

New Directions

DISABILITY RIGHTS
NORTH CAROLINA



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Champions for Equality and Justice

Disability Rights North Carolina Receives Advocacy Awards

Disability Rights North Carolina recently received two awards that recognized its advocacy work on behalf of people with disabilities. Disability Rights NC received the Advocacy Award during the National Disability Rights Network (NDRN) annual conference held in Los Angeles in June 2010. The award was given in recognition of the nonprofit organization's outstanding work in protecting the rights of people with disabilities to live in the community. In August, The Arc of NC recognized Disability Rights NC with its 2010 President's Award for "providing exceptional advocacy on behalf of people with intellectual and developmental disabilities" including "lawsuits, collaboration with other organizations on public policy and widespread information dissemination." Vicki Smith, Executive Director of Disability Rights NC, accepted both awards on behalf of the organization's Board of Directors and staff.

Prior to the NDRN award presentation, Assistant Attorney General Thomas Perez of the US Department of Justice (DOJ) spoke about the Americans with Disabilities Act's (ADA) promise and progress in civil rights enforcement. He noted that, despite the ADA and the *Olmstead* decision, "tens of thousands of Americans with disabilities are still unnecessarily and unconstitutionally confined in institutions, some with unspeakably dangerous conditions."

Perez's remarks were made during a plenary session highlighting the advances in the realization of rights since the ADA was enacted 20 years ago. Disability Rights NC received the Advocacy Award based on its filing of *Marlo M.* in the US District Court for the Eastern District of North Carolina in December 2009. *Marlo M.* was the first time that the DOJ supported the argument that if states are required to provide services to people with disabilities in the most integrated setting, then states are obligated to keep them in such a setting. "In the three years since becoming North Carolina's federally mandated protection and advocacy system, we have been challenged to fulfill the expectations of the disability community," Smith said

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From the Director

The genesis of protection and advocacy systems (P&As) was the poor living conditions and lack of services for people with developmental disabilities in institutions. Years ago, when the media exposed the terrible conditions in the Willowbrook facility in New York, Congress was spurred to create a system of protection that would keep people safe from harm while living in the care and treatment of others. While our responsibilities have grown over the years, making sure that people with disabilities are safe — wherever they live — is still a core function of Disability Rights NC as the State's P&A.

Safety comes in many forms. It means being in the right placement to receive the services, support and treatment you need. It means being

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Above: The Advocacy Award presented to Disability Rights NC at the NDRN annual conference in June 2010.

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.

Advocacy Awards

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as she accepted the award. “We had to hit the ground running. It is an honor to be recognized by our peers. Our ongoing challenge will be to see that the state’s budget crisis does not reverse the progress made over the past 20 years. This award marks but one small success in the journey to create a state, a nation, where every individual has access to equal opportunity and equal justice.”

From the Director

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safe from sexual predators inside the place you live. It means not being hit, slapped or sat on by people hired to care for you. It means being able to communicate with your doctor and all health care providers. It means getting health care when you need it. It means not waiting for days for a bed to open up, sometimes hundreds of miles from where you live. It means living in a home that is clean and doesn’t smell like an outhouse. It means being cool in the summer and warm in the winter inside your home.

Feeling safe is a fundamental need. When it is not met, bad things happen. Sadly, thousands of people with disabilities do not feel safe where they live. There are too many examples in North Carolina — including a residential facility for children with mental health needs, a residential school educating children who are deaf, and over 6000 adults living in adult care homes without adequate treatment options — where residents are not always safe. This needs to change. All public and private facilities licensed to care for people with disabilities or provide them shelter must be safe havens.

The work of Disability Rights NC continues to highlight the need for a change. The culture in which substandard living conditions or the lack of appropriate treatment is the norm must change, both within the facilities and in the community. Access to both physical and mental health care must be improved.

Perhaps, someday, living conditions for all North Carolinians with disabilities will be safe. Someday, people with disabilities will have access to the care they need. Until then, Disability Rights NC will continue to “work for justice, upholding the fundamental rights of people with disabilities to live free from harm ...”

Vicki Smith, Executive Director

Disability Rights NC 2010 Legislative Agenda Report

Before the 2010 short session of the NC General Assembly, Disability Rights NC planned an ambitious legislative agenda to protect the rights of people with disabilities. It was not an easy session, but we had some successes. Below are highlights of the legislation related to our top legislative priorities. The full legislative report can be found on our website's Public Policy page.

Children with Disabilities

◆ **Corporal Punishment:** We worked with other groups to ban the use of corporal punishment on kids with disabilities in our schools. While a full ban was not achieved, there is now an opt-out that allows parents of children with disabilities to “opt out” of local corporal punishment (i.e., paddling or spanking). School districts that continue to use corporal punishment (43 of 115 school districts still allow corporal punishment) will be required to report annually to the State Board of Education (SBOE):

- The number of students who received corporal punishment;
- The number who were children with disabilities;
- The grade level of the students;
- The race and ethnic origin of the students; and
- The reason for the administration of the corporal punishment.

Disability Rights NC believes that the use of corporal punishment is abusive and will continue to work for a total ban.

◆ **Residential Schools Leadership:** The legislature made a number of changes regarding the oversight of the Schools for the Deaf and the Governor Morehead School for the Blind:

- Consolidation of the director and principal positions at the schools;
- Transfer of the schools from the Office of Education Services (OES) in DHHS to the SBOE; and
- Dissolution of the OES effective June 1, 2011, with the SBOE and DHHS developing a transition plan by December 1, 2010.

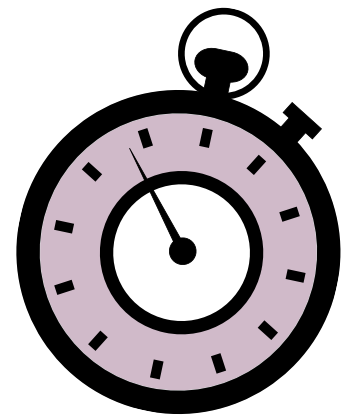
An interim superintendent will be appointed immediately and recommendations for the position on a permanent basis will be made by May 1, 2011. The OES Central Office and Exceptional Children Support programs were eliminated effective October 1, 2010. The full residential and instructional school schedules were also restored. We hope that the transition to the SBOE will improve the quality of education at the schools. Disability Rights NC will continue to seek full protections for students in the residential setting (such as Human Rights Committees and ombuds positions),

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Get the Latest Policy News!

Keep up with the latest news regarding state and federal legislative initiatives affecting people with disabilities and learn more about Disability Rights NC's role in policy-making. Visit Disability Rights NC's policy blog at www.drncpolicy.blogspot.com.



Get the News Faster!

You can now 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.



Charlie Barnes Wins CFO of the Year Award

Charlie Barnes, Chief Financial Officer of Disability Rights NC, was presented *Triangle Business Journal's* 2010 CFO of the Year Award for Small Nonprofits (annual budget under \$5 million).

As the organization's founding CFO, Charlie created all of the fiscal systems necessary to operate a sizable nonprofit organization that is funded with multiple restricted grants. Executive Director Vicki Smith credits Charlie with playing a prominent role in managing the organization's tremendous growth during an economic downturn. Starting with 26 staff members and a budget of \$300,000 in July 2007, the organization now has a staff of 42 and an annual budget of nearly \$3 million.

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regardless of what entity oversees the education program.

◆ **Residential Facilities Admissions:** While the state falls far short of a continuum of care in this area, the DHHS budget amended the 2009 budget provision related to Level III and IV residential placements for children to clarify that only one of the following criteria is required before admission to such a placement: (i) Placement is a step down from a higher level placement such as a psychiatric residential treatment facility inpatient; (ii) Multisystemic therapy or intensive in home therapy services have been unsuccessful; or (iii) A Child and Family Team has reviewed all other alternatives and recommends Level III or IV placement to maintain health and safety of the child. It also directs DHHS to study the effectiveness of the 120-day length of stay limitation and the number of children staying in Level II, III and IV facilities. Disability Rights NC continues to represent children who are not receiving necessary mental health treatment. *Please contact us if your child or a child you serve is not receiving appropriate mental health services.*

◆ **Public School Students with Special Needs:** Efforts to extend protections for students who have not yet been identified as needing special education services but whose behavior and performance clearly indicate the need for such services were successful. This protection was scheduled to expire on March 1, 2011. The new law extends the disciplinary protection until June 1, 2013, which gives the legislature time to evaluate the provision. *Please contact us if your child has been placed on long-term suspension and was not identified as a child with a disability but should have been.*

Services in the Community for People with Disabilities

◆ **Funding:** We work with other groups to ensure adequate funding for people with developmental disabilities and mental illness to stay in the community. There were some victories on this front but some changes made by budgetary provisions will continue to wreak havoc with the limited services we now have:

- \$40 million for MH/DD/SA community services was restored to the budget.
- Additional funds for local inpatient psychiatric beds. We hope that increasing this local bed capacity will reduce the amount of time individuals in need of acute psychiatric treatment spend waiting in local emergency rooms for beds at the state psychiatric facilities. There are also provisions seeking further

study of this issue. One budget provision calls for an evaluation of behavioral health crisis services by state and local hospital emergency departments, broken down by LME catchment area, by March 1, 2011. *If you have had to wait in a local emergency room for psychiatric treatment, please contact us.*

- We advocated for modification of the 2009 budget provision eliminating state-funded services to individuals who also receive CAP-MR/DD services. We sought to ensure that those state-funded services would stay in place for certain recipients whose high needs cannot be adequately addressed with CAP-MR/DD services alone. However, we were unsuccessful. We were successful in inserting language that directs the DHHS Division of Medical Assistance to develop a new CAP-MR/DD service definition to better meet the needs of individuals who have a high intensity of behavioral needs, reside in small residential placements, and require 24/7 supervision. DHHS must report on the status to the Joint Legislative Oversight Committee on MH/DD/SAS and other committees by October 1, 2010. We reviewed the proposed service definition in its early stages and are hopeful that it will be available soon.
- Major changes were made to the Medicaid-funded Personal Care Services (PCS) program. The current program will be eliminated and replaced with two new services, In-Home Care for Children and In-Home Care for Adults, that will serve a narrower group of individuals. A \$59.8 million reduction comes with this change. *Please contact us if you are experiencing lengthy delays in accessing PCS or if you are a current recipient of PCS and your services have been reduced or terminated, particularly if you are in danger of moving to an institutional setting like a nursing home or adult care home, as a result.*

◆ **Affordable Housing:** People with disabilities need access to safe, accessible, affordable housing as well as appropriate services. Through our case work and our policy work, we advocate for the expansion of Permanent Supportive Housing (PSH) programs in NC. While no money was allocated for PSH during the legislative session, two studies were authorized. One provision authorizes the Legislative Research Commission to study the feasibility and cost-effectiveness of establishing a statewide supportive housing initiative for individuals with MH/DD/SA disabilities. The other mandates DHHS to conduct a study through a task force and propose recommendations by January 31, 2011 on the cost-effectiveness of supportive housing as an alternative to institutionalization of the MH/DD/SA populations.

◆ **Service Termination Due Process:** We worked with other groups to ensure the availability of due process procedures for people with disabilities who experience reductions and terminations of Medicaid-funded services.

Honoring Disability Advocates

Disability Rights NC joined with the MS Society of NC, The Arc of NC and other advocacy organizations to advocate for the passage of HB 2076, A Joint Resolution Honoring North Carolinians with Disabilities and Their Advocates and Honoring the Twentieth Anniversary of the Passage of the Americans with Disabilities Act. The Resolution honored several NC disability rights advocates, including Deborah Greenblatt. Deborah was the Executive Director of Carolina Legal Assistance, which became Disability Rights NC in 2007. She lost her battle with cancer in 2005, but her passion for protecting the rights of people with disabilities echoes daily in the work of the Disability Rights NC staff.

Report from Disability Rights NC Leads to DHHS Investigation of NC School for the Deaf

Over an 18-month period, Disability Rights NC investigated reports of abusive behavior towards students at the North Carolina School for the Deaf in Morganton. In early July 2010, Disability Rights NC released the results of its investigation to NC DHHS leadership. As a result, NC DHHS Secretary Lanier Cansler launched an investigation into the allegations.

DHHS Deputy Secretary Maria Spaulding led the investigation and assembled a team to conduct a thorough probe covering several years of alleged misconduct. In mid-August, DHHS reported that Janet McDaniel was terminated as the school's director. On September 27, 2010, DHHS released its public report. You can find a copy of DHHS's report on Disability Rights NC's website.

In a press release issued by DHHS on July 16, Secretary Cansler said "The findings of Disability Rights NC are significant enough to warrant a full investigation into the actions of the school's top administrator and staff. Our zero-tolerance policy is designed to ensure the protection of our children. Based on our early findings, some staff may not have acted in the best interests of our children. We take these reports seriously and we are acting on them."

Disability Rights NC Files Complaint with the US Department of Justice

On July 26, 2010, Disability Rights NC filed with the US Department of Justice (DOJ) a complaint against the State of North Carolina on behalf of all persons with mental illness living in Adult Care Homes in North Carolina. A complaint filed with the DOJ is not the same as a legal action filed in a court of law.

Through its complaint, Disability Rights NC has asked DOJ to investigate its claim that people with mental illness in North Carolina are being placed improperly in Adult Care Homes in violation of the integration mandate of the ADA. If DOJ finds merit to the claims made in the complaint, it may work with the State of North Carolina to effect policy changes to correct the civil rights violations or, if necessary, file legal action against the State of North Carolina.

Adult Care Homes are licensed assisted living facilities that provide three meals a day, housekeeping services, and personal care services for seven or more residents. According to information released by an NC Institute of Medicine (IOM) Task Force in December 2009, North Carolina had 627 Adult Care Homes with 36,564 beds. A subsequent report released by IOM revealed 6,432 persons with mental illness reside in Adult Care Homes and Family Care Homes (for two to six unrelated residents). Despite the prominent role Adult Care Homes play in the North Carolina mental health system, Adult Care Homes are not regulated as mental health facilities.

Over the past two years, Disability Rights NC has investigated reports of four deaths in Adult Care Homes. At least one of the residents involved in each incident had a mental illness. In May 2010, with the help of several UNC-Chapel Hill law students, Disability Rights NC visited 15 Adult Care Homes across North Carolina. The investigation revealed the large size and institutional quality of the Adult Care Homes visited, as well as a near-total lack of community interaction for residents, most of whom desire to live more independently.

Report on Adult Care Homes in N.C.



Disability Rights NC has released a detailed report on recent violent acts in Adult Care Homes and proposed solutions to placing people with mental illness in those homes. The report is available on our website.

A Message from the Disability Rights NC Director of Public Policy**Celebrating the 20th Anniversary of the ADA in Our Nation's Capital**

I was excited to celebrate the ADA's 20th anniversary in Washington, DC on July 26 at the National Council on Disability (NCD) Summit on Disability Policy along with hundreds of people with disabilities, family members, and advocates. The theme of the summit was Living, Learning & Earning. It was designed to launch a national dialogue on disability policies and programs in the 21st century and on what remains to be done to achieve the ADA's goals of

equality of opportunity, full participation, independent living, and economic self-sufficiency. It was an amazing opportunity to hear from veteran and rookie advocates, along with numerous federal government department heads and people with disabilities from all over the country.

I learned so much from the other attendees — from how Oregon has managed to eliminate all of its institutions for people with intellectual and developmental disabilities and serve all residents in the community, to Washington's expansive service animal laws. But the theme I heard over and over again was the need for all disability groups to come together on common goals. Such a coalition was necessary to pass the ADA and is necessary to move us forward in the 21st century. Every community has struggled to form such a coalition; those who have succeeded in doing so have become a strong political force. I can't wait for people with disabilities in North Carolina to exercise their political strength as an organized constituency!

And what is the constant refrain that a coalition needs to address? Freeing the people with disabilities who are still institutionalized. "Free our brother and sisters." I heard this again and again.

The highlight of my trip was attending the White House ADA Anniversary Celebration. About 300 people congregated on the South Lawn to hear performances by Nathaniel Anthony Ayers (the musician whose life was depicted in the movie *The Soloist*) and singer Patti LaBelle. Remarks by actress Marlee Matlin, President of Access Living Marca Bristo, and Actor Robert David Hall, of CSI fame, preceded the introduction of President Obama, who recognized that the ADA is about independence, not dependence.

As Marca Bristo said in her comments at the White House event, civil rights do not self-enforce. People with disabilities must seek independence. We need to stop talking about "protecting the vulnerable" and talk about asserting people's civil rights.

Annaliese Dolph, Director of Public Policy

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*Democracy
is never a
thing done.
Democracy
is always
something that
a nation must
be doing.*

Archibald MacLeish

Get the Vote Out!

Did you know that Americans with disabilities vote at a much lower rate than the rest of the population? This November, let's change that statistic and get out and vote.

Ways to Vote

- ◆ Vote inside a polling site which should be accessible (but some are not);
- ◆ Curbside voting is available at every polling site for people who cannot get into the building;
- ◆ Absentee ballot by mail (contact Disability Rights NC or your local Board of Elections for more information about voting by absentee ballot); and
- ◆ Absentee One-Stop voting allows voters to vote in person before the election and register to vote if not already registered (this ends 3 days before election day).

If you encounter a problem in exercising your right to vote, call Disability Rights NC at 1-877-235-4210 for assistance.

www.disabilityrightsnc.org

Advocacy System

North Carolina's Protection and

is available in alternate formats.

Upon request, information

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