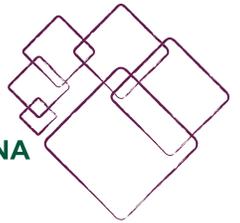


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DISABILITY RIGHTS
NORTH CAROLINA

Champions for Equality and Justice



Volume 22 • Spring 2016

Third Annual Disability Advocacy Conference



“This is a conference not to be missed. The staff at Disability Rights North Carolina and expert presenters provide a wealth of information for individuals with disabilities, their families, community advocates and providers.”

This year’s Disability Advocacy Conference, held on April 20, 2016 with a record attendance of more than 200 people, was punctuated by a thought-provoking keynote address.

The Honorable Kristin Booth Glen opened the conference with a challenge to view guardianship in a different light. She asked the audience to consider guardianship as a deprivation of an individual’s basic civil rights, and urged them to elevate supported decision-making as the preferred method of assisting an individual with a disability.

Judge Glen’s address was followed by breakout sessions on different disability topics and the networking lunch, which allowed participants to speak with members of the staff of Disability Rights NC and other disability advocates about certain topics over lunch.

We appreciate the support of our volunteers who gave their time during the conference and awards reception: **VanaMary Issac, Ashley Lindsay, Jessica Martz, Keir Morton-Manley, and Tempest Stokes.** And we thank our sponsors whose support enabled us to provide registration scholarships to 23 advocates with limited incomes.

We hope to see you at next year’s conference. Mark your

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Ten Things You Should Know About Vocational Rehabilitation



North Carolina offers free employment services for people with disabilities who want to work. The Division of Vocational Rehabilitation Services (VR) is a state agency, and is one provider of these services. To qualify for VR services, a person must have a disability that makes it harder for him or her to find work and would have an easier time finding work with help from VR.

- 1. Eligibility Timeline.** After applying for services, VR has 60 days to determine if you are eligible for VR services.
- 2. Eligibility Assessments.** VR may ask you to provide medical and other information to help VR understand how your disability interferes with your ability to work. VR also may ask you to participate in work trials. These work trials must take place in the “most integrated setting possible,” which would not include a workplace that employs only people with disabilities.
- 3. Supplemental Security Income (SSI)/Social Security Disability Insurance (SSDI).** If you receive SSI or SSDI benefits, you are presumed eligible for VR services.
- 4. Certificate of Eligibility.** VR must provide you with a letter explaining if you are eligible for services. If you are not found eligible, the letter must explain how you can challenge the decision.
- 5. Employment Plan Timeline.** Federal law requires that once you are found eligible for VR services, VR must complete your employment plan within 90 days unless you and VR agree to an extension of time.
- 6. Employment Goal.** You have a right to select your own employment goal so long as it is consistent with your strengths, resources, priorities, concerns, abilities, capabilities, and interests. The VR counselor can help you explore different career options and identify your strengths and weaknesses, but it is your right to choose your specific employment goal. The VR counselor is not allowed to select an employment goal for you.
- 7. Informed Choice.** You have a right to make informed choices about any assessments, services, and service providers. VR counselors must explain all of the options available to you before you are asked to choose a service or the company you receive it from. VR is required to develop different services and service provider options for you to choose from.
- 8. Making Changes to an Employment Plan.** You have a right to change your employment plan. Major changes, such as changes to your employment goal, services, or service providers, will require you to update your employment plan.
- 9. Right to Appeal.** VR must provide you notice of your right to an impartial due process hearing whenever VR reduces, suspends, or terminates your services. You may challenge any determination made by VR that affects the provision of VR services.
- 10. Reapply for VR Services.** If VR closes your case or you are found ineligible for services, there is no waiting period to reapply for VR services. You may reapply at any time. You may be required to go through the VR eligibility process again.

The Social Security Administration has reviewed this article for technical accuracy only; this should not be considered an official Social Security communication.

State Forced to Eliminate Institutional Bias in Personal Care Services

When Medicaid recipients need help with things like bathing, eating, and dressing, Medicaid pays for personal care services. When a recipient applies for these services, a nurse assesses them to determine the number of hours, if any, for which they qualify.

Five years ago, Disability Rights NC, the National Health Law Project, and Legal Services of Southern Piedmont filed a class action lawsuit, *Pashby v. Delia*, on behalf of Medicaid recipients who were living at home, but who were at risk of being forced into adult care facilities to receive the personal care services they needed. The suit charged that a new state policy set a higher bar for those living at home to qualify for the services than for those living in adult care facilities. This created a bias towards institutional living.

During the course of the legal battle, the State agreed to change the policy so that the assessment was identical, at least on paper. In practice, however, the institutional bias remained. For example, because people living in adult care homes are provided meals, they often were automatically assessed as needing help with meal preparation; but, if they lived at home, they were less likely to be assessed as needing help with meal preparation.

On April 1, 2016, the federal court approved a settlement of the legal action, with the State agreeing to assess the need for personal care services the same way for all Medicaid recipients, regardless of where they lived. The settlement impacts more than 10,000 people with disabilities in North Carolina who were members of the plaintiff class.

Under the terms of the settlement:

- ◆ The eligibility criteria for determining hours of personal care services must be the same for Medicaid recipients living at home and those residing in adult care facilities or other institutions.
- ◆ The assessment methods must be comparable, including practices, forms, procedures, and instructions.
- ◆ The assessor must schedule the assessment ahead of time.
- ◆ Reasonable efforts must be made to contact the recipient before a denial is issued on the basis of failure to schedule the assessment.
- ◆ A caregiver or other trusted individual must be allowed to attend the assessment.
- ◆ Evidence of cognitive limitations must be taken into consideration when attempting to schedule or assess.

Disability Rights NC Welcomes Two New Staff Members



Matt Herr has joined us as Public Policy Analyst. Matt decided to go to law school and become a disability

advocate after working extensively with children who have disabilities. While in school, Matt was diagnosed with multiple sclerosis, which reinforced his commitment to “walking the walk” as a disability advocate. Matt graduated from UNC School of Law with honors in 2014 and then clerked for Chief Judge Linda McGee at the NC Court of Appeals. When not working, Matt enjoys spending time with his wife and kids, exploring North Carolina’s natural beauty, cooking delicious food, and brewing beer.



Josh Prater has joined us as a Paralegal. Before joining Disability Rights NC, Josh worked as a lab tech, a teaching

assistant for students with autism in Wake County Schools, and a paralegal at a small plaintiffs’ wage and hour firm. Josh is a North Carolina native, a Raleigh transplant, and enjoys minor league baseball, reading, cooking, and canoeing.

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Read more about our board members at
www.disabilityrightsn.org/meet-our-board.



State Forced to Eliminate Bias

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The State also agreed to reassess members of the plaintiff class for whom personal care services were denied or terminated and who meet certain conditions (i.e. they must still be eligible for Medicaid and cannot currently be receiving personal care services).

In the landmark *Olmstead* decision of 1999, the US Supreme Court interpreted the Americans with Disabilities Act to require public agencies to provide services in the community that allow people with disabilities to move out of institutions. Since then, several federal appellate courts have issued decisions that interpreted the *Olmstead* decision to mean that public agencies were *obligated* to provide services to people living in the community that are adequate to prevent them from being placed *at risk* of institutionalization.

The *Pashby* case marks the first time the “at risk” principle was affirmed in the Fourth Circuit (the US Court of Appeals that serves North Carolina, South Carolina, Maryland, Virginia, and West Virginia). While granting a preliminary injunction stopping the State from implementing its new policy in 2011, US District Court Judge Terrence Boyle said the policy put North Carolinians “who have been successfully living in their own homes... at risk of segregation, in the form of institutionalization.” The Fourth Circuit Court of Appeals affirmed that principle in 2013 when it denied the State’s appeal.

Medicaid-Covered Services for Children Often Go Unclaimed

A Medicaid benefit for children under 21 would cover essential services for thousands of children with disabilities in North Carolina if it was properly administered.

The benefit is called EPSDT – Early and Periodic Screening, Diagnosis, and Treatment. It is based on the principle that early detection and treatment of health conditions makes for healthier children and adults, which also saves money for families and the Medicaid program. The goal is to ensure that individual children get the health care they need when they need it – the right care to the right child at the right time in the right setting.

The EPSDT rule works like this: the federal Medicaid program requires states to cover some types of health care services and makes others optional. However, for Medicaid-eligible children under 21, any or all of those optional services must be provided if they are medically necessary to correct or ameliorate defects and physical and mental illness and conditions discovered by screening services. “Ameliorate” means to improve or maintain a person’s health in the best condition, compensate for a health

problem, prevent it from worsening, or prevent the development of additional health problems.

The problem is that many parents, and even some professionals, are unaware of the rule or are misinformed about what it covers. The misinformation was confirmed recently when a new law that will require private insurers to cover some autism treatments was passed in North Carolina. A news story stated that Medicaid would not cover these treatments and a parent who was quoted in the story made the same mistaken assumption.

The fact is that EPSDT covers accepted autism treatments such as Applied Behavior Analysis (ABA). In 2014, when the Centers for Medicare and Medicaid Services clarified that states are required to provide these services, it noted they should “work expeditiously and should not delay or deny provision of medically necessary services.”

At least 24 states already offer services to children with autism spectrum disorder. At least five states have been sued for failing to provide these federally mandated services.

Another service important to children with disabilities is case management, which is not covered by Medicaid in NC for adults. Like ABA therapy, the EPSDT rule makes case management a covered service for Medicaid-eligible children and adolescents when it is medically necessary.

Experts recognize that case management is the core element of service delivery for at-risk populations. Effective case managers are typically trained in special education, social work or psychology. They are responsible for advocacy and the development and execution of individual treatment programs for children, and for monitoring the outcomes of those programs. This requires a familiarity with the needs of each child, the complicated rules governing eligibility for specific services and restrictions associated with each service definition, as well as the availability of services in each area of the state. Case management services significantly enhance positive outcomes for children and adolescents and keep them in their homes and communities.

If you have a child under 21 on Medicaid, be sure to request any of the services your child needs on either the mandatory or optional services list. A full list of EPSDT services can be found on the website of the NC Division of Medical Assistance (<http://dma.ncdhhs.gov/providers/programs-services/medical/Health-Check-Early-and-Periodic-Screening-Diagnosis-and-Treatment>).

Parents should speak with their child’s health care providers to decide whether autism-related services may be medically necessary for their child. Requests for ABA services for children up to age 3 should go to the NC Division of Medical Assistance. For children aged 3 to 21, requests are made to the State’s contractors for behavioral health services – the LME/MCOs.

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Karla Blackwell, Administrative Assistant

Carolina Herrera, Receptionist

Allyson Hilliard, Accounting Assistant

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Lisa Grafstein, Managing Attorney

John Rittelmeyer, Director of Special Litigation

Cas Shearin, Director of Investigations and Monitoring

Jennifer Bills, Senior Attorney

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Virginia Fogg, Senior Attorney

Anthony Garcia-Copian, Intake Specialist

Iris Green, Senior Attorney

Marian Hartman, Advocate

Chris Hodgson, Attorney

Lucy Ireland, Attorney

Tadra Martin, Attorney

Gabrielle Martino, Investigator

Kady McDonald, Intake Specialist

Kishona Mimms, Investigator

Lisa Nesbitt, Attorney

Steve Noblitt, Advocate

Susan Pollitt, Senior Attorney

Josh Prater, Paralegal

Lisa Rabon, Senior Attorney

Katherine Slager, Attorney

Holly Stiles, Attorney

Kathy Smith, Advocate

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Policy & Outreach

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Kristin Parks, Lobbyist

Third Annual Advocacy Conference

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calendar for Thursday, April 20, 2017 when we return to The Friday Center in Chapel Hill.



Chris Trottier receives the first Adele Foschia Award from Vicki Smith at the 2016 Awards reception.

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.

**The Fourth Annual
Disability Advocacy Conference
will be held on Thursday, April 20, 2017
at The Friday Center in Chapel Hill, NC.**

**Registration will open in December.
Sponsorships available – contact Elaine at
Elaine.whitford@disabilityrightsn.org.**



Judge Glen gave the keynote address to open the conference.

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Reviews from Participants

“The Disability Rights Advocacy Conference is one of the best in the state. The issues covered are full of facts, not spin, so it is easy to understand the real issues at hand.

The information is current, relevant, and important. If you are an advocate at heart, don't miss this!”

“I have attended all three years and learn something new that is very relevant to my work every year.”

“What a fabulous conference. I will definitely be here every year! Because of the unique expertise that Disability Rights NC staff have, I was able to gain knowledge and information that I couldn't have received elsewhere.”

Three Outstanding Advocates Honored at Conference

At a reception held after the conference, Disability Rights NC recognized three outstanding disability rights advocates. Sandra "Sam" Hedrick and Bethany Smith are the 2016 recipients of the Champions for Equality and Justice Award. Christine Trottier is the first recipient of the Adele Foschia Award for Lifetime Cross-Disability Advocacy.



Left to right: Bob Hedrick, Sam Hedrick, Nik Ellis, and Gray Ellis.

Sam Hedrick

Sam Hedrick's favorite quote is Mahatma Gandhi's, "Be the change you want to see," fitting for a woman who has committed herself to making significant improvements in the quality of care and services provided to people with disabilities.

Several years ago, Disability Rights NC identified a client at a State facility as being in the wrong place given his needs. He felt misplaced, unsafe, and stunted in his life's development and asked to be given a chance to live outside the institution. After four service providers declined to work with him, Disability Rights NC attorney Susan Pollitt decided to call the person in the state who knew the field the best to help her brainstorm other possible resources. She called Sam Hedrick. Within a few days, Sam was on the case. Not only did she take on coordinating his services, she agreed to meet with the client every week over the following months. After a great deal of coordination and negotiations, the State funded the services this client needed to live in the community, as is his legal right under the *Olmstead* decision. The client was discharged from the institution and now lives in his own home.

Sam was president of RHA Howell -- a provider of services for people with disabilities in North Carolina -- at the time, and now is Executive Vice President for RHA Health Services. This case is only one example of the tenacity that has characterized her many years of providing services for people with disabilities. Her advocacy has ranged from serving children and adults on the autism spectrum with the highest, most complex needs to focusing on supportive employment services. She also has paid special attention to the needs of military veterans, including women veterans who have survived sexual trauma.

Sam has an interesting and varied background. She entered the field of nursing, and after a period of time, decided to put her advocacy skills to use in a different direction. She earned a law degree and was a public defender for six years. With an understanding of the challenges for people with disabilities based on the experiences of a family member, Sam used her background to create a new role. She fights for people with disabilities and their families, who so often have difficulty navigating the State's system of services.

Sam won a Health Care Hero Award from the Triangle Business Journal in 2014. The award recognized her for "improving the care in health care," based on her work at RHA

View the video presentations of our award recipients at www.disabilityrightsn.org/champions-awards

Howell. There she built up the agency's medical expertise so it could provide effective case management for children and adults with complex needs.

Sam also developed programs to reward employees and reduce turnover, including a program that invests in the education of employees, providing substantial opportunities to earn high school diplomas and college and post-graduate degrees. The program resulted in a drop in the turnover rate from 75 percent to less than 30 percent.

Bethany Smith

Bethany Smith is all too aware of the stigma of mental illness. Addressing the ignorance surrounding such issues has become her purpose in life, and the 25-year-old has plenty of personal experience to back up her message.

After an adolescence spent in and out of mental health facilities struggling with behaviors related to childhood trauma, Bethany spent two years at Cherry Hospital in Goldsboro. When Disability Rights NC attorney Kristine Sullivan met her there, she observed how Bethany had already begun advocating for herself. Bethany asked Kristine every question in the book about her rights as a patient, from whether she had a right to dye her hair to questions about medical interventions.

Her advocacy extended to her fellow patients. For example, while serving on the patient Quality Council, she helped resolve an issue for a number of patients whose money had been removed improperly from their accounts to pay for medical appointments; they had not been aware of this practice beforehand. The hospital's clinical director thanked Bethany personally for bringing the matter to the attention of the management team.

Bethany also worked as an assistant to the director of the Psychosocial Rehabilitation program, where she was in a good position to advocate for other patients. She gave a talk to new patients at their orientation, and served as a liaison to the management team. A staff member described her as "the voice for other people here."

Bethany engaged in creative pursuits as well, drawing and writing poetry and skits for patient performances. She wrote for the patient newsletter, and she wrote a 10-page article on changes to criteria in the DSM-V, the Diagnostic and Statistical Manual of Mental Disorders.

When Bethany experienced problems at a different hospital later, she had developed the skills to know what to do. She called Kristine Sullivan and reported that she had been restrained in what seemed an improper manner. She had not been behaving aggressively and had, in fact, sunk down on the floor when staff members and hospital police forcibly carried her from the main ward to an acute unit. The subsequent investigation by Disability Rights NC confirmed the impropriety of the hospital staff's actions.



Bethany Smith, left, and Kristine Sullivan.

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Outstanding Advocates Honored

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Adele Foschia Award



Adele Foschia helped Disability Rights NC become the results-driven organization it is today. Even after she turned

the leadership reins over to Vicki Smith, she never wavered as an enthusiastic supporter of the organization. For that reason and in recognition of the fact that Adele spent her entire professional life serving people with all types of disabilities, Disability Rights NC created a new award in her name to recognize individuals who have dedicated their life to advocating for people with all types of disabilities.



Christine Trottier and her family. Left to right: Liz Heinberg, Ben Heinberg, Christine Trottier, and Rich Trottier.

This act of self-advocacy helped many other patients. Responses by state and federal regulators forced the hospital to make changes in its policies and provide additional training to staff. Within just one month of instituting those changes, the hospital reported a 30 percent decrease in its use of police interventions to manage patient behavior.

Bethany is determined to continue her quest for patient rights. She is studying to be a patient representative at Pitt Community College in Greenville, where she lives and studies with two roommates. She is pairing that creativity with her passion for progress and writing a book about her experiences being institutionalized, with a hope to end some of the ignorance surrounding mental health issues.

Christine Trottier

After earning a bachelor of arts from Syracuse University and a juris doctor from Hofstra University School of Law, Christine Trottier (known by many as “Chris”) began her career as a Reginald Heber Community Law Fellowship Attorney, a program that began in the Office of Economic Opportunity, President Johnson’s War on Poverty. Thirty-seven years later, she retired from Disability Rights NC, leaving a legacy of measurable progress in protection and advocacy for North Carolinians with disabilities.

Chris began her career helping to launch Carolina Legal Assistance (CLA), which advocated for clients in psychiatric hospitals who were denied basic rights, including the right to refuse treatment. For example, CLA represented a woman who refused surgery as a cancer treatment and was promptly declared incompetent through the “lunacy statute” without notice or hearing.

Chris worked alongside executive director Deborah Greenblatt to achieve steady reform in those early years, including repeal of that statute and other policy reforms. CLA filed successful class action lawsuits. One case brought services to children who were being denied appropriate education and treatment. Another brought relief for adults who were being illegally confined in psychiatric facilities.

Chris helped steer CLA through a process that ended in its 2007 designation as North Carolina’s protection and advocacy agency, shouldering the responsibility for protecting the rights of North Carolina citizens with disabilities under the Americans with Disabilities Act and other federal laws. CLA was renamed Disability Rights North Carolina later that year.

One of Chris’s signature projects was the Special Education Juvenile Justice Project (SEJJP). The SEJJP was designed to provide legal advocacy for youth who are caught in the school-to-prison pipeline. By insisting on their right to appropriate educational services, Chris and her team forced systemic change that resulted in maintaining education services for at-risk students. Changes have included robust training for teachers

From the Director



Disability Rights NC exists because disability advocacy leaders envisioned the impact a protection and advocacy system (P&A) could make in the lives of North Carolinians with disabilities if it was not an agency of the State.

According to the combined history of Carolina Legal Assistance and the Governor's Advocacy Council for Persons with Disabilities, redesignation was attempted over 8 different times before finally succeeding in 2007 when Governor Easley redesignated the federally mandated P&A to what is now known as Disability Rights NC.

Why did people like Deborah Greenblatt, Adele Foschia, Dave Richard, Adonis Brown, and so many more work so hard?

Because they believed in a future where every child with a disability stays in school and receives a free appropriate public education.

They believed in a future where all children with disabilities receive transition services to help them plan for their move from high school to post-secondary education and meaningful employment.

They believed in a future where our state provides services to people with mental illness and intellectual and developmental disabilities in the community instead of isolating them in restrictive settings.

They believed in a future where everyone has the opportunity to easily register to vote and cast their vote.

They believed in a future where people with disabilities are fully included in all aspects of community life, free of discriminatory attitudes and biases.

They believed in a future where people with disabilities have a voice – both individually and in coalition – in the development of services and policy that impacts them.

They knew the P&A would have to be strong and tenacious. For their vision to be realized, the Board of Directors would need to come from the disability community and represent the full spectrum of disability and all areas of the state. They also knew that the independent P&A would need a strong and passionate staff who could change systems by challenging the status quo.

They created a P&A that uses every tool in its tool box, including litigation to remove the state's institutional bias and change the discriminatory practices of public and private agencies, monitoring the conditions of thousands of institutional settings to make them safe until people could move into more integrated settings, investigating allegations of abuse and neglect to stop dangerous practices, and maintaining a presence among state policy-makers.

In the nine years since redesignation, the Board and staff of Disability Rights NC have made a difference. But the culture of institutionalization, segregation and isolation, suspension, stigma, and fear are deeply ingrained in our state. The idea that disability means unable or incapable is pervasive. And the mistaken belief that people with disabilities must be limited in their personal decision-making has become an epidemic.

We have a lot of work left to do. Working together and across disabilities, we can make a difference. This is a call to action. Join us. Together we can make our shared vision a reality.

Vicki Smith

Vicki Smith, Executive Director

and administrators and less reliance on exclusionary discipline practices, such as suspensions.

The focus on systemic change has been an underlying theme throughout Chris's career. She has been called an impact litigator and never hesitated to chase issues into the public policy arena. She has mentored dozens of attorneys who have become powerful advocates.

In 2009, Chris won the Deborah Greenblatt

Outstanding Legal Services Attorney Award, presented to an attorney employed by a legal services organization who provides exemplary legal service through an agency or other non-profit entity that serves low-income citizens. With the Adele Foschia Award, we honor her lifelong, tireless advocacy for children and adults with disabilities. We believe Adele would be proud that Chris was the first recipient of the award named for her.

Services Denied to Woman with Alzheimer's Disease

In the world of Medicaid-covered services, a simple misunderstanding or misinterpretation can have a profound effect on a family.

Martha's mother has Alzheimer's disease. At nearly 90 years old, she needs help with daily living tasks, and she was getting 80 hours in personal care services each month. When she came home from a rehabilitative facility after a fall, she had even more trouble, with no capacity to bathe or dress herself, and extremely limited ability to move around and eat by herself.

So Martha requested an increase in her mother's personal care services. Unfortunately, after an assessor came to their home to evaluate her mother's needs, her request for additional services was not only denied, but her existing personal care service hours were eliminated.

Disability Rights NC agreed to help Martha with her mother's situation, and after mediation,

the 80 hours per month in personal care services were restored and an additional 50 hours per month was granted for a total of 130 hours per month.

Where was the disconnect? When the assessor asked Martha if she worked, she replied, "Who has time to work?" She was caring for her mother full time, which, in the eyes of the assessor, meant her mother's needs were not going unmet. But Martha wanted and needed to work and would be doing so if she was able to leave her mother's care in the hands of a service provider for part of the week.

In this case, it took filing an appeal of the determination and mediation to clear up the matter. Martha's mother eventually received the services she desperately needed, but the time and effort spent in appealing the decision might have been avoided if both sides had been clear about Martha's need and desire to work.

www.disabilityrightsnc.org

North Carolina's Protection and
Advocacy System

Upon request, information
is available in alternate formats.

3724 National Drive, Suite 100
Raleigh, North Carolina 27612
919-856-2195
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