From the Director
Perfect Storm – An Imperfect Analogy

Excerpted from an article published August 8, 2011 in Progressive Voices on the NC Policy Watch website

Like many programs, mental health services suffered big cuts in North Carolina’s recently passed budget. This would be bad under the best of circumstances. Unfortunately, lawmakers made things even worse by focusing cuts in such a way that will make the already flawed system even less effective than it already is.

One exception to the rate cuts, for instance, was the line item for so-called “adult care homes” – the flawed private facilities in which people with disabilities are frequently institutionalized.

The central finding of the DOJ is that North Carolina lacks an adequate community support system for people with mental illness. As a result, individuals are institutionalized in more expensive and more restrictive settings in Adult Care Homes. “Most people with mental illness receiving services in adult care homes could be served in more integrated settings, but are relegated indefinitely and unnecessarily to adult care homes because of systemic State actions and policies,” wrote US Assistant Attorney General Thomas Perez. “Reliance on unnecessary institutional settings violates the civil rights of people with disabilities. Community integration will permit the State to support people with disabilities in settings appropriate to their needs in a cost-effective manner.”

“Our findings are consistent with . . . conclusions made in several State-issued and State-funded reports,” Perez wrote. A January 2011 state-funded report issued by the NC Institute of Medicine concluded that adult care homes “are not optimal for community integration” and that “[r]esidents of ACHs may be cut off from active participation in the local community . . . .” The same report admitted that there is an institutional bias in North Carolina: “People who enter an ACH or other type of facility can obtain certain financial assistance, services, and supports that are not equally available to people with similar levels of disability and financial need who choose to remain in their own homes.”

Continued on page 3
The state’s reliance on adult care homes has also put it in the potentially expensive position of violating federal Medicaid regulations. Medicaid will not fund services provided in “institutes of mental disease” (IMDs), which are facilities with more than 16 beds in which more than half the licensed beds are occupied with people who have a primary diagnosis of mental illness. Dozens of North Carolina’s adult care homes match this description all too well.

Finally, CMS has said, “no more.” Medicaid dollars will cease flowing to those adult care homes soon. Without this funding, many of them will be forced to close. If an adult care home is found to be an IMD, but has accepted Medicaid funding, the State may have to pay back any Medicaid funds it spent on its residents. It is estimated that at least 38 North Carolina adult care homes, housing over 1,200 people with mental illness, may be classified as IMDs. These folks will lose their beds – with few alternative options – because the State has, for decades, neglected its legal obligation to develop the community supports and appropriate housing they need to live successful and safe lives.

In short, North Carolina’s perfect storm is the result of the State’s failure to cultivate an adequate community based system of care for people with mental illness and other disabilities. This perfect storm, like the fictional one, is a storm of devastating magnitude, and there will not be a happy ending. The presence of federal authorities in North Carolina has raised the potential threat of this storm to a “Category Five.” Unlike the weather, which we still haven’t figured out how to control, this perfect storm was preventable, and that is what is most tragic.

Vicki Smith
Executive Director
The DOJ will work with the State to negotiate a voluntary compliance agreement. If negotiations are unsuccessful, Perez wrote, “the Attorney General may initiate a lawsuit pursuant to the ADA . . . to correct [the] deficiencies.”

Federal law requires the State to provide care in a setting that lets people remain as integrated as possible in the community – a standard that North Carolina repeatedly fails to meet, according to the DOJ.

A copy of the 16-page report from Perez to state Attorney General Roy Cooper dated July 28, 2011 is available on our website.

“Most people with mental illness receiving services in adult care homes could be served in more integrated settings, but are relegated indefinitely and unnecessarily to adult care homes because of systemic State actions and policies.”


Visit to HVO

This summer, Executive Director Vicki Smith visited Haywood Vocational Opportunities (HVO) in Waynesville, NC. HVO is a not-for-profit, social enterprise that provides vocational training and employment opportunities for adults with disadvantages and disabilities. HVO’s training programs are nationally accredited by the Commission on Accreditation of Rehabilitation Facilities. HVO believes that people have the right to be respected, earn a fair wage, and have equal opportunities.

Left to right: Phyllis Brooks, HVO Vice-President of Employment and Training; Vicki Smith; Cindy Fisher, HVO Director of Developmental Disabilities Services; and George Marshall, HVO President.

US Department of Justice Finds ADA Violation

Continued from page 1
What it means...

**CAP/DA** is a North Carolina Home and 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 the mental retardation/developmental disabilities (ICF/MR). It allows these individuals the opportunity to be served in the community instead of residing in an institutional or group home setting.

**Human Rights Committees:** Each state facility, LME and provider agency must have a human rights committee to protect the rights of clients.

**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 and substance abuse services in the catchment area served. LME responsibilities include offering consumers 24/7/365 access to

---

**Disability Rights NC 2011 Legislative Year in Review**

This is a brief overview of our policy work this year. More detailed descriptions of bills introduced and passed during the session are available on our website in the Public Policy section.

**Ensuring Accessibility and Increasing Employment Opportunities**

- **Ensure the right of people who are deaf or hard of hearing to serve as a juror.**

  HB 234 amends the current Juror Qualifications statute to remove the ability to hear as a requirement to serve as a juror. It also amends the statute to allow potential jurors with a disability to request to be excused if the person believes that their disability may interfere with their ability to serve as a juror. HB 234 became effective July 1, 2011.

- **Ensure voter identification initiatives do not discriminate against people with disabilities.**

  HB 351 (the “Voter ID” bill) requires photo identification before voting. The Governor vetoed the bill, but the House and Senate voted to override the veto. The bill does not contain an exception for people with disabilities. It requires voters to present photo identification at polling places in order to vote, including (1) a NC drivers license; (2) a special identification card from the DMV (which will be free to anyone eligible to vote who does not have a valid photo identification); (3) a valid identification card issued by any state or federal agency; (4) a valid employee ID card issued by any state, county, municipal or federal agency; (5) a valid US military ID card; (6) a valid tribal ID card; or (7) a valid NC Voter Identification card (a new form of photo ID to be issued by county boards of election). To obtain a Voter ID card, a person must present a photo identity document or a non-photo identity document if it has the person’s name, evidence that the person is registered to vote in NC, and documentation showing the person’s name and residence address. The proposed Voter ID card is only valid as long as the person resides at that address and remains qualified to vote – each time a person moves, he/she will have to obtain a new card and surrender the old card. To register and vote at a one-stop site, a voter will have to present photo ID as described above.

Continued on page 5
On Target • Page 5

◆ Conform state laws to the ADA Amendments Act.

SB 384 amends the NC Persons with Disabilities Protection Act to conform to the Americans with Disabilities Amendments Act of 2008, assuring equal protection for people with disabilities under state and federal law. It became effective when signed by the Governor on May 26, 2011.

◆ Keep people with disabilities in the workforce through full implementation of the previously enacted Medicaid Buy-In provisions.

NC DHHS has not yet fully implemented the buy-in for workers with disabilities. CMS has, however, clarified that the proposed buy-in premiums are permissible. We look forward to working with the Department in the coming months.

Maintaining Educational Opportunities

◆ Ensure budget reductions and new policies do not reduce educational opportunities entitled to students with disabilities.

Budget cuts in education largely spared programs specifically designed to serve students with disabilities. Although the line-item funding for teachers and teaching assistants was not cut, huge “flexibility cuts” to LEA funding will mean fewer teachers, assistants, and other support personnel.

◆ Advocate for an Internal Advocate and a mandated Human Rights Committee at all residential schools for students who are blind and deaf.

HB 866 was introduced but did not pass. It would have codified the transfer of control of the State’s Residential Schools (the Governor Morehead School for the Blind, the Eastern North Carolina School for the Deaf in Wilson, and the NC School for the Deaf in Morganton) to DPI and required rules providing for codes of conduct, policies and procedures for academic performance and academic discipline, and fees for extracurricular activities and athletics. The bill required that each school establish a “Student Rights Advisory Committee” to monitor, review, and evaluate programs and procedures related to student rights, safety, security, and quality of life. This section on the Student Rights Advisory Committees is intended to codify the committees currently known as Human Rights Committees. The bill did not proceed, leaving open a number of unanswered questions about the oversight of the

What it means...

Continued from page 4

services, developing and overseeing providers, and handling consumer complaints and grievances.

Medicaid Buy-In: This program allows adults with disabilities to obtain Medicaid coverage even though their income level would otherwise disqualify them for coverage. Buy-in participants pay premiums based on income.

Useful Acronyms

CMS – Centers for Medicare and Medicaid Services

DHHS – NC Department of Health Human Services

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

DPI – NC Department of Public Instruction

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

IMD – Institute for Mental Disease

LMEs – Local Management Entities

PRTF – Psychiatric Residential Treatment Facility

SBOE – NC State Board of Education

Continued on page 6
three schools now that they have transitioned to DPI, particularly since the budget requires the closure of one of the schools.

**Legislative Year in Review**  
*Continued from page 5*

**Input on Targets Received**  

The scope of our work each year is guided by Targets established by the Board of Directors. Our Targets determine how we spend our time and resources during the year. In June, we asked you to tell us what you thought about our proposed 2012 Target areas by taking an online survey. We heard you loud and clear – 808 people representing 82 counties in North Carolina completed the survey! The responses came from people concerned with all types of disabilities:

- Intellectual Disability............... 49.1 %
- Other Developmental Disability.......................... 43.8 %
- Physical Impairment................. 49.1 %
- Mental Illness............................. 48.6 %
- Deaf or Hard of Hearing.......... 23.1 %
- Blind or Visually Impaired...... 21.6 %
- Traumatic Brain Injury.......... 29.0 %

*(Survey allowed respondents to select more than one disability.)*

Your input confirmed that we are focusing on legal and advocacy issues important to you.

**Protection from Abuse**

- Ensure that residents in all types of facilities are protected from abuse and neglect.

HB 374 makes clear that records in the custody of the State concerning the North Carolina Eugenics Board program are not public records to the extent they concern: (i) persons impacted by the program, (ii) persons or their guardians or authorized agents inquiring about the impact of the program on them, or (iii) persons or their guardians or authorized agents inquiring about the potential impact of the program on others. It states that a person impacted by the program may obtain her individual records under the program, and a guardian or authorized agent of that person may also obtain them. This could be an important tool for establishing a diagnosis before the age of 22 for our clients, as well as in criminal cases. It became effective when signed by the Governor on June 22, 2011.

**Advancing Fairness in Capital Procedures**

- Amend capital procedures to allow a defendant’s mental illness to be considered at the start, rather than the end, of a trial.

HB 659, seeks to amend the capital trial, sentencing and post-conviction procedures for a person with a severe mental disability to address the issue upfront in trial, and to remove the death penalty as the highest punishment if the individual qualifies as a person with severe mental disability under the law. It provides that “Not Guilty by Reason of Insanity” is not an available defense if prior alcohol or drug use is the sole cause of the psychosis. HB 659 passed successfully out of the House with strong bipartisan support with an 84-31 vote. It received a favorable report from the Senate Judiciary II committee and has been referred to the Senate Appropriations committee. We hope that the bill will be voted upon by the full Senate during the 2012 short session.
The Education Team works on behalf of children who are illegally excluded from public schools based upon behaviors related to their disabilities and unidentified educational needs. Often our clients are suspended from school, experiencing academic difficulties (retention, failing grades and failing end-of-year assessments) and involved in the juvenile court system. Some of our clients, before our involvement, have long histories of academic struggles accompanied by behavioral issues triggering school suspensions.

The goal of the Team’s legal representation and advocacy is to keep at-risk students with disabilities in school, improve their literacy and reduce their long-term suspensions and commitment to the juvenile justice system. The team is knowledgeable about the substantive and procedural requirements of special education law and uses that knowledge to achieve favorable outcomes for its clients and improve communication between the parent and school system. The Education Team has been successful in using the state administrative complaint process as a legal strategy to address individual and systemic violations for the benefit of all special education students in a school system.

The Education Team consists of two attorneys and one advocate: Christine Trottier (Team Leader), Lisa Rabon and Debbie Thome.

Disability Rights NC filed a state administrative complaint against the Wayne County Public School System on behalf of students with disabilities who had been illegally suspended without the benefit of ongoing educational services and disciplinary safeguards. On May 17, 2011, DPI issued a report finding that the school system had (i) failed to develop and review IEPs as required under the IDEA and (ii) failed to provide the appropriate procedural safeguards when disciplining students with disabilities.

DPI required the school system to provide 60 hours of compensatory education to a student with disabilities who had been suspended from school without educational services. DPI also required the school system to provide training for the Exceptional Children (EC) director and coordinators, principals and assistant principals, and EC teachers at five schools, including the topics of discipline, IEPs, parental participation in IEP Team meetings and provision of a free appropriate public education (FAPE).
Legal Update

In the past three months, Disability Rights NC has filed two federal lawsuits challenging issues created by the state budget cuts – the Pashby and K.C. cases.

Personal Care Services - Pashby v. Cansler, No. 5:11-CV-273-BO (E.D.N.C.)

This lawsuit challenges the new DHHS rules restricting coverage of Medicaid-covered Personal Care Services (PCS) for adults. These services are provided to elderly and disabled individuals who require assistance with certain basic tasks of daily living, such as eating, bathing, dressing, and toileting. Under the new rules, effective June 1, 2011, PCS coverage will be terminated for about 3,500 to 4,000 elderly, blind, or disabled North Carolina citizens who rely on these services to live safely in their homes and communities.

While eligibility for in-home PCS is being limited, individuals who reside in assisted living facilities known as Adult Care Homes (ACHs) need to satisfy much less restrictive criteria to qualify for PCS in the ACH. Most ACHs are large, institutional settings and many are located in isolated rural areas, far from the communities in which the residents would otherwise live.

The lawsuit claims that the new restrictions on in-home PCS violate the integration mandate of the Americans with Disabilities Act (ADA) as interpreted by the US Supreme Court in Olmstead by forcing Medicaid recipients into ACHs as a condition of receiving necessary services – services that could be provided in a community setting. The lawsuit also states claims for violation of the Medicaid Act and due process rights of PCS recipients.


This lawsuit challenges the manner in which DHHS, acting through its contractor PBH (formerly Piedmont Behavioral Healthcare), has implemented a new version of a Medicaid waiver program known as the Innovations Waiver. PBH, a managed care experiment within the LME system, made substantial changes to the Innovations Waiver serving those with Intellectual and Developmental Disabilities. The changes included the implementation of as many as 31 tiers within the waiver, each with its own budgetary limit. The tier assignment process, which resulted in substantial service cuts for a number of waiver recipients, was conducted without benefit of any appeal or due
process procedure that would allow the recipient to challenge the tier assignment.

The lawsuit claims that the process of converting waiver participants to the new tiered system violated the due process rights of the Medicaid waiver recipients. The lawsuit also states a claim for violation of the Medicaid Act because the tier assignment process was conducted without applying reasonable, objective standards.

Settlement of Olmstead Case - Marlo M. v. Cansler

In December 2009, Disability Rights NC filed a lawsuit in federal court on behalf of Marlo and Durwood, adults who have mental illness and one or more developmental disabilities. Marlo and Durwood had each lived in their own home with 24-hour care and support for many years when they received notice that their state funding would terminate on December 15, 2009. Disability Rights NC sued to stop the cuts that would likely force Durwood and Marlo into group or institutional housing. Disability Rights NC argued that such a move would be a violation of Marlo and Durwood's right – and the right of all people with disabilities – to live in the community of their choice.

In May 2011, Disability Rights NC reached an agreement with the Beacon Center to settle the Marlo M. lawsuit. As part of the settlement, the State and the Beacon Center LME agreed not to cut Durwood or Marlo's state funding. The agreement recognizes that Marlo and Durwood's homes remain the most integrated and clinically appropriate housing available to meet their needs.

Though Marlo M. settled before it reached trial, its impact has been and will continue to be felt in North Carolina. When US District Court Judge Terrence Boyle decided to grant Marlo and Durwood's request for an injunction (which prohibited the State and the Beacon Center from withdrawing any supports and services while the case was in his court), he did so in a precedent-setting written 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. Judge Boyle's decision has now been cited by persons with disabilities and their advocates in court cases across the nation. Most recently, the US Department of Justice cited the Marlo M. decision in its July 28, 2011 Letter of Findings to the State of North Carolina as authority for the DOJ’s finding that our State's mental health system unnecessarily places people at risk of institutionalization in violation of their rights under the ADA.
Team Spotlight: Kids Team

The Kids Team is led by Attorney Iris Peoples Green and includes two advocates, Kirby Morrow and Rodney Crooms. Ricky Scott, an advocate on temporary assignment, is working with the Team through the end of September. The Kids Team works to ensure that children with mental health needs have access to services in their community. It provides advocacy and legal representation for children with mental illness under age 21 using Medicaid's early periodic screening, diagnosis and treatment (EPSDT) entitlement as the legal tool to secure the services. The Kids Team works diligently with child and family teams to ensure that children receive medically necessary mental health supports and services so that they can remain in their homes with their families.

The Kids Team actively participated in ensuring that children were transitioned to appropriate placements and linked to supports and services during the Dorothea Dix PRTF and Old Vineyard closures. The Team is now working with stakeholders to reform the current system of care model so that children with multiple, complicated issues can access services and placements within North Carolina as efficiently as children with less complicated issues.

Seated, Advocate Kirby Morrow and Team Leader Iris Green. Standing, Advocates Ricky Scott and Rodney Crooms.
Community Monitoring Project Report

In the Spring 2011 edition of this newsletter, we announced that the National Disability Rights Network (NDRN) awarded funding to Disability Rights NC to monitor and advocate on behalf of individuals with developmental disabilities transitioning from institutions to community living. In the first four months of the project, our Advocates Debbie Thome and Angie Downs:

◆ Visited 23 community settings across the State where six or fewer people with developmental disabilities resided;

◆ Interviewed 60 individuals with developmental disabilities – 7 of whom were transitioning from an institution into a community setting;

◆ Interviewed 46 people employed by the facilities monitored;

◆ Discovered safety and rights violations in 5 of the facilities; and

◆ Provided or are providing advocacy to residents in 14 of the community settings. (Five (5) of the residents who received or are receiving advocacy are transitioning individuals.)

The types of facilities monitored by the Advocates include companion-model apartment living; supervised apartment living; one farm house that is part of a cluster of group homes for people with autism located on land where residents work in farm-related businesses such as herb production and a Community Supported Agriculture program; a family home converted to a group home enabling a brother and sister to transition from nursing homes and live together; group homes in urban and rural settings; and group homes for adults and for children. In several cases, the Advocates visited the day programs in which the residents participate.

The monitoring project, which supplements Disability Rights NC’s established facility monitoring program, will continue through the end of September 2011.

Disability Rights NC Staff

Executive
Vicki Smith, Executive Director

Finance & Operations
Charlie Barnes, Chief Financial Officer
Janice Willmott, Chief Administrative Officer
Edward Salerno, IT Administrator
Karla Blackwell, Receptionist
Allyson Hilliard, Accounting Assistant
Mavis Jones, Office Manager
Haydee Martinez, Administrative Assistant

Legal & Advocacy
Adrienne Allison, Director of Advocacy and Compliance
John Rittelmeyer, Director of Litigation
Cas Shearin, Director of Investigations and Monitoring
Jennifer Bills, Lead Attorney
Elizabeth Edwards, Lead Attorney
Lisa Graefstein, Lead Attorney
Iris Green, Lead Attorney
Susan Pollitt, Lead Attorney
Chris Trottier, Lead Attorney
Diana Burch, Advocate
Sonya Clark, Advocate
Rodney Crooms, Advocate
Angie Downs, Advocate
Kim Fakhoury, Paralegal
Dan Fox, Advocate
Anthony Garcia-Copian, Intake Specialist
Nancy Hitchcock, Intake Specialist
Morris McAdoo, Attorney
Kady McDonald, Intake Specialist
Kirby Morrow, Advocate
Karen Murphy, Advocate
Steve Noblitt, Advocate
Lisa Rabon, Attorney
Mercedes Restucha-Klem, Attorney
Holly Stiles, Attorney
Andrew Strickland, Attorney
Kathy Smith, Advocate
Kristine Sullivan, Attorney
Debbie Thome, Advocate

Policy & Outreach
Annaliese Dolph, Director of Public Policy
Elaine Whitford, Director of Development
Corye Dunn, Policy Analyst
Gabrielle Martino, Outreach Specialist
The Arc of NC Pledges to Support Pro Bono Legal Services Program

The Arc of NC pledged its support of Disability Rights NC’s pro bono program with a gift of $15,000. The funds will be used to support the work of our staff to find pro bono attorneys for people with developmental disabilities who call for legal assistance but cannot be directly served by Disability Rights NC’s advocates and attorneys.

Tracy Warren, Board President of The Arc of NC stated, “The Arc is pleased to support the pro bono project because it will assist people with disabilities throughout the state during these incredibly challenging times. We hope this gift will encourage others to support this critical effort by Disability Rights NC.” You can support the program by volunteering as a pro bono attorney or by giving a donation to support the program.

The Arc is a 50-year-old advocacy and service organization for people with intellectual and developmental disabilities. They are a member-driven organization started by families and governed by a board of volunteers, mostly family members and people with disabilities.

Three Disability Rights NC Representatives Honored

In June, the NC Mental Health Consumers Organization recognized three representatives of Disability Rights NC for their outstanding work on behalf of mental health consumers. We congratulate Executive Director Vicki Smith, Advocate Karen Murphy and PAIMI Advisory Council Chair David Cornwell “for going the extra mile for mental health consumers in NC.”