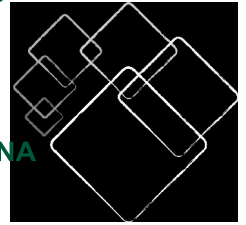


# New Directions

DISABILITY RIGHTS  
NORTH CAROLINA

*Champions for Equality and Justice*



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## Disability Rights North Carolina Files “Reverse-Olmstead” Federal Lawsuits

Disability Rights NC recently filed lawsuits in federal court on behalf of two people whose rights would be violated and lives adversely affected by cuts in state funding.

Marlo and Durwood are both adults who have mental illness and one or more developmental disabilities. With 24-hour care and support, they have been able to live in their own homes. Marlo has been living in her home for more than four years. She is a small person who lives in an apartment adapted to her stature so she can do her own laundry and fix her own meals. Durwood grew up in various institutions until finally moving into his own home ten years ago.

In late November 2009, both Marlo and Durwood received notice that the state funding they rely upon to remain in their homes would be terminated on December 15, 2009. The proposed funding cut would have forced them into group or institutional housing. They called Disability Rights NC for help.

The *Marlo M.* lawsuit is a “reverse-*Olmstead*” claim because it seeks to prevent the re-institutionalization of the individual. The case caught the attention of the U.S. Department of Justice which intervened, alleging that the state’s actions in the *Marlo M.* complaint violate the inclusion mandate of the Americans with Disabilities Act (ADA), as confirmed in the Supreme Court’s *Olmstead* decision. Marlo and Durwood did not seek money damages. Instead, they asked the court to prevent the Beacon Center — a local management entity (LME) responsible for managing the provision of state-funded mental health and substance abuse services — from terminating their state-funded services. In December, U.S. District Court Judge Terrence Boyle granted an injunction which prohibited the State from withdrawing support and services from Marlo and Durwood. In Judge Boyle’s precedent-setting decision, he found that (i) a reverse-*Olmstead* claim constitutes a violation of the ADA just like a regular *Olmstead* claim, and (ii) a court should issue injunctive relief to prevent forced institutionalization if it can be established that such a placement is likely.

### ***Olmstead* Decision**

The case of *Olmstead v. L.C. and E.W.* was filed by two women who were intermittently hospitalized in a psychiatric hospital for decades, despite recommendations from their doctors that they could live in the community with state-funded support and services. In 1999, the U.S. Supreme Court ruled the “integration mandate” of the ADA required states to provide services in the most integrated setting appropriate to the needs of the disabled person. The 6-3 decision in *Olmstead* ended segregation of people in institutions when community placement is desired by the individual and recommended by the individual’s health care providers. The Court noted that, during the congressional debate of the pending ADA legislation, many U.S. representatives articulated a desire that the ADA would result in a decrease in the institutionalization of persons with disabilities.

## Director's Message

Many people with disabilities can live in the community when they receive appropriate support and services. The benefits are obvious.

In his order granting a motion for preliminary injunction in *Marlo M.*, Judge Terrence Boyle of the U.S. District Court for the Eastern District of North Carolina stated: "First, the public interest lies with upholding the law and having the mandates of the ADA and Rehabilitation Act enforced.... As the funding originates from tax dollars, the public interest clearly lies with maintaining Plaintiffs in the setting that not only fulfills the important goals of the ADA, but does so by spending less for Plaintiffs' care and treatment."

By definition, if an individual has been determined eligible for a waiver, their care costs less in the community than it would in a facility. Moreover, providing services in the community creates jobs across the state of North Carolina.

Yet, in spite of these benefits, services for many people with disabilities are being cut or reduced. The state's budget crisis has caused a fragile system of care to become further fractured. This backward trend is in clear violation of the intent of the integration mandate of Americans with Disabilities Act and the U.S. Supreme Court's decision in *Olmstead*.

Disability Rights NC focused resources to respond to this challenge by identifying seven Target areas for 2010. This newsletter highlights the work of our Target Teams.

Vicki Smith  
Executive Director



## Services to Support Community Inclusion

**Disability Rights NC preserves the level of services in the community so that people with disabilities who currently live in a community setting are able to stay in their current placement, avoiding a move to more restrictive settings.**

KW is a 27-year-old female with cerebral palsy who must use a wheelchair to get around. She cannot dress herself, feed herself or take care of other activities of daily living without assistance. Currently in graduate school, she has been living in her own apartment with the help of a roommate.

Things were going well for KW until her roommate moved out. KW had already applied for a CAP/DA slot and was also on a waiting list for CAP/MR/DD. Shortly after her roommate moved out, KW learned that the CAP/MR/DD waiting list was very long. She also learned that CAP/DA slots had been reduced due to cuts in state funding.

During KW's wait, her family and friends helped provide her with the services that she needed. Disability Rights NC wrote letters and made several phone calls to DHHS staff regarding KW's need for an emergency CAP/MR/DD slot. Not long after Disability Rights NC's actions, KW received a phone call stating that she had received a slot. She now can remain in the community and continue graduate school with the goal of opening her own business.



## Repeated Short-term Institutionalization and Extended ER Stays

**Disability Rights NC assesses and investigates the causes of repeated short-term institutionalization, including extended stays in Emergency Rooms (ER) experienced by adults with mental illness living in the community.**

Disability Rights NC is actively investigating several reports of individuals who experience extensive waits for appropriate mental health services. A disturbing trend is emerging. For North Carolinians requiring mental health treatment, the pattern plays out the same way:

- ◆ A Greensboro man was confined for five days in the emergency room at Moses H. Cone Memorial Hospital, awaiting transfer to Central Regional Hospital in Butner. During his five-day stay, he was accompanied by two police officers and remained handcuffed to a bed.
- ◆ Another man was forced to wait for eight days in the emergency room at Forsyth Medical Center, at times in handcuffs, until he was eventually transferred to an acute psychiatric care facility.
- ◆ According to information presented to the Human Rights Committee at Cherry Hospital, several patients waited up to 96 hours until available space at Cherry or another facility opened up. In one case, a patient waited in the emergency room for more than three days, only to be discharged to his home.

The pain involved in a mental health crisis may be different, but it is just as serious and excruciating as the pain of a physical injury. An individual having a mental health crisis may experience hallucinations, delusions or paranoia, all of which are less understood by emergency responders. Often it is not an ambulance that responds to the call for help, but the police. And, more often than not, instead of seeing a treating physician, the individual “sees” a magistrate judge. Instead of being attended by medical personnel during transport, they may be handcuffed and transported to the hospital in the back seat of a police car. Instead of receiving immediate treatment when they get to the emergency room, they may wait - not for minutes or hours, but for days. Their wait ends only when space at an appropriate psychiatric facility becomes available.

## **Children in Residential Placements**

**Disability Rights NC ensures that children with mental illness residing in residential placements receive appropriate discharge planning and treatment when their residential facility is eliminated.**

Disability Rights NC reviews public records submitted weekly by LMEs to the DMH/DD/SAS to track the children being transitioned from residential placements to areas that have little or no youth mental health services available. These records do not report the outcomes of the transitioned children. We have

## What it means...

**CAP/DA** is a North Carolina Home & Community-Based Services Waiver that provides a package of services to allow adults (age 18 and older) who qualify for nursing facility care to remain in their private residences.

**CAP MR/DD Waiver:** Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities is a special Medicaid program started in 1983 to serve individuals who would otherwise require care in an intermediate care facility for people with mental retardation/ developmental disabilities (ICF/MR). It allows the opportunity to serve eligible people in the community instead of more institutional settings. The cost of community care must be cost-effective when compared to the cost of ICF/MR care.

**Intensive In-Home Service** is a team approach designed to address the identified needs of children and adolescents who, due to serious and chronic symptoms of an emotional, behavioral, and/or substance use disorders, are unable to remain stable in the community without intensive interventions. This service may only be provided to individuals through age 20.

**LME:** Agencies of local government-area authorities or county programs who are responsible for managing, coordinating, facilitating and monitoring the provision of mental health, developmental disabilities

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## What Happens When People with Disabilities Live in the Community?

When people with disabilities are allowed to live in the community with state-supported services, they can engage in activities that many people take for granted, such as:

- ◆ Choosing when to watch TV.
- ◆ Choosing when to go to bed.
- ◆ Going grocery shopping.
- ◆ Choosing what they will eat for dinner.
- ◆ Cooking dinner for their friends and family.
- ◆ Joining a social club or group.
- ◆ Opening a bank account.
- ◆ Balancing their checkbook.
- ◆ Scheduling their dentist and doctor appointments.
- ◆ Accepting employment.
- ◆ Riding the bus.
- ◆ Using a cell phone.

*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.*

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increased monitoring in rural areas to assess the success or failure of the transition. We are beginning to see more children discharged from residential placement — not because those placements are no longer medically necessary, but because paperwork was not properly submitted.

ZP is eighteen years old and suffers from bipolar disorder, autism and obsessive compulsive disorder. ZP's condition improved while he resided at a level III home for two-and-a-half years. His treatment team decided it was appropriate to develop a discharge plan for ZP, conditioned on ZP's receipt of intensive in-home services. After two months at home, ZP had not received the recommended in-home services and ZP's mother helplessly watched her son regress. Disability Rights NC intervened and reported ZP's situation to his LME and case management provider. Within a week, a treatment team was established and ZP began receiving the in-home services he needed.



## Accommodations to Support Community Inclusion

**Disability Rights NC ensures that people with disabilities receive the accommodations they need to participate in community life.**

People with disabilities have gained many rights through laws such as the Americans with Disabilities Act, Help America Vote Act and the Fair Housing Act. Yet, in spite of these protections, discrimination against people with disabilities continues. This discrimination creates unnecessary barriers to daily living in employment, housing, voting, access to professionals and other aspects of community life. People who use companion animals often are denied housing or meals in restaurants because “pets are not allowed.” Many public buildings and areas are not accessible to people with physical disabilities.

TC is a person with deafness who applied for certification as a Certified Nursing Assistant (CNA). She contacted Disability Rights NC when the CNA testing board denied her request for accommodations — a request which was supported by her Vocational Rehabilitation counselor. One of the accommodations she requested was an assistive device to enable her to use a digital blood pressure cuff. Disability Rights NC is working to get all necessary accommodations in place for TC so she can retake the test successfully, become certified and be eligible for employment as a CNA.



## Education

**Target** Disability Rights NC promotes the use of positive behavioral supports for students with special needs, thereby reducing the inappropriate use of seclusion or restraint and number of students out of school due to unilateral action of school administrators.

Every year the NC Department of Public Instruction (DPI) generates reports about school suspensions and dropouts in North Carolina. At a recent meeting of the Youth Accountability Planning Task Force, DPI gave a presentation about dropout statistics and contributing factors in short- and long-term suspensions. Their report suggests a direct link between suspension and dropout, and positive behavioral supports were cited as an effective alternative for reducing school suspension and dropout among at-risk students. In spite of this, schools continue to resort to more exclusionary strategies instead of teaching exceptional students more appropriate behaviors.

NK is a 10-year-old boy with autism. He was placed in a self-contained classroom reportedly designed for children with behavioral challenges. One day at school, NK was restrained in a time-out room because he refused to clean cafeteria tables. Disability Rights NC learned of the incident and the report that NK had been injured as a result of the restraint. Disability Rights NC confirmed that NK had been restrained in a dangerous face-down position by two male teaching assistants, which resulted in injury. After Disability Rights NC's investigation, NK's school placement was changed and there have been no issues with restraint or seclusion since he has been in the new classroom. After investigating NK's case, Disability Rights NC uncovered information that prompted a broader investigation into the restraint and seclusion practices involving other children at this school. (Download Disability Rights NC's report "Seclusion and Restraint: A Dangerous Education" at <http://www.disabilityrightsn.org/pages/249/school-seclusion-and-restraint-prone/>)

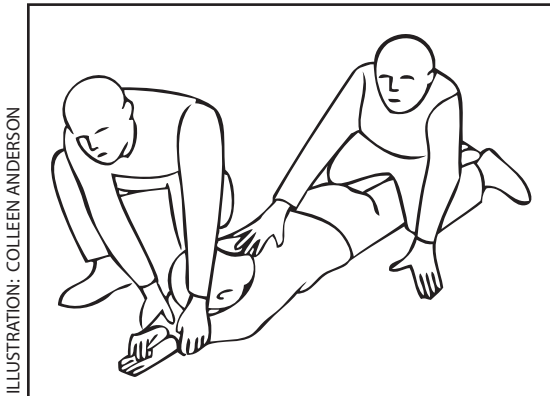


ILLUSTRATION: COLLEEN ANDERSON

**Left: An example of prone restraint. This dangerous technique should never be used!**

## What it means...

*Continued from page 3*

and substance abuse services in the catchment area served. LME responsibilities include offering consumers 24/7/365 access to services, developing and overseeing providers, and handling consumer complaints and grievances.

## Useful Acronyms

**DHHS** – Department of Health Human Services

**DHSR** – Division of Health Service Regulations

**DMH/DD/SAS** – Division of Mental Health Developmental Disabilities Substance Abuse Services

**DPI** – Department of Public Instructions

**ICF/MR** – Intermediate Care Facility for (people with) Mental Retardation

**LMEs** – Local Management Entities

## How Budget Cuts Affect Real People

The cuts in state funding provide a one-two punch to individuals with disabilities living in congregate settings. The first is a direct punch to the levels of staffing and the quality of life in state facilities. The massive cuts to the DHHS budget are likely to impact facility staffing. Funding for auxiliary services and treatment models that directly improve the residents' quality of life are also being reduced. The cuts have severely reduced or eliminated support services offered to residents. These conditions might exacerbate symptoms and/or behaviors of the residents, which is likely to result in longer stays at these facilities rather than discharge to the community. In addition, decreased and temporary staffing increases the likelihood of inappropriate responses by staff (increased restraint and/or seclusion or other forms of abuse).

The second punch comes in the form of greater reliance on more restrictive and institutional placements as community supports break down. Disability Rights NC has people on the ground monitoring admissions to these facilities as well as the conditions in those facilities.



## **Target** Disability Rights NC continues its ongoing monitoring of conditions in facilities regulated by the Division of Health Service Regulation (DHSR).

Disability Rights NC instituted an office-wide facility monitoring project last quarter in response to massive budget cuts by the NC General Assembly. Nearly every staff member has been assigned a facility to monitor on a monthly basis. Disability Rights NC staff regularly attend Human Rights Committee meetings at each psychiatric hospital (Broughton, Central Regional, Cherry and Dix), all of the developmental centers (Caswell, J. Iverson Riddle, Murdock), Longleaf Neuro-Medical Treatment Center, the Eastern North Carolina School for the Deaf (Wilson), Governor Morehead School for the Blind and the North Carolina School for the Deaf (Morganton). In addition, staff monitored more than 20 other facilities, including adult care homes, group homes for people with developmental disabilities and/or mental illness and/or traumatic brain injury and nursing homes.

Even though this monitoring project is in its infancy, there have been several positive outcomes already: (i) we have identified clients through this process; (ii) policies and procedures about clients' rights at facilities were strengthened and, in some cases, brought into compliance with state and federal law; (iii) residents received visits from caring advocates; and (iv) more Disability Rights NC staff members had the opportunity to visit our clients in their home environments.



## **Target** Disability Rights NC investigates reported deaths and other serious allegations of abuse that occur while people with disabilities are in the care and treatment of others in accordance with case selection criteria.

Federal and state law require certain facilities to report deaths to Disability Rights NC when they involve homicide, accident, suicide or violence, or if they occur within seven days of restraint or seclusion. A new state law requires state-operated facilities to report to Disability Rights NC all deaths that occur at their facilities, as well as any death that occurs within 14 days of discharge from any state facility. Disability Rights NC reviewed 27 deaths between October 1 and December 31, 2009.

Disability Rights NC continues to conduct unannounced monitoring at a private residential treatment facility (PRTF) in the

southwestern part of the state, after a report released in June 2008 detailed shocking and excessive use of restraint and seclusion at the facility over a four-month period. Thus far Disability Rights NC has been able to obtain new policies and procedures regarding the use of restraint and seclusion at the facility, and our staff continues to receive and track bi-weekly reports regarding the numbers of restraints.

## **Incarcerated Individuals**

**Disability Rights NC ensures that service needs of people with disabilities who are in juvenile justice facilities and prisons are correctly identified and treated while they are incarcerated and when they transition to the community.**

Governor Bev Perdue named 34 members to the “StreetSafe Task Force.” Attorney General Roy Cooper and Department of Correction Secretary Alvin Keller serve as co-chairs. Secretaries Linda Hayes and Lanier Cansler also serve on the task force. Governor Perdue described Project StreetSafe as “bringing together faith-based organizations, non-profits, local and state government agencies, business leaders and members of the community to develop a plan to combat recidivism and reintegrate offenders safely into the community.” Disability Rights NC is participating as a member of the Task Force Workgroup titled “Overcoming Health and Addiction Challenges.”

## **A Big Step Forward**

On March 3, 2010, the U.S. House of Representatives passed the “Keeping All Students Safe Act” (HR 4247) which would prevent harmful seclusion and restraint practices in public schools. The bill, as written, eliminates dangerous practices and provides strict limitations on use. Importantly, the bill also requires the use of de-escalation techniques and/or the implementation of a student’s Behavior Intervention Plan prior to the use of physical restraint or seclusion. The vote was 262 in favor and 153 against. Voting by the NC Representatives followed party lines — Democrats voted in favor and Republicans voted against the bill.

## **DRNC Works to Educate Public**



On February 22, four attorneys from DRNC — Jennifer Bills, John Rittelmeyer, Holly Stiles and Andrew Strickland — spoke at the UNC Center on Poverty, Work and Opportunity about the *Marlo M.* case. Their audience included law students, representatives from the School of Government, local mental health providers and members of a local advocacy group. During the presentation, they described the legal and mental health frameworks that shaped the case, the interplay between the tangle of funding sources, and the disastrous consequences of budget cuts on mental health reform in NC.

# Focus on Disability Rights NC: The Home Team

The Home Team at Disability Rights NC works to protect some of the most vulnerable members of the disability community — people who are at risk of being institutionalized. The Home Team uses



creative legal strategies to allow people to remain in their own homes and fights tirelessly for the necessary support services. In the past year, the Home Team enjoyed two major successes. It led Disability Rights NC's work on the *Marlo M.* case, as reported on page 1 of this issue of our newsletter. It also worked with nearly 25 recipients of private duty nursing to prevent termination of their services. The Team won individual administrative appeals and successfully negotiated several policy changes with DHHS to protect recipients in the future, making litigation unnecessary.

**Seated: Home Team members Karen Murphy and Sonya Clark. Standing: Jennifer Bills, Andrew Strickland and Morris McAdoo.**

The Home Team has three attorneys — Jennifer Bills, Morris McAdoo and Andrew Strickland — and two advocates, Karen Murphy and Sonya Clark. Jennifer is the Team Leader and supervising attorney.

[www.disabilityrightsnc.org](http://www.disabilityrightsnc.org)

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