its expansion. Another \$2.5 million will support additional psychiatric beds in community hospitals.
- ◆ More concerning is the \$110 million cut to funding for the Managed Care Organizations (MCOs) that handle behavioral health services. MCOs are not allowed to reduce the services they provide to the community, so this cut will force them to spend existing reserve funds.
- ◆ NC START, which provides respite, crisis, and consultative services to adults with both I/DD and mental illness, will receive \$1.54 million to expand its services to children and adolescents, and to add respite services for both children and adults. We expect DHHS will have to identify additional funds to make this promise real.
- ◆ Funding of \$12 million represents modest progress toward addressing deplorable conditions for prisoners with mental illness. Governor McCrory and prison officials, including Commissioner of Adult Correction and Juvenile Justice David Guice, had requested twice that level of funding after the death of an inmate in 2014 brought attention to the significant deficits in the prison system's mental health policies and practices.

While the budget funds mental health staff positions and additional beds in Central Prison's mental health facility, as well as treatment units in eight other state prisons, funding for improved screening and assessment of inmates as they enter the system was noticeably absent. But the budget does require the creation of a study committee appointed by the Legislative Oversight Committees on Health and Human Services and Justice and Public Safety. The committee will study the intersection of public safety and behavioral health and report their findings and recommendations to their respective committees. This will be an avenue to move forward with efforts to improve mental health assessment and treatment in state prisons.

Issue Spotlight: Accommodations for Students with Disabilities in Higher Education

When spring graduates at UNC-Wilmington walked across the stage to accept their degrees this year, Thomas was not among them. He did not know that he had graduated.

Thomas, who was finishing a film degree, has a learning disability that makes it difficult for him to process written language. He received special education services in elementary and high school, with an Individualized Education Plan (IEP) to guide his instructors in the specialized instruction he needed.

It's a different story in higher education. While colleges and universities may not discriminate against students with disabilities, they have no obligation to identify them or follow IEPs that were in place during high school. The higher education student must take the initiative to get the support and accommodations he/she needs, often by working with the disability services office at his/her school. This is not an easy process because skepticism about invisible disabilities prevails in many colleges and universities.

In high school, Thomas's learning disability prevented him from succeeding in his foreign language class so his IEP team substituted with other classes. When Thomas first asked the disability services office at UNC-W to waive his foreign language requirement, he was directed to a faculty member who told him a student generally had to fail a language class four or five times to be excused from the requirement. The school required a recent evaluation and proof of disability before it would agree to review his request for a waiver of the requirement. After reviewing the test results, a UNC-W disability services staff member denied his request for a waiver in a two-sentence email, without explanation or avenue for appeal.

Thomas called Disability Rights NC for help. He thought he was looking at another semester, probably more, of language classes that he would fail. An attorney at Disability Rights NC gave Thomas recommendations on how to navigate the process and continue to pursue his request for a waiver. It was only after he persisted, asking for a meeting and an explanation, that another administrator told him a course substitution—replacing the foreign language courses with alternative courses—might



Left to right: Yasmin Farahi, Attorney; Cindie Steeber; and Katherine Slager, Attorney.

be possible. After jumping through a couple more hoops, Thomas finally got that course substitution approved. When he sat down with the head of the foreign languages department, they found that two of the classes he had already taken would give him the required credits. He was already done!

Sometimes students with disabilities need more extensive advocacy from Disability Rights NC. Cindie Steeber, who is deaf, communicates primarily through American Sign Language (ASL) interpreters. The 50-year-old resident of Shelby is pursuing a criminal justice degree at a community college to increase employment opportunities. Her frustration with the quality and consistency of the ASL interpreters provided to her by the college, some of whom were students still taking sign language classes, led her to contact Disability Rights NC.

Disability Rights NC filed a complaint with the U.S. Department of Education Office of Civil Rights on Cindie's behalf. That office mediated an Early Complaint Resolution, under which the college agreed to improve its interpreter services and allow Cindie to retake classes.

"I can't wait to graduate -- that makes me smile -- and put on that cap and gown and be queen for the day," she said, reporting that the situation is much improved.

Many colleges and universities take great care to ensure that they are compliant with the law, and that their students with disabilities are provided with

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equal opportunity to earn a degree. Using litigation to resolve the issue is a last resort, but sometimes it is necessary.

Last year, Disability Rights NC filed a lawsuit against Duke University on behalf of a divinity school student diagnosed with dyslexia. The student had chosen Duke over another school based on discussions he had with admissions officers prior to his registration, during which he was assured the materials he needed to do his coursework would be provided in a form that he could access. It didn't happen that way, and the student had to drop multiple courses and switch programs. When he submitted a grievance he was told he would lose his scholarship if he did not withdraw it. His case is pending.

Access to education is essential to full participation in our society, and Disability Rights NC protects that right for students with all types of disabilities.



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