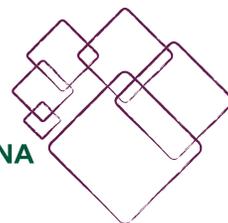


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DISABILITY RIGHTS
NORTH CAROLINA

Champions for Equality and Justice



Volume 24 • Summer 2017

Disability Rights NC sues the State for its treatment of people with I/DD

A lawsuit filed by Disability Rights NC on May 24, 2017 against the State of North Carolina and the NC Department of Health and Human Services (DHHS) alleges that North Carolina's system of care is fractured and inefficient, forcing thousands of people with intellectual and/or developmental disabilities (I/DD) to live in institutions. The State also has failed to provide many people with the services they need to live in and participate in their communities, leading to segregation and risk of institutionalization.

Under North Carolina law, DHHS must provide services to people with I/DD in the most integrated setting appropriate for their needs. But North Carolina's system of care favors institutionalization over community-based services. This is not only a violation of the law, but also a waste of money. Institutionalization costs more than twice as much as providing services in a community-based setting, on average.

We filed the lawsuit in partnership with the national law firm Drinker Biddle & Reath LLP, which participates in this case as part of its High Impact Litigation Project with the Barbara McDowell Foundation, named for the late Barbara McDowell, a well-known appellate litigator and wife of former Drinker Biddle partner, Jerry Hartman. The plaintiffs are five people with I/DD who are subject to improper segregation or are at risk of segregation or institutionalization.

- ◆ Samantha is 28 years old and has significant medical needs and I/DD. For most of her life she has lived at home, thanks to support services provided by DHHS. However, Samantha's services have been cut over the past several years, causing her to lose reliable staff who helped her maintain an engaged life. As a result, she had to move into an institution,



From the Director

Ten years ago, Disability Rights NC opened its doors as North Carolina's protection and advocacy (P&A) agency. The first P&A program was created in 1975 after a series of television reports exposed the deplorable conditions at Willowbrook, a large New York state institution for people with I/DD. Similar concerns about the abuse and neglect in mental health facilities led to the expansion of the P&A system to include people with mental illness. Safeguarding the well-being of individuals living in institutions remains a major focus of the work of Disability Rights NC. But over the years, the scope of P&A work expanded to include protecting the rights of people with all types of disabilities to ensure full access to inclusive educational programs, healthcare, accessible housing, and productive employment opportunities, just to name a few.

Before July 2, 2007, the P&A

Continued on page 2

Continued on page 12

Check Out Our YouTube Channel!

We've got new resources and fun videos up on our YouTube channel. We just put up a video about the new supports available to children with complex behavioral needs. There also are videos explaining the recent changes to the Innovations Waiver. Plus, you can learn about the inspiring work of the recipients of this year's Champion for Equality and Justice Awards and Adele Foschia Award for Lifetime Cross-Disability Advocacy.

We have more videos in the works that will provide important information and advocacy tools. Subscribe to our YouTube channel at www.youtube.com/disabilityrightsncc.



Disability Rights North Carolina is a 501(c)(3) nonprofit organization headquartered in Raleigh. Its team of attorneys, advocates, paralegals, and support staff provide advocacy and legal services at no charge for people with disabilities across North Carolina. It 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.

Disability Rights NC sues the State

Continued from page 1

and the State has not taken steps to help Samantha move back into the community.

- ◆ Marie is 26 years old. She lived in an adult care home for several years after multiple hospitalizations due to her I/DD and other impairments. At the adult care home, Marie did not receive therapeutic services or assistance in becoming independent. Instead, her behavior was controlled with psychotropic drugs, which made her unstable on her feet and incontinent. Although she has left the adult care home, Marie is on a waiting list for services and is not receiving the support she needs to develop skills to live independently, placing her at risk of re-institutionalization.
- ◆ Connie has physical disabilities in addition to I/DD. She lives in her community, volunteers for Meals on Wheels, socializes with women in her neighborhood, and shops at the mall—all with the help of paid staff. But the State says Connie's services must "fade" after 90 days. That means she will receive less support, even though her disabilities and her need for support has not changed. This 90-day limit places Connie at risk for segregation or institutionalization.
- ◆ Jonathan is 41 years old, has autism, and is deaf. He lives in a group home three hours from his family, despite his family's efforts to find a place closer to home. Jonathan desperately wants to live near his family, and the distance negatively affects his mental health. The DHHS contractor that oversees Jonathan's care is required to ensure that there are enough providers and that services are available in the places where people need them. But the contractor has failed in its responsibilities. As a result, Jonathan remains far from home and has become increasingly withdrawn and isolated.
- ◆ Mitchell is 21 years old and has autism and seizures. He has significant communication and behavioral support needs. Mitchell lives with his mother, and he relies on DHHS for the supports he needs to remain at home and avoid institutionalization. However, the State's budgeting tool for services miscategorized his needs, so his service budget was reduced and his services were threatened. Additional reductions to Mitchell's budget are slated for the coming years, placing him at risk of segregation or institutionalization.

Read the complaint we filed against the State and NC DHHS on our website, www.disabilityrightsncc.org.

Ten year anniversary celebration and awards ceremony to be held on July 27

In July 2007, Governor Mike Easley designated our predecessor organization, Carolina Legal Assistance, as the protection and advocacy agency for the State of North Carolina. (We changed our name to Disability Rights North Carolina two months later.)

Join us to celebrate our first ten years and hear from some of the people who were involved in our creation and development as a strong voice for North Carolinians with all disabilities.

Registration is now open for our anniversary event. There is no charge for the event, but you must register to attend. The registration link is on our website under "Events."

Thursday, July 27, 2017, 4:30pm - 7:30pm
Awards Presentation at 6:30pm
Embassy Suites RDU
201 Harrison Oaks Blvd., Cary, NC



Matt Potter

Also at the celebration, we will present our 2017 awards. This year, we have two Champions for Equality and Justice honorees.

◆ **Matt Potter** is a self-advocate and an advocate for others who uses his exceptional communication skills to amplify the perspectives of people with disabilities. Matt has served on numerous boards, and he is widely praised for both his ability to bring people together and his determination to hold providers accountable.

◆ **Advocates for Medically Fragile Kids NC** is a group of true "warrior moms." When they saw that the services their medically fragile children rely on were in jeopardy of elimination, they joined together and got to work. Thanks to their advocacy, thousands of families in North Carolina have access to essential services and medical care. The Advocates for Medically Fragile Kids NC is led by **Jenny Hobbs, Elaine Nell,** and **Natalie Weaver.**



Left to right: Elaine Nell, Natalie Weaver, and Jenny Hobbs

This year's recipient of the Adele Foschia Award for Lifetime Cross-Disability Advocacy is **Beth Garriss Hardy.** For decades, Beth has been a committed champion for people with mental illness, children experiencing the trauma of homelessness, and efforts to secure and expand disability rights.



Beth Garriss Hardy

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Finance & Operations

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Karla Blackwell, Administrative
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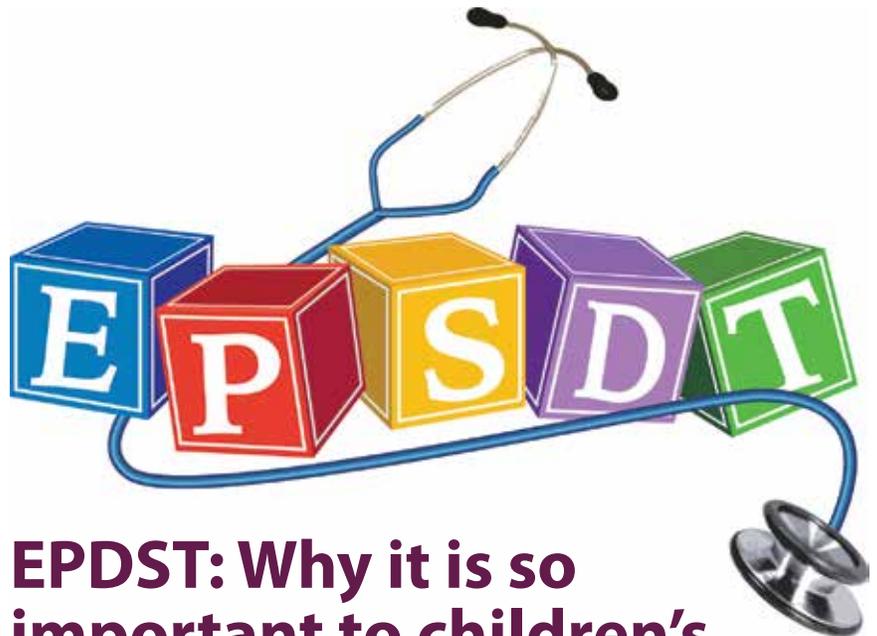
Policy & Outreach

Corye Dunn, Director of Public Policy

Elaine Whitford, Director of
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Matthew Herr, Policy Analyst

Diane Morris, Communications and
Events Coordinator



EPDST: Why it is so important to children's well-being

In October, Disability Rights NC reached a settlement with the State of North Carolina regarding its care of children with complex behavioral health needs—that is, children who have an intellectual and/or developmental disability and a mental illness.

We entered into negotiations with the NC Department of Health and Human Services (DHHS) more than two years ago when the attorneys at Disability Rights NC realized that many children with dual diagnoses were not getting the help they needed. In North Carolina, the behavioral health system (which deals with intellectual and development disabilities) is separate from the mental health system. Many children who needed help from both systems were shuffled between them, never getting the right supports or treatments. We filed the complaint against the State because it was not following the rules of EPSDT (Early and Periodic Screening, Diagnostic, and Treatment), which is part of the federal Medicaid law.

The Power of EPSDT

EPSDT says that children (under age 21) who receive Medicaid services are entitled to all rehabilitative services that are medically necessary to make or keep them physically and mentally healthy. So what does that mean?

It means that Medicaid should cover the cost of any service for a child that does the following:

- ◆ Improves or maintains the child's health in the best condition possible
- ◆ Compensates for a health problem
- ◆ Prevents a health problem from getting worse
- ◆ Prevents the development of additional health problems

If a service, treatment, or piece of equipment does any of these things for a child who has Medicaid, it is considered “medically necessary.” Therefore, Medicaid must cover it. EPSDT also requires that Medicaid cover a given service in any amount that is medically necessary. The limits North Carolina places on Medicaid services for adults do not apply to children.

EPSDT is a powerful tool for improving the health and well-being of North Carolina’s children. Unfortunately, we have found that parents, doctors, providers, and even government officials do not understand the scope of EPSDT.

New Supports Available

As a result of our settlement agreement with the State, there are new supports available to children who have both an intellectual and/or developmental disability and a mental illness.

First, the State has created a uniform process for identifying and assessing these children. Each boy or girl will get a comprehensive assessment to make sure he or she has the right diagnoses and gets the right services. The family will have a team working with them—a care coordinator, the clinician who does the assessment, and possibly a case manager—to make sure the necessary services and treatments are put in place.

There are two new resources available to families of children in crisis. One is called NC START—Systemic, Therapeutic Assessment, Respite and Treatment. This comprehensive program provides community-based crisis prevention and intervention services to individuals with developmental disabilities and complex behavioral health needs through crisis response, training, consultation, and therapeutic supports.

The second is a new outpatient assessment clinic at the Murdoch Developmental Center in Butner. This center provides diagnostic and assessment services. However, it is currently a pilot program, open two-and-a-half days a month and serving only families in the 25 counties of North Carolina’s central region. The State will collect data on the program to help guide future expansion of this service.

If you want to know more about this settlement agreement, the rights of children with Medicaid under EPSDT, and how you can help enforce those rights, check out www.disabilityrightsn.org/epsdt.

Annual Target Survey Now Open: We Need to Hear from You!

Each year, Disability Rights NC seeks public input on what areas of disability advocacy it should focus. With limited resources, it’s impossible to address every violation of rights experienced by a person with a disability in North Carolina. But we try to make as big an impact as possible and improve systemic problems.

Please take a few minutes to complete an online Survey to help us determine if the Proposed 2018 Targets adequately represent the needs of people with disabilities in our State. The survey also offers an opportunity for the public to tell us about other issues that are important to people with disabilities in North Carolina.

Learn more about the Proposed 2018 Targets and get the link to the Survey on our website. Or call 877-235-4210 if you need a copy of the survey mailed to you or you need assistance completing the survey.

Si necesitas ayuda o traducción en español para completar esta encuesta por favor llame a Rita Landeta al 877-235-4210 or 919-856-2195 or rita.landeta@disabilityrightsn.org.

The Survey will remain open until early August 2017.



Get the News Faster!

Receive the Disability Rights NC quarterly newsletter, periodic news updates, calls to action and event information by email. Sign up for eNews on our website:

www.disabilityrightsn.org.

Cases reinforce the right to service animals

Service animals enable people with disabilities to maintain independence. That's why it is so important that service animals and their handlers not be separated, if at all possible.

Two recent cases—one in North Carolina and one that went before the U.S. Supreme Court—reinforce the right of people with disabilities to have their service animals with them in all but the most exceptional circumstances.

Mr. Wiker and the Podiatrist

Roger Wiker is visually impaired and uses a guide dog, Fred, to navigate his environment. He took Fred with him to an appointment with a podiatrist for routine care, but the office staff would not let Fred guide Mr. Wiker to the examination room or remain with him during his appointment, saying it was a sterile environment.

Disability Rights NC filed suit against Piedmont HealthCare, a large multispecialty practice group, on Mr. Wiker's behalf. As an individual with a disability, Mr. Wiker has the right to have his guide dog with him in most areas of a doctor's office or hospital. The lawsuit alleged that separating him from his guide dog would violate his rights under the Americans with Disabilities Act and Rehabilitation Act.

We resolved the case out of court. Piedmont HealthCare agreed to adopt system-wide policies clarifying that service animals are generally permitted in its facilities. It sent this policy out to all of its practices, which include more than 50 locations and nearly 200 physicians. The new policy will benefit people with disabilities throughout the Piedmont region.

Ehlana, Wonder, and the Supreme Court

Earlier this year, the U.S. Supreme Court unanimously sided with Ehlana Fry, a Michigan girl whose school refused to let her bring her service dog, Wonder, to class. The issue in the case was whether Ehlana's complaint was a special education issue or a possible violation of the Americans with Disabilities Act.

If the justices had ruled that Ehlana's case was a special education issue, she and her parents may have had to go through a time-consuming dispute resolution process with the school district before she would have had access to the courts. Instead, the Court unanimously agreed that Ehlana could proceed directly to federal court under the Americans with Disabilities Act.

"This victory will, once and for all, remove unfair legal hurdles for victims of discrimination across the country that prevent students from seeking justice guaranteed by the Americans with

Disabilities Act," said Michael J. Steinberg, legal director of the American Civil Liberties Union of Michigan, which represented Ehlana and her parents.



Ehlana Fry with her service dog, Wonder.

The right of students with disabilities to use service animals in school facilities derives from the Rehabilitation Act of 1973 and the Americans with Disabilities Act. These laws ensure that people with disabilities who have service animals enjoy equal access to publicly-funded facilities, services, and places of public accommodation. That includes public and private schools.

The U.S. Department of Justice and the Office for Civil Rights at the U.S. Department of Education have recognized that separating a person from his service animal for any period of time can be harmful for both. For example, a student whose service animal assists her with behavioral challenges may regress without her service animal there to redirect her behavior or provide calming deep pressure therapy. Meanwhile, a highly trained service animal is sitting at home with limited opportunity to practice and perform its learned skills and tasks, which may lessen in quality and effectiveness.

These cases serve as a reminder to all places of public accommodation—including businesses, schools, and medical facilities—that people with disabilities have a right to have their service animals with them in most situations.



Traveling with a service horse.

Frequently Asked Questions About Service Animals

What is a service animal?

Service animals are dogs or miniature horses that have been individually trained to do work or perform tasks on behalf of a person with a disability. This definition is found in the Americans with Disabilities Act (ADA). Other federal laws, such as the Fair Housing Act and the Rehabilitation Act, do not define service animals. As a result, many courts rely on the ADA definition when evaluating a person's right of access in settings covered by these other federal laws. Animals that have not been trained to do work or perform tasks, such as emotional support animals, are not considered service animals.

Where are service animals allowed?

Service animals are allowed anywhere where a public entity is providing or funding a service or program. They are allowed in places of public accommodation—that is, in places, buildings, or outdoor spaces open to the general public that a person can enter with or without a fee. This includes businesses, restaurants, theaters,

museums, and many other places. Service animals are also allowed in rental and owner-occupied housing.

When can service animals be asked to leave?

A service animal can be excluded if the animal's presence would pose a direct threat or fundamentally alter the nature of the program or service being provided. For example, a zoo may be able to exclude a service dog from areas where the animals on display are natural prey or predators of dogs. Service animals may also be excluded if they are not under control or are not housebroken. A service animal cannot be excluded because other individuals have allergies or a fear of dogs.

What questions can someone ask me to determine if my dog or miniature horse is a service animal?

They may ask what skills or tasks the animal has been trained to perform, and how those skills or tasks assist you, the individual with a disability.

Bottom Dollars reveals problems with sheltered workshops

In March, Disability Rights NC hosted a series of screenings of an important documentary called *Bottom Dollars*, which looks at sheltered workshops and the sub-minimum wage.

Federal law allows businesses to pay people with disabilities less than minimum wage. Congress created the law in the 1930s to encourage employers to hire veterans with physical disabilities. Today, this law has expanded into a parallel system of employment for hundreds of thousands of people with disabilities.

Nearly 250,000 people are paid sub-minimum wages—on average, less than \$2 an hour. Most of them work in sheltered workshops, where they are segregated from their communities.

In *Bottom Dollars*, we meet people with intellectual and developmental disabilities who worked hard, received excellent performance reviews, and still were paid less than minimum wage. Many of the people profiled in the movie had jobs in sheltered workshops and found their tasks to be boring and unrewarding. Their lives changed dramatically when they entered jobs in their communities with fair wages.

We held screenings of the documentary in Raleigh, Winston-Salem, Asheville, and Greenville. At each event, many audience members reported they didn't realize that many adults with I/DD are funneled into sheltered workshops without being given a chance to explore employment in their communities.

You can learn more about sheltered workshops, the sub-minimum wage, and the *Bottom Dollars* documentary at www.bottomdollars.org.

Stories from *Bottom Dollars*

Gloria Marrero of Rochester, NY has worked in a sheltered workshop for eight years sorting items. Those who work with Gloria say she is "reliable, friendly, always on time and never missed work." Even though Gloria performs her job well and her employer considers her to be an "excellent worker," she is paid only \$3.50 per hour.

Charles Biel of Baltimore, MD went to the School for the Blind throughout high school. He was excited to start working once he was out of school, but he was placed in a sheltered workshop. Charles was treated unfairly in this workshop and did not receive fair payment for the work that he performed. Charles wants to work but also wants to receive a fair wage for what he does.



Gloria Marrero



Charles Biel



Meet our newest board members

Left to right: **Tori Ekstrand, Kim Lan Grout, Jill Scercy, and James Booker.**

Disability Rights NC is committed to having a Board of Directors that represents a diversity of disabilities as well as different parts of the state. This year, we have four new board members.

Tori Ekstrand is an assistant professor at UNC-Chapel Hill's School of Media and Journalism. She teaches media law and researches web accessibility for people with disabilities. Tori has students, colleagues, friends, and families members with physical and mental health disabilities. She shuns "inspiration porn" in media stories about people with disabilities and firmly believes that disability law and policy must be crafted with and by those they affect: "Nothing About Us Without Us."

Kim Lan Grout is a writer, photographer, and disability advocate. She is the founder of the Redefining Disabled Project, a co-founder of the Accessible Icon Project in Durham, and one of the producers of the award-winning documentary, "Farmer/Veteran." When she was 18, Kim's left leg was amputated above the knee because of a congenital vascular syndrome. Today, Kim Lan lives a full life alongside her husband and their two daughters, the younger of whom was diagnosed with Type 1 Diabetes at just two years old. It is with love for life and love for her "broken" body that she works to make our world more inclusive and aware and fights the able-istic status quo.

Jill Britton Scercy is the director of the Greenville center of UNC-Chapel Hill's TEACCH Autism Program. She graduated from East Carolina University and is a licensed marriage and family therapist. Before joining TEACCH, she worked in public mental health and then private practice with families and children with mental health challenges and developmental disabilities. Jill has been involved both locally and on the state level with advisory councils for public education. As the mother of a son with autism, she co-led a parent support group for 14 years. Jill is honored to serve on the board where abilities are emphasized and all rights for individuals are protected.

James Booker started working in the field of disabilities as a counselor at a summer camp for children with disabilities. After graduating, he became a teacher's assistant in public separate schools, working primarily with children with profound medical needs. He has since become a clinical supervisor to a direct care provider, and he has served on the Deaf-Blind Advisory Council. He and his wife have spent the last several years as foster parents to children with disabilities. The biggest influence in James' life is his son, who he adopted at the age of three. His son suffered a TBI as a result of Shaken-Baby Syndrome and is deaf and blind. Not a day goes by that James doesn't learn something new from his son, and he will do anything to make his life just a little easier.

Fourth annual conference sees highest attendance yet



Keynote speaker Dr. Kevin Ann Huckshorn addresses the audience.



Hope, a service animal in training, represented Eyes Ears Nose and Paws—a nonprofit in Carrboro that trains and places assistance dogs.



Sponsors Neuro Community Care and Monarch shared information about resources and services for people with disabilities.

In just four years, the Disability Advocacy Conference presented by the staff of Disability Rights NC has become one of the best ways for disability rights advocates, state policymakers, attorneys, and people with disabilities to come together to learn about the issues facing people with disabilities in our State and be a part of the solution.

This year's conference featured Dr. Kevin Ann Huckshorn as the keynote speaker. Dr. Huckshorn, a nationally recognized expert on trauma-informed care, introduced many of our attendees to the principles of systems of care that are trauma-informed. She compared this to traditional human service settings and explained the importance of a trauma-informed approach. Several people described her presentation as “eye-opening”, and several people with disabilities commented that their life might be very different had they received services in a trauma-informed setting.

In addition, the staff of Disability Rights NC led 17 breakout sessions on a variety of disability rights topics, such as Medicaid, legislative activity, employment, working with Vocational Rehabilitation, higher education, special education, disability litigation trends, and disability issues in law enforcement and the justice system. The Conference not only is an opportunity to learn from the Disability Rights NC staff but also allows disability rights advocates and self-advocates to recharge with inspiration and new connections.

This year, 216 people attended. Our generous sponsors made it possible for us to give 31 scholarships to people who did not have the financial means to pay the full conference registration fee.

Mark your calendars for next year! The 2018 Disability Advocacy Conference will be held on Thursday, April 19, 2018 at the Friday Center in Chapel Hill.

New policy addresses mental health needs of public school students

The State Board of Education (SBE) has approved a new policy to improve mental health services for public school students in North Carolina. Mental and behavioral wellness is directly linked to overall positive student achievement, school climate, and high school graduation rates. It also helps to prevent risky behaviors, disciplinary incidents, and substance abuse.

Complete implementation of this policy is critical. Research shows that in North Carolina, nearly 1 in 5 students will experience a mental health disorder in any given year. Of those students, 75%—or nearly 227,000 students—will NOT receive treatment. Suicide is the second leading cause of death among people aged 10 to 24, and in North Carolina, the total number of youth suicides has doubled in recent years.

These disturbing statistics come from the School Mental Health Initiative (SMHI), a multi-disciplinary partnership of public educators, community-based mental health clinicians, lawyers, advocates, university faculty, and parents. Disability Rights NC was one of the participants. SMHI met regularly for more than two years to develop recommendations that would provide students with equitable access to high-quality and well-coordinated mental health services.

The cornerstone of the new policy is ensuring adequate mental health services are available to all students, regardless of where they live in our state. Many rural areas in North Carolina lack local mental health services. The new policy addresses that deficit by requiring each school system to “develop and implement a plan for assessing and improving upon the effectiveness of existing supports for the mental health and substance use needs of its student population.”

The success of the policy hinges on another key requirement: training for all school personnel in mental health and substance abuse awareness within the first six months of employment, at no cost to school systems. Under the policy, DPI must create and help implement the training, including face-to-face and online content, technical assistance, and materials.

This new policy will empower schools to address a primary barrier to the success of many students—the lack of mental health care for children. Just as we have recognized as a nation that we can’t expect students to do well in school when they are hungry, we also can’t expect them to focus on their lessons when they are struggling to understand and overcome their own mental health challenges.

2017 Disability Advocacy Conference Sponsors

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From the Director

Continued from page 1

in North Carolina was a part of the state government – the Governor’s Advocacy Council for Persons with Disabilities (GACPD). Many people believe that GACPD still exists. In fact, it has not existed since June 29, 2007. The staff at GACPD worked hard to be strong advocates for the rights of people with disabilities. But it was difficult to hold the State accountable when they were an agency of the State.

As a private, nonprofit organization, Disability Rights NC has demonstrated over the last ten years how much people with disabilities in North Carolina needed an independent organization with legal expertise to hold the State accountable for providing the services they are legally obligated to provide. While we have open lines of communication with state leaders and policymakers, there comes a point when legal action is the only way to uphold the rights of the people we are here to protect. And our attorneys not only take that legal action, but have been successful in obtaining court orders and settlement agreements that ensure people with disabilities have the

opportunity to live independently in the communities of their choice with full access to the community.

I would like to say that we’ve solved all the problems people with disabilities face, but the systems in place to serve people with disabilities and the laws that support their rights are complex and, unfortunately, many of the systems are broken or inefficient. I can promise you that the staff at Disability Rights NC will continue tirelessly to chip away at the obstacles that North Carolinians with all types of disabilities face.

But we can’t do it without you. Please join our efforts as a champion for equality and justice for people with disabilities. Whether you share our Facebook posts, share our eNews with your friends and colleagues, tell people with disabilities about our services, attend our annual Disability Advocacy Conference or other events, provide pro bono services, support us with a donation, or advocate for systems change, we need you to continue to be a part of our community.

Vicki Smith Executive Director

www.disabilityrightsnc.org

North Carolina's Protection and
Advocacy System

Upon request, information
is available in alternate formats.

3724 National Drive, Suite 100
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