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Volume 12 • Spring 2012

Come to Our Birthday Party!

On July 1, 2012, Disability Rights North Carolina will be five years old! Join us on Thursday, June 21, 2012 from 4:00 to 7:00 p.m. at Raleigh’s McKimmon Center for a celebration of our work.

Our staff and board will present displays and fun activities to demonstrate what we do to improve the lives of people with disabilities in our state. We will serve light snacks and birthday cake. We will be giving away great door prizes throughout the event and every person attending will receive a special “party favor.”

This event is FREE, but we need to know that you plan to join us. Please R.S.V.P. using the link on the Events Page of our website – www.disabilityrightscnc.org.

Since this event is free, we need “birthday gifts” (a.k.a. sponsorships) to help underwrite the costs. For a $250 sponsorship, you will be recognized at the event. You will also have the opportunity to give a special birthday wish to Disability Rights NC, which will be displayed at the event and in subsequent publications. Contact Elaine Whitford at elaine.whitford@disabilityrightscnc.org for more information on sponsorship.

Disability Rights NC to Receive Award

On May 10, Disability Rights NC will receive the prestigious Defenders of Justice Award from the North Carolina Justice Center. The award honors individuals and organizations that have made significant contributions in the fight against poverty in North Carolina. Tickets are available for the awards dinner to be held on May 10, 2012 from 6:00 to 9:00 p.m. in Durham, NC. For more information or to purchase tickets, visit the Justice Center’s website – www.ncjustice.org. All ticket proceeds support the Justice Center’s general operating fund.

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Our Newest Board Member: Janna Shisler

At its meeting on March 23, the board appointed Janna Shisler to the seat vacated by Vera Luck last fall. Janna's interest in serving on the Board was triggered by a growing awareness of the significant legal and advocacy work being accomplished by Disability Rights NC on behalf of people with disabilities in the state.

Janna has a special interest in access to healthcare issues and ensuring that people with disabilities are considered and included as reform progresses. She believes community inclusion is critical to accomplishing much of what we hope to achieve in all aspects of disability policy and would like to see this as a central theme.

Janna has firsthand knowledge of the joys and challenges faced by people with disabilities. In 1979 during her sophomore year in college, Janna suffered a spinal cord injury in a hayride accident. She says, “It took me many years to understand and become aware of the fact that there existed a vibrant and active community of people with disabilities who lived full, proud, happy lives. I carried stereotypes of the broader society of which I was a part until that fateful night of the hayride. I am blessed to have met many outstanding advocates who have enriched my life. I want to continue to work toward building the society that they committed themselves to bringing about.”

Janna graduated from Indiana University with a bachelor's degree in political science. She received her juris doctorate degree from the Indiana School of Law in Indianapolis in 1988 and, several years later, returned to law school and completed an LL.M. in Health Law, Policy and Bioethics. Janna started her legal career with a federal judicial clerkship and then accepted a position with the state teachers retirement fund. She spent most of her active legal career as general counsel for the Hoosier Lottery where she handled a broad spectrum of legal, human resources and policy issues in a corporate setting.
It’s Time to Get Out the Vote!

Everyone is equal in the voting booth. “One person, one vote” means we each have an equal say in elections. But we only have that say if we vote.

In 2008, only 55% of people with disabilities in North Carolina voted, while 69% of people without disabilities voted. That means there is a 14% voting gap between voters with disabilities and voters without disabilities.

To help North Carolina citizens with disabilities, Disability Rights NC created a Voting Guide which explains everything you need to know about how to register and vote in North Carolina. The Voting Guide includes important dates, a step-by-step checklist for voting, and ideas on getting more involved. There are also helpful links to other voting resources.

Look for the Voting Guide and other elections resources on our Voting website page.

Is Your Polling Place Accessible?

There are approximately 3000 polling places in North Carolina. Disability Rights NC recently released its report on Accessible Voting in North Carolina summarizing a multi-year effort to assess polling places across the State.

Disability Rights NC conducted extensive on-site surveys of early voting and Election Day polling sites throughout North Carolina in 2008 and 2010. The purposes were to assess physical barriers to on-site voting and identify inaccessible features to the local boards of elections. Disability Rights NC surveyed 161 voting sites in 59 of North Carolina’s 100 counties during the early voting periods of the 2008 and 2010 General Elections, and 352 voting sites on either Election Day 2008 or 2010.

Review the complete report on our Voting website page and see how accessible the polling places in your county are.

Is your polling place fully accessible? Let us know if you encounter problems, and specifically what the problems are. We’ll make sure that accessibility issues are reported to the County Boards of Elections.

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
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Lisa Nesbitt, Attorney
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Lisa Rabon, Attorney
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Holly Stiles, Attorney
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Kathy Smith, Advocate
Kristine Sullivan, Attorney
Debbie Thome, Advocate

Policy & Outreach
Elaine Whitford, Director of Development
Corye Dunn, Director of Public Policy
Gabrielle Martino, Outreach Specialist
Volunteer Spotlight: Margaret Schucker

During the past fourteen months, Margaret Schucker has completed more than 120 hours of volunteer work at Disability Rights NC. Margaret helps the Outreach Team enter names and addresses into the mailing databases and helps put together special mailings. Director of Development Elaine Whitford applauded Margaret’s commitment, “Margaret is here pretty much every week. We can rely on her to take care of the job at hand, whatever that may be. Margaret has been a valuable asset in the growth of our organization.” Earlier this year, Margaret completed the two-part Disability Advocacy Training Exchange (DATE) volunteer training presented by Disability Rights NC.

Margaret first learned about Disability Rights NC when she read an article in the News & Observer about the organization’s role in the investigation of the School for the Deaf in Morganton. She contacted the organization about volunteering because she thought “it was a worthy thing to do.” Margaret reports that she has continued to volunteer because there is always something she can do every week.

Margaret and her family (husband, John; children, Jack and Caroline) have lived in Raleigh for sixteen years. She grew up in Brooklyn, NY and studied Mathematics as an undergraduate at SUNY-Binghamton. She later received a masters degree in Landscape Architecture from NC State University. Margaret previously worked as the Historic Preservation Planner for the Town of Hillsborough. She enjoys gardening, knitting, photography and refinishing furniture.

Margaret says the most interesting thing she has learned as a volunteer with Disability Rights NC is how much technology, such as email and texting, has aided people with hearing impairments.

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.

Self-Advocacy Tip

Know what you are going to request before you get to the meeting or start the phone call. Write it down. And plan how you will respond if you don’t get what you ask for.

Do you have a good self-advocacy tip? If so, email it to Gabby at gabrielle.martino@disabilityrightsnc.org and we just might publish it in our next newsletter!
Kids Report Published

In December, Disability Rights NC released a report outlining the troubling experiences of four children with dual disabilities that occurred in 2011. (A copy of the report is posted on our website.) A lack of available mental health services led to long waits in emergency rooms, hospitalizations hours away from home, and institutionalization out-of-state. One 11-year-old child was subjected to excessive doses of medication leading to physical harm. Another was subjected to restraints in a state hospital that led to bruising on his arms, legs and torso.

In all four cases, the children’s experiences would have been different if the State’s recently presented plan – the System of Care model – had been implemented. This plan requires community-based services to be tried before more restrictive out-of-home placements. Funding cuts and a failure to hold the state’s Local Management Entities (LMEs) accountable make implementation of the System of Care model nearly impossible.

The information included in the report prompted NC DHHS to create three new foster care definitions – Therapeutic Family Services, Intensive Therapeutic Family Services and Specialized Residential Services – and new beds for these children. The service definitions are awaiting approval by the Centers for Medicaid and Medicare Services (CMS).

Dear Gabby

Gabby heard some great questions over the past few months as she traveled the State and introduced citizens to Disability Rights NC.

Q: How does Disability Rights NC define disability?

A: Disability Rights NC defines disability in the same way the Americans with Disabilities Act does. All people with disabilities, visible and hidden, including:

- a person with a physical or mental impairment that substantially limits one or more major life functions (eating, breathing, caring for oneself, working, walking, etc.), OR
- a person with a record of such an impairment (even if that record is inaccurate), OR
- a person who is regarded as having such an impairment.

Q: What do Disability Rights NC DATE volunteers do?

A: Our DATE volunteers act as a volunteer corps of self advocates across the state. During two 6-hour trainings, volunteers learn basic self advocacy and communication skills and how to support another person’s self advocacy. They are then matched with “DATEs” in the community who need help advocating for themselves. We also have volunteers who help us on individual projects such as data entry and big mailings.

Q: Do we ever charge a fee for services?

A: No. The services provided by Disability Rights NC – including our newsletters, information and referral, and direct legal services – are all free.
Every day, the Staff and Board of Directors of Disability Rights North Carolina work with citizens of our State who dedicate their lives to creating and protecting opportunities for people with disabilities in North Carolina to live full and satisfying lives. In October, we honored a few of them with the Champions of Equality and Justice Award. Each of this year’s award recipients worked to establish and improve fundamental systems that are the keys to an independent life for people with disabilities.

**Julia Bick – In Memory**

Julia Bick was a visionary in the expansion of affordable housing opportunities for people with disabilities in North Carolina. Julia’s relentless advocacy led to the creation of the North Carolina model of integrated supportive housing. In her position as Housing Coordinator for the NC Department of Health and Human Services, and working closely with the NC Housing Finance Agency, she promoted a program that effectively combined Low Income Housing Tax Credits with a state-funded operating subsidy program and other enhancements to create integrated, accessible, affordable community housing for low-income persons with disabilities.

Julia knew how to make an innovative idea become a reality. Her work resulted in the designation of approximately 2,200 apartments set aside for people with disabilities. About half of the 2,200 apartments were fully accessible. The successful outcomes from the North Carolina program prompted the states of Louisiana, Pennsylvania and New Mexico to adopt the North Carolina model and formed the basis of the innovations in the Frank Melville Supportive Housing Investment Act of 2010, which resurrected HUD’s Section 811 supportive housing program. The Act will create thousands of new, affordable and accessible units every year.

Julia passed away on January 4, 2011, just hours after President Obama signed the Melville Act into law. We will miss Julia’s passionate advocacy, but will continue our work to build upon her legacy.

**Michael Maybee**

For more than two decades, Michael Maybee has advocated for full community inclusion of people with disabilities in North Carolina. A colleague of Michael’s described his advocacy as more of a religion than a professional duty.

In 1990, he developed and implemented the supported employment program for Watauga Opportunities, Inc., located in Boone, NC. Watauga Opportunities is a nonprofit community rehabilitation program providing vocational training, job placement, employment opportunities, community opportunities and residential services to adults who have barriers to employment.
and community inclusion. Today, Michael leads Watauga Opportunities as its President and CEO.

Michael’s leadership is recognized by advocates across the state due to his service on many state and regional councils and boards. Michael is Past Chair of the NC State Rehabilitation Council, which provides oversight, guidance and advice to the State Division of Vocational Rehabilitation. He is a founding member of the NC Chapter of the Association for Persons in Supported Employment and Past President of the NC Association of Rehabilitation Facilities. He is Past President of the Marketing Association of Rehabilitation Centers, a collaborative group of community rehabilitation programs in Western NC. He serves on the NC Vocational Rehabilitation/Community Rehabilitation Program task force, is an organizing member of the NC Employment First Steering Committee and was a member of the recent NC Institute of Medicine’s (IOM) Developmental Disabilities Task Force.

Dr. Charles Walker

When Dr. Charles Walker became blind in 1987, he learned how to advocate for himself. Since then, he has used his advocacy skills to help people with blindness gain full access to community programs and worked to change attitudes.

Charles established himself as a role model for overcoming the challenges of blindness by first obtaining his GED and continuing his education through a doctoral program at NC State University. As a graduate student, he conducted a national study investigating the attitudes of counselors in graduate programs towards people with blindness. The study revealed that the graduate programs were largely devoid of education and information about blindness. He has developed several models and tools to measure attitudes towards people who are blind or visually impaired. As an adjunct professor of counselor education, Charles includes disability awareness components in his course curriculum.

Also during his graduate program at NCSU, Charles advocated for and acquired a talking elevator in Poe Hall and a talking computer and scanner in the Learning Resource Library. He was involved in student government and supported legislation to give people with disabilities greater access to college sporting events.

Through his service on the Raleigh Mayor’s Committee for Persons with Disabilities, Charles proposed a two-tiered transportation plan for Accessible Raleigh Transportation, which was adopted by the City Council. Charles has served as a member of the Board of Directors of the Raleigh Lions Clinic for the Blind, where he works to increase employment for people who are blind or visually impaired. His work with Bridge II Sports includes planning and production of a Paralympics Academy for people who are blind or visually impaired.

2012 Champions of Equality and Justice

The awards reception for the 2012 recipients of the Champions of Equality and Justice Awards will be held in October. We are now accepting nominations for the 2012 Champions of Equality and Justice. If you know an individual deserving of recognition, please nominate them. You will find more information and the nomination form on our website – look for the Champions Award page.

Previous Award Recipients

2009
Marian Hartman
Greg McGrew
NC IOLTA

2008
The Honorable William Creech
Lockhart Follin-Mace
Jo Anne Jeffries
Robert Reilly - In Memory
Accessing Recreational Venues

KE, an individual who is deaf, planned a visit to an historic estate with his wife. KE is a savvy traveler and called a month ahead of his visit to request an interpreter for the tour of the estate. He was told that they could not provide an interpreter but would send a transcript of the audio tour so that he could read the information as he walked through the estate. This was not a satisfactory replacement for being able to look around as he received the information about the estate during his tour.

Disability Rights NC intervened by advocating for reasonable accommodation rights under the ADA and recommending to the estate's staff that their website be upgraded with accommodations as available information. The result was that KE was invited back to tour the estate with an interpreter. The estate now provides interpreters for visitors who need and request them, and the estate has modified their website to include accommodations information.

CH is blind and a very accomplished skier, sometimes a ski racer. He requires the assistance of a ski guide to “interpret” the downhill course so that he knows when to change directions or avoid another skier. CH faced resistance from western NC ski resorts when he asked them to provide a lift ticket for the ski guide at no extra cost to CH.

Disability Rights NC intervened and advocated for his right to a reasonable accommodation under the ADA for the ski guide at no additional cost to him. CH received a refund for the money that he had paid for the additional lift tickets, and in the future all ski guides’ lift tickets will be complimentary as reasonable accommodation for equal access as defined under ADA.

Need a DATE?

Disability Rights NC supports strong self-advocacy through its Disability Advocacy Training Exchange (DATE) program. Over the past six months, nearly 80 individuals completed training to volunteer in the DATE program. Each month, we receive many more calls for help than our staff can respond to directly. When appropriate and with the caller’s consent, we assign a trained DATE volunteer to work with the caller. The DATE volunteers help people with disabilities by supporting their self-advocacy.

DATE volunteer trainings will be held in Goldsboro and Greenville in May 2012. Check out the Events page on our website for more details and to sign up.

Staff News

Staff Attorney Kristine Sullivan wrote a manual on restraint and seclusion recently published by Council of Parent Attorneys and Advocates, Inc. (COPAA) titled The Right to be Safe in School: Advocacy and Litigation Strategies to Combat the Use of Restraint and Seclusion. The manual discusses advocacy and litigation strategies and examines federal and state policy initiatives aimed at eliminating the use of restraints and seclusion for managing the behavior of students with disabilities in school. Kristine has worked with Disability Rights NC since 2007.

Participating in the life of a community is an important part of our human dignity. The Community Access Team (CAT team) works to ensure that every North Carolinian with a disability has the opportunity to work, play and pursue a fully integrated and engaged life.

The CAT team handles cases involving equal access to public accommodations and healthcare, employment discrimination and voting rights. Our clients may face employment barriers ranging from the denial of a reasonable accommodation to a discriminatory firing. Many public accommodations fail to provide meaningful access, including interpreters for deaf patrons or modification of policies that prevent equal access.

In addition to individual case work, the CAT team is currently involved in several projects:

- monitoring facilities that employ people with disabilities at subminimum wage;
- ensuring access to healthcare for deaf and hard of hearing patients;
- increasing voter registration and engagement among people with disabilities; and
- assessing the availability of assistive technology in movie theaters.

The members of the CAT team are: Dan Fox (Advocate), Lisa Grafstein (Attorney/Team Leader), Steve Noblitt (Advocate), Mercedes Restucha-Klem (Attorney) and Holly Stiles (Attorney).

“All human beings are born free and equal in dignity and rights.”

The Universal Declaration of Human Rights, Article 1
Legal Update

Judge orders restoration of services and certifies class action in *K.C. v. Cansler and PBH, 11-CV-0354-FL (EDNC).*

On March 29, US District Court Judge Louise Flanagan ordered the State of North Carolina to halt reductions to home and community-based services and restore lost services until the state Medicaid agency and its managed care contractor, PBH (formerly Piedmont Behavioral Healthcare), comply with legal requirements for providing Medicaid beneficiaries with adequate notices and opportunities for impartial hearings when their services are denied, reduced or terminated. The Court noted that without an injunction, the plaintiffs – children and adults with disabilities – would experience deteriorating health, financial strains and the threat of having to go into institutions to receive care.

This lawsuit was filed by Disability Rights NC and co-counsel, Legal Services of Southern Piedmont and the National Health Law Program, in 2011 to challenge the manner in which DHHS, acting through its contractor PBH, had implemented a new version of a Medicaid waiver program known as the Innovations Waiver. PBH, a managed care organization 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.

Judge Flanagan also certified the case to proceed as a class action. Disability Rights NC is working on obtaining a list of all class members and will send a notice to the class.

CMS approves extension of IHCA through December 2012.

On April 4, NC DHHS Acting Secretary Al Delia informed the legislature’s Government Operations Committee that CMS had approved an extension of the current service through December, and that a new service under Section 1915(i) would begin on January 1, 2013. The extended service (effective from May 1, 2012 until December 31, 2012) differs from the current service in that there is no distinction made between the eligibility criteria for In-Home and Adult Care Home services. Disability Rights NC will monitor the implementation of the modified service to determine if the service criteria for Adult Care Homes is, in fact, the same as the In-Home service – something that will require approximately...
20,000 independent assessments of Adult Care Home residents – will true comparability be achieved.

The new rules were the subject of a lawsuit filed by Disability Rights NC against the State. *Pashby v. Cansler*, No. 5:11-CV-273-BO (E.D.N.C.). The new rules restricted coverage of Medicaid-covered Personal Care Services (PCS) for adults receiving in-home PCS while individuals residing in assisted living facilities known as Adult Care Homes (ACHs) needed to satisfy much less restrictive criteria to qualify for PCS in the ACH.

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 v. L.C.* 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.

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**Our New PAIMI Advisory Council Chair**

Sheila Wall-Hill, as Chair of the PAIMI Advisory Council, recently joined the Board of Directors as the Council Liaison.

Sheila became active with Disability Rights NC when she recognized that the organization was changing the way the system worked for the better. She saw that the advocates and attorneys at Disability Rights NC were helping parents make educated decisions about their children’s care. She says that the staff are “real people who really care about families.” As the chair of the PAIMI Advisory Council, Sheila will work to ensure that the Council is the voice of the people being served by the mental health system and is a trusted resource for the staff and board at Disability Rights NC.

Sheila touts herself as one of the few people living in Charlotte who actually grew up there. She received a bachelor’s degree in Biology from Johnson C. Smith University. After receiving her master’s degree in Microbiology at Ohio State University, Sheila returned to Charlotte in the early 1980s and worked as a science lab manager at Gaston Community College for 15 years. She left that job to provide care for a son with disabilities. As Sheila worked to ensure that her son received the services he needed, she learned that it was difficult for a parent to have a voice in what those services were and who would provide them. In 2002, she started a support group for parents of children with disabilities and ParentVOICE was born out of that effort.

ParentVOICE provides information, support and opportunities that strengthen and inspire youth with behavioral, emotional and mental health challenges, and their families, to learn, lead, participate and advocate for quality services and successful outcomes. ParentVOICE is now a program of the Mental Health Association of Central Carolinas, and Sheila is the Peer Support Coordinator for the program.

In her spare time, Sheila enjoys intense thriller movies and books – the kind that keep you on the edge of your seat. She also likes to travel and is a huge fan of the Carolina Panthers. She has two adult sons, Philip and Sabian.
From the Director

Self-Advocacy Is Key to Services

This spring is full of change.

Eastern Carolina Behavioral Health (ECBH) will be the next Local Management Entity (LME) to become a Managed Care Organization (MCO). Phase 1 of the expansion will be complete with PBH (formerly known as Piedmont Behavioral Healthcare), Western Highlands and ECBH LMEs operating as MCOs. The next wave will be on July 1, 2012 when Sandhills Center and Smoky Mountain Center make the transition. By midsummer over half of the state’s counties will be operating as MCOs.

In May, the General Assembly officially starts its short session. Conventional wisdom does not help much in predicting the outcome of this critical session – and a lot is at stake.

While most change provokes anxiety, some change can make a positive impact on the service system. Strong, independent advocacy is critical. But skilled individual self-advocacy is the foundation.

Information and skilled self-advocacy are the building blocks to a service system that supports the rights of people with disabilities to live free from harm in the communities of their choice with the opportunity to participate fully and equally in society.

Vicki Smith, Executive Director