THE FEDERALLY DESIGNATED PROTECTION AND ADVOCACY ORGANIZATION FOR THE STATE OF NORTH CAROLINA

# DISABILITY RIGHTS NC: AN INTRODUCTION

DISABILITY RIGHTS NC (DRNC) VOLUNTARILY SUBMITS THE FOLLOWING IN RESPONSE TO SESSION LAW 2023-135



801 CORPORATE CENTER DRIVE, SUITE 118 RALEIGH, NC 27607

919-856-2195 EXT 294 • 877-235-4210 • 919-856-2244 FAX • TTY USERS, DIAL 711

This report is a snapshot of Disability Rights North Carolina's (DRNC's) efforts to carry out its mission to advance the rights of people with disabilities under federal programs and other funding streams to address serious, often dangerous unmet needs its constituents face day in and out. It is not intended to be an exhaustive report but rather to illustrate the depth and breadth of the organization's work with and on behalf of disabled North Carolinians.

#### **OUR CONSTITUENTS AND CLIENTS**

About <u>one-third of adults in NC have some sort of disability</u><sup>1</sup>. Add to that, <u>more than 203,000 children</u> <u>in NC are disabled</u><sup>2</sup>. Every community and the majority of households in the state includes people with disabilities. Disabled people are infants, older adults, professionals, students, parents, employers, workers, health care providers, voters, elected officials, enlisted military, veterans and more. People with disabilities are part of every racial, socio-economic, religious, and political category. Wherever people with disabilities live, work, play, or learn in NC, DRNC has a role to play.

#### WHAT IS A P&A, AND WHY WERE THEY CREATED?

DRNC is the Protection & Advocacy (P&A) organization exclusively focused on the legal advocacy needs of North Carolinians with disabilities. Every US state and territory has a P&A. Together, the 57 P&As comprise the National Disability Rights Network (NDRN). DRNC is the only organization dedicated to advancing and defending the legal rights of people with all types of disabilities, of all ages, across the entire state of NC. Almost all of DRNC's staff, board, and advisory council members are disabled and/or family members of disabled people. Within the constellation of interests that comprises the disability realm, DRNC's unique and critical role is to bring the rights and aspirations of disabled people themselves to the fore.

The P&A network was created by Congress in the 1970s to address widespread, inhumane abuse and rampant discrimination against disabled people. Since inception, the P&As have had a lifesaving mandate to identify and remedy abuse, neglect, and exploitation of people with disabilities in congregate facilities. The P&As have necessarily expanded their focus from facilities to the community as disabled people have managed to make progress enforcing their civil right to be included in the mainstream of society, particularly since the enactment of the Americans with

<sup>1</sup> https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/north-carolina.html

<sup>2</sup> https://publicschoolsfirstnc.org/resources/fact-sheets/facts-about-special-education/

Disabilities Act in 1990. The P&As have also expanded from advocating for people with intellectual and developmental disabilities, to people with mental health disabilities, to people with all disability types, including physical, sensory, learning, and traumatic brain injuries.

The P&As provide an invaluable service to people with disabilities and to all state and federal legislators, 100% of whom have disabled constituents. While the P&As continue to find egregious violations against people with disabilities every day, there is no question that the P&A network has vastly improved the lives of people with disabilities and their families, and allowed members of their constituencies to become educated, employed, and contributing members of their communities, where segregation and isolation were once routine.

# **DRNC'S STRUCTURE**

P&A funding includes federal and private funding. DRNC is skilled at complying with the requirements of every funding stream, and DRNC's independent audits consistently reflect outstanding financial management. Investments in DRNC's work result in meaningful outcomes.

The federal funding DRNC receives is restricted by the disability group or issue area served. DRNC has grants limited to advocacy for disabled people with brain injuries, assistive technology needs, who have representative payees, and for voting rights advocacy. Consistent with the P&A's genesis described above, an essential function of the P&As is monitoring places where people with disabilities receive services to prevent abuse and neglect. Another essential service P&As provide is known as "information and referral," which means responding to the thousands of contacts that come each year from people with disabilities, their family members and advocates, and helping them navigate their way to resolution of the myriad issues DRNC's constituents encounter. DRNC also devotes significant resources to outreach and education, to ensure disabled people throughout North Carolina understand their rights, available resources, and that DRNC exists to assist them. In addition, foundations and private monies fund specific work projects and activities.

P&As have some flexibility to shape their work in response to the most pressing needs of their constituencies. This work is developed in collaboration with the disability community. DRNC refers to these advocacy goals as "<u>targets</u>"<sup>3</sup> that address longstanding, serious, systemic barriers. DRNC continually gathers data and information through its work and interaction with its client community, supplemented by an annual survey, the results of which are carefully reviewed by the organization's

<sup>3</sup> https://disabilityrightsnc.org/who-we-are/targets/

governing bodies and staff, to secure input and perspectives from key constituents and other stakeholders on how to best use DRNC's limited resources to address the most pressing legal needs of people with disabilities in NC, and to identify emerging trends. DRNC also conducts multiple virtual and in-person events each year to learn from people with disabilities, their family members, and other stakeholders through outreach and advocacy efforts. DRNC's specialized legal expertise and broad, deep understanding of the legal and policy landscape at the state and federal levels that affect disabled people help us plan for the years ahead.

# **COMMUNITY ACCESS**

Through its Community Access work, DRNC advocates for people with disabilities to have the same freedoms, choice, and opportunities to live their lives as other community members. DRNC advocates for equal access to community services and programs, fair and integrated jobs, and the right to make important life decisions without unnecessary restrictions. Recent examples of work in this area follow.

- Firefighter receives testing accommodations for the state EMT exam<sup>4</sup>
- North Carolina High School Athletic Association agrees to alter its age-eligibility rule for student athletes with disabilities<sup>5</sup>
- A large private university agrees to hire a consultant and revise its policies and guidelines to provide blind students timely access to accessible course materials
- UNC Health Care ordered to provide healthcare documents to blind patients in accessible formats and agrees to settlement<sup>6</sup>
- Police officers receive workplace accommodations and do not have to undergo illegal medical examinations<sup>7</sup>
- Winston-Salem adopts service animal policy after police forced a blind customer out of Hanes Mall<sup>8</sup>

<sup>4</sup> https://disabilityrightsnc.org/news/press-release/firefighter-first-in-nc-to-get-accommodations-for-emt-exam/

<sup>5</sup> https://disabilityrightsnc.org/stories/drnc-short-story-andrew-fevang/

<sup>6 &</sup>lt;u>https://disabilityrightsnc.org/news/recent-ruling-helps-blind-patients-at-unc-health/</u> and <u>https://disabilityrightsnc.org/</u> news/press-release/blind-patients-receive-settlement-from-unc-health-care-system/

<sup>7</sup> https://disabilityrightsnc.org/news/press-release/police-officer-ada-lawsuit/

<sup>8</sup> https://disabilityrightsnc.org/news/press-release/winston-salem-service-animal-policy-first-among-largest-nc-cities/





People with disabilities are at an increased risk of abuse and discrimination...

When DRNC met Ty...



https://www.youtube.com/watch?v=FbDEH-lvm\_U

# 1

2

DRNC staff found Ty in a psychiatric hospital, in a wheelchair, unable to speak or walk. DRNC learned Ty couldn't speak or walk because he was dangerously overmedicated. 3

After DRNC advocacy, Ty was released and now lives in his community. He is involved in his church, works part-time, and is supported by family and friends.

#### **ACCESSIBLE VOTING**



DRNC's nonpartisan accessible voting work helps ensure people with disabilities are able to vote. One in four people eligible to vote has a disability, but disabled people don't vote at the same rate as people without disabilities, mainly because of barriers to voting. DRNC's team engages in the following voting rights advocacy:

- Distributing information on voting rights and how to register to vote through Meals on Wheels programs
- Making and distributing accessible voter guides in multiple formats and languages
- Monitoring curbside voting
- Testing the physical accessibility of voting
- Organizing accessible voting machine monitoring with partners
- Ensuring complaints about accessibility during the voting process are triaged quickly (through DRNC's hotline 1-888-WeVote2) and that appropriate agencies are notified to address the issues quickly
- Providing disabled voters accurate, reliable information about voting laws

# **CRIMINAL JUSTICE SYSTEM**

People with disabilities are overrepresented at every stage of the criminal process. From law enforcement involvement to courtrooms and especially in NC's jails and prisons, the state's system impacts the lives of people with disabilities and their families. Nearly two in five people (38 percent) of people incarcerated have a disability<sup>9</sup>. Unfortunately, many disabled people become entangled in the system as a direct result of unmet needs and systemic discrimination.

#### DRNC'S ADVOCACY IN THIS AREA HAS INCLUDED:

- ensuring disabled people receive prescription medication in jail;
- helping people with disabilities in prison get necessary accommodations such as hearing aids, ramps, or braille to access programs and services;
- collaborating with other mental health advocacy organizations to improve the

<sup>9</sup> https://bjs.ojp.gov/library/publications/disabilities-reported-prisoners-survey-prison-inmates-2016

identification and treatment of people with disabilities in prisons and jails;

- monitoring and reporting on dangerous conditions for people with disabilities in jails, and advocating for systemic change;
- producing a first-of-its-kind <u>database</u><sup>10</sup> on projects addressing TBI in criminal settings across the country to identify potential efforts that would benefit North Carolinians;
- seeking implementation of the NCGA-mandated Medicaid suspension in jails and a reduction in reliance on solitary confinement;
- providing advocacy to individuals who have experienced abuse or neglect in prisons; and
- continuing advocacy efforts to improve the state's approach to capacity restoration for those ruled incapable to proceed to trial.

<sup>10</sup> https://disabilityrightsnc.org/news/press-release/innovative-nc-program-launches-national-tbi-database/

# **OLMSTEAD V. L.C., FAIR HOUSING, AND MEDICAID ENFORCEMENT**



In 1999, the US Supreme Court ruled that it is discrimination on the basis of disability to force disabled people to live in a facility to get basic supports for their activities of daily living. Under the Olmstead ruling, forced segregation of people with disabilities is illegal under the Americans with Disabilities Act (ADA).

When people need services because of a disability, the Olmstead decision says that they have the right to choose to receive services in the community. This does not mean that people must leave a facility or congregate care setting – it means that disabled people have a legal right to live in the community if they want to. To have a real choice, community services must be as available and adequate as facility-based care. Short of this equitability, people do not have a real choice. Olmstead means that disabled people don't have to accept being segregated in facilities to get the help they need.

DRNC helps enforce Olmstead rights. Staff advocate for them to receive home- and community-based services (HCBS), and also help people with disabilities keep their housing using the state and federal Fair Housing Acts.

Examples of this advocacy include:

- An Autistic 14-year-old in the custody of a county Department of Social Services (DSS) was stuck in a hospital psychiatric emergency department for more than 8 months because DSS refused to allow her access to available home and community-based services, even after her MCO found and approved the services. During those 8 months, the child's condition deteriorated because she did not have any schooling or services appropriate for her disability, including assistive technology for communication. Ultimately, DSS sent this child to an institution in another state. DRNC continued advocating with DSS for discharge to her home and family with appropriate services and supports rather than continued institutionalization. With DRNC's intervention, she was finally returned to her family with the services and support she needs to be successful, including an Innovations Waiver slot.
- A man with mental health and physical disabilities had his Section 8 voucher improperly terminated by a Public Housing Authority (PHA) because the PHA incorrectly counted

his live-in aide's income towards the client's available income and disqualified him for the Section 8 subsidy. Neither the client nor his landlord was given notice of the termination, and more than a year went by before his landlord realized that they were not receiving the program subsidy in addition to the rent paid by DRNC's client. At that point, they notified the tenant that he owed \$5,000 in back rent for the missed subsidy payments but elected not to evict him while he tried to work out the issue with the PHA and contacted DRNC for help. DRNC staff requested a hearing with the PHA, and the hearing officer determined that the client's voucher should be reinstated. They recognized that his live-in aide was permitted to live with him as a reasonable accommodation under the Fair Housing Act. They also agreed that the aide's income should never have been counted as part of the household income for purposes of the Section 8 voucher program in computing his subsidy payment. Because the PHA had improperly computed the client's rental payments, based in part on the aide's income, DRNC's client is being reimbursed by the PHA for more than \$6,000 in over-payments. And he no longer faces eviction.

#### SAMANTHA'S STORY

"I kept telling them she's going to have to go to an institution, and they just didn't care... The whole system is just messed up."

- Samantha's Dad

"We have no choice but to sign"

 under Mom's signature admitting Samantha to an institution After five years of litigation and a court order, the young woman was able to leave the institution for her own home. "God is giving her a blessing for all the trials she had to endure."

– Samantha's Mom



#### **JENNY'S STORY**

Jenny entered the foster system as an infant, when DSS learned her birth mom regularly fed her vodka.

Jenny had challenging behaviors and impulse control problems in school, and was in and out of psychiatric hospitals for years. But nobody tested her for fetal alcohol spectrum disorder (FASD).

At age 15, Jenny was involuntarily committed to a "therapeutic" setting that was dangerous and counter-productive. She came home in a worse condition and "shell-shocked," according to her adoptive mother.

After DRNC advocacy, her MCO tested Jenny for FASD and diagnosed her. Her MCO agreed to support Jenny's family with respite and in-home assistants trained in FASD. The family is grateful but worries that help arrived too late.

DRNC successfully represented a child in a Medicaid appeal after the NC Department of Health and Human Services (DHHS) Division of Health Benefits (DHB) denied him a walk-in tub under the CAP/C waiver program. The CAP/C program is a Medicaid waiver program that helps medically fragile kids live at home with their families instead of in a hospital or other institution. The waiver includes reimbursement for home modifications so families can modify their homes to support the needs specific to their child's disability. Here, a 12-year-old with Duchenne Muscular Dystrophy was denied a replacement walk-in tub (for a typical step-over tub) so he could access the tub with less parental support. Not only did he want more privacy in bathing without having to rely on parental support, but at 180 pounds, his parents had difficulty lifting him in and out of the tub, creating a safety hazard for all of them. DHB's position was that replacement tubs were categorically excluded under the CAP/C Waiver and moved to have the family's appeal dismissed. DRNC intervened to oppose the state's motion and brought its own summary judgment motion on behalf of the client. DHB had ignored the plain language in the Clinical Coverage Policy and failed to consider language in the Waiver that specifically contemplates replacement tubs. After receiving DRNC's opposition and motion, DHB reversed its decision before the judge could rule on the motions, and this 12-year-old boy received the walk-in tub.

# **PROTECTING BENEFICIARIES WHO HAVE REPRESENTATIVE PAYEES**



#### Signed into law by President Trump, the Strengthening Protections for Social Security

<u>Beneficiaries Act of 2018</u><sup>11</sup> directs protection and advocacy system organizations, such as DRNC, to conduct reviews of representative payees who manage Social Security Administration (SSA) funds on behalf of a disabled beneficiary. These reviews are conducted with anyone who serves as a payee, including a family member, DSS agency, state-operated hospital, or congregate care provider such as a group home, adult care home, or nursing home. Under federal law, certain payees must be reviewed every three (3) years. This is called a Periodic Review, and State hospitals, large volume payees, and fee-for-service payees fall into this category. Other payees are selected using SSA's algorithm (this is confidential information, and only SSA knows how this algorithm works). These are called predictive model reviews. SSA also assigns DRNC educational visits with new payees, and Quick Response Checks (QRCs) based on allegations SSA receives regarding a payee's performance. Lastly, DRNC receives calls and online intakes from beneficiaries or third parties who report a concern about a rep payee. DRNC reports these allegations directly to SSA, which determines if a review is warranted.

DRNC's representative payee team operates uniquely within the P&A. Each member of this team must pass a federal background check and maintain federal security clearance. The team's work is "firewalled" from other P&A staff who do not have SSA clearance. Because of strict confidentiality requirements, SSA does not permit the Rep Payee program to share detailed information about this work, unless specifically authorized by SSA. SSA considers DRNC's work product to be their property and not the property of the P&A. SSA has directed any request for SSA records to be made through the SSA Regional Office.

SSA does allow the release of general information about the substantial body of work DRNC has completed under this program since late 2018. The following are some examples:

- The team of six (6) investigators has conducted more than 3,000 interviews with payees, beneficiaries, and other third parties (e.g., guardians, people acting under a Power of Attorney) as part of the review process
- The team immediately alerts SSA and other appropriate authorities when dangerous or unsafe conditions are discovered during a review
- DRNC investigators have made over 450 unique referrals, including helping beneficiaries

<sup>11</sup> https://www.ssa.gov/legislation/legis\_bulletin\_042418.html

open ABLE accounts, filing reports to the IRS regarding Economic Impact Payment (EIP/ Stimulus funds) fraud, and even applying for library cards. Each of the investigators has human services and/or social work experience including at DSS food and nutrition services, child and adult protective services, victim's advocacy services, and group home ownership. The team uses this collective, statewide knowledge to help connect SSA beneficiaries with as many requested services and supports as possible.

#### **K-12 EDUCATION**

DRNC's education team is focused on making sure schools meet disabled students' needs and that these students receive the free and appropriate education (FAPE) required by federal law. Even one suspension or expulsion for a discretionary offense almost tripled the likelihood that a student would enter the juvenile justice system the following year<sup>12</sup>. To ensure disabled students are not excluded from school for reasons related to their disabilities, DRNC undertakes the following work:

- Advises families of their rights and options to address a child's needs
- Represents students and their families when they have been excluded from school because of their disability
- Monitors at the state's Youth Development Centers, addressing individual and systemic issues
- Collaborates with stakeholders, including the NC Department of Public Instruction, Local Educational Authorities, families, and advocates on policy issues that affect students with disabilities
- Creates training videos for parents and other advocates on common special education topics and issues related to students with behavioral challenges in the school setting. Based on stakeholder feedback, these videos are short and multi-sensory (audio and visual) to provide this crucial rights education in a format easily accessible by families. DRNC publishes and promotes this training to educators, advocates, and families.

<sup>12</sup> SJP Toolkit (nccourts.gov)

#### **OUTREACH**



In addition to the many forms of outreach described in the introductory section of this report, DRNC conducts intentional outreach efforts to educate disabled people across NC about their rights and available services, and to connect them with resources. DRNC staff travel throughout the state, from Murphy to Manteo, engaging in various initiatives and partnerships including flu and COVID-19 vaccine events, listening sessions, and information distribution. Almost all DRNC staff engage in community outreach. Additionally, DRNC has staff specifically dedicated to this purpose. Examples of this outreach work include:

- DRNC staff provided training and/or presentations to more than 65 organizations throughout the state last year
- DRNC hosted a panel discussion with veterans regarding injuries during service specifically brain juries, experiences in training and deployment, and the impact of crisis to support veterans and help the public understand the impact of brain injury. How does TBI impact service men and women and their loved ones<sup>13</sup>?
- DRNC hosted listening sessions in Washington, Red Springs, Bolton, and Elizabeth City focused on understanding the specific barriers encountered by people with disabilities in rural and marginalized communities when attempting to access broadband networks. By actively listening to the experiences and concerns of these communities, DRNC seeks to advocate for improved access to the broadband services that are crucial in today's digital age
- DRNC partnered with Gaston County Public Health to host the second annual "Walk and Roll Together, Gaston/Caminemos y Rodemos <u>Juntos Gaston</u><sup>14</sup>," in downtown Gastonia. The free event invited community members to learn about communityfocused organizations, businesses, and providers, including DRNC services. More than 700 people and organizations participated in this festive, celebratory event specifically inclusive of Latino/Hispanic communities.
- DRNC works in partnership with the NC Reading Service to host <u>a monthly podcast<sup>15</sup></u>
- 13 <u>https://disabilityrightsnc.org/community-living-and-equal-access/traumatic-brain-injury-tbi/brain-injury-and-veterans-panel/</u>
- 14 <u>https://www.gastongazette.com/picture-gallery/news/2023/10/07/photos-from-walk-and-roll-together-2023/71100845007/</u>
- 15 https://disabilityrightsnc.org/news/listen-to-drnc-on-north-carolina-reading-services-legal-matters/

called Legal Matters.

- DRNC <u>regularly issues newsletters</u><sup>16</sup> about its work, community events, and information for people with disabilities, their family members, and other stakeholders. <u>Sign up for</u> DRNC's newsletter here<sup>17</sup>.
- DRNC's outreach efforts invest in the development of advocates with intellectual and/or developmental disabilities, such as through DRNC's Ambassadors program, a collaboration with the <u>NC Council on Developmental Disabilities</u><sup>18</sup>. This project has been critical in accomplishing a wide variety of outreach work, from hosting information sessions to distributing educational materials.
- DRNC has partnered with the Ambassadors, the NC Council on Developmental Disabilities and the Carolina Institute on Development Disabilities, flu and COVID-19 vaccine providers, and numerous community-based organizations and leaders to offer access to vaccines for disabled people and older adults who want them, particularly those residing in rural and marginalized communities. DRNC recognizes the importance of ensuring equitable access to healthcare services and has actively engaged in addressing the challenges faced by these communities.
- In the past several months, distributed in person to more than 1,000 people disabilityfocused resources and materials.



Caminemos y Rodemos Juntos, Gastonia, NC, October 7, 2023

<sup>16</sup> https://disabilityrightsnc.org/news-events/newsletter-archives/

<sup>17</sup> https://disabilityrightsnc.org/contact-us/newsletter

<sup>18</sup> https://nccdd.org/

#### **INFORMATION, REFERRAL, AND INTAKE**



DRNC's intake staff field well over two thousand requests for assistance every year. The demand for DRNC's information and referral (I&R) services has significantly increased in recent years. People with disabilities and their legal representatives may request help by phone or through DRNC's website. In the last year, DRNC provided legal representation to nearly 700 people who came to DRNC through I&R services.

Requests came from 65 counties across the state, with a concentration in the most populous counties. For those to whom DRNC cannot offer legal representation, typically because they present with issues outside DRNC's established advocacy targets (see page 3), DRNC provides extensive information about the state's systems and referrals to other potential resources.

Legislators can refer constituents with disability-related legal concerns to us by phone at 919-856-2195 and <u>disabilityrightsnc.org</u><sup>19</sup>. In addition, DRNC staff are always happy to provide technical assistance to legislators and staff so legislators can provide information directly to their constituents.

<sup>19</sup> www.disabilityrightsnc.org

#### **INVESTIGATIONS AND MONITORING**



Investigations and monitoring are two of the original core functions for all P&As. No matter what other work DRNC chooses to do as NC's P&A, federal law mandates that DRNC conduct monitoring in places where disabled people receive services and investigate serious allegations of abuse and/ or neglect. Like all DRNC's work, the need far outsizes the resources available, so DRNC must make strategic choices about where to focus resources at any given time.

The federal law and regulations that govern the P&A systems provide the P&As unique authority to access people and records to monitor in settings where disabled people receive services, and to investigate allegations of abuse and neglect when necessary. This unique authority is called Access Authority and was granted to the P&As to fulfill the critical role of identifying and remedying systemic failures that cause injury, harm, and death to people with disabilities.

Monitoring, as described in federal law, is access to public and private facilities and community service providers for the purpose of (1) providing information and training on, and referral to programs that benefit people with disabilities; and providing information and training about individual rights and services available from the protection and advocacy network; (2) monitoring compliance regarding the rights and safety of people with disabilities; and (3) inspecting viewing, and photographing/ videotaping all areas of the facility that are used by, or accessible to residents/program participants. Monitoring is best accomplished in-person but can be virtual when resources or conditions warrant (e.g., during the pandemic).

P&As have the authority to investigate abuse and neglect of individuals with disabilities if the incidents are reported to the system or there is probable cause to believe the incidents occurred. Federal law prohibits P&As from disclosing the identity of people who report abuse and/or neglect to the organization. In investigations, the P&A/DRNC does not have a client. Instead, DRNC staff play an independent fact-finding and analysis role when staff investigate. DRNC staff share those findings and analyses with the service provider and, where necessary, appropriate state and federal authorities, but are prohibited from sharing them publicly.

Examples of outcomes of DRNC's monitoring and investigations work include:

 DRNC investigated the death of EE, a 43-year-old man, who died in a face-down (prone) restraint at a State-operated Intermediate Care Facility for people with intellectual and/ or developmental disabilities. In its detailed findings and analysis, DRNC recommended a ban on the use of this dangerous restraint technique. The then-Secretary of DHHS banned the use of prone restraint in all State-operated facilities and all DHHS-licensed service providers.

- DRNC successfully advocated for a resident of a State-operated facility who
  has developmental disabilities, including cerebral palsy that makes her speech
  difficult to understand even for staff who work with her daily. Staff worked with
  her home/life specialist to make a speech referral, and with the speech therapist,
  who reached out to the NC Assistive Technology Center for a consultation to
  develop a communication book for DRNC's client while determining how best to
  meet her communication needs through assistive technology.
- DRNC staff presented at the State-wide Attorney Guardian ad Litem (GAL) Continuing Legal Education conference on the topic, "Children's Rights in Congregate Care." This allowed DRNC to reach an estimated 70 GAL attorneys across the state. The program was recorded and will be broadcast to all GAL volunteers statewide. A significant outcome from the conference has been the building of important connections between GAL attorneys and DRNC to help keep children in psychiatric residential treatment facilities (PRTFs) free from abuse, neglect, and exploitation. DRNC met with the GAL program administrator, staff attorney, and associate council to determine the best way to advocate for kids in congregate care. DRNC and the GAL program have agreed to continue meetings as needed to strategize on developing a process for us to share information.
- DRNC successfully advocated for a resident who is Deaf/blind with no means of communication at one of the State-operated developmental disability centers. As a result of DRNC's advocacy, the facility director arranged for consultants from Helen Keller Institute to conduct training for staff on working with Deaf/blind individuals.

# POLICY ADVOCACY



DRNC collaborates with stakeholders, lawmakers, and state agencies to ensure that state laws, rules, and procedures affecting people with disabilities comply with the ADA and other governing law. Much of DRNC's policy work involves collaborating within coalitions comprised of subject matter specialists and educating policy makers about the needs and aspirations of the disability community and the ways laws may affect them. DRNC regularly educates and works in partnership with multiple state agencies and municipalities to find practical solutions that resolve issues and preserve the rights of people with disabilities. Most often, this collaborative work produces significant impact and isn't known to the public. DRNC has, for example, worked with NC Division of Motor Vehicles to ensure that agency's processes for issuing ID cards were accessible and clear; with NC Administrative Office of the Courts disability coordinators to improve court service access; and with NC Department of Adult Correction to address health and safety concerns in prisons.

Below are some recent examples of important NCGA policy changes to which DRNC contributed:

- Alternatives to Guardianship (SB615) creates a mechanism for families of people with disabilities to learn about less restrictive forms of guardianship. DRNC worked for years with Rethinking Guardianship, AARP, Coalition on Aging, and other groups to advocate for this change.
- The Kinship Care rate increase allows for family members of a child at risk of entering DSS custody to be paid at half the foster care rate. DRNC has long advocated with groups such as NC Child and NC Association of Social Workers for increased kinship supports to keep families together.
- Eligibility for consideration for medical release by the Department of Adult Correction was expanded to allow the geriatric release of people 55 years old or older (had been 65) who have a disease that makes them medically incapacitated, as well as allowing the release of someone who is terminally ill and within 9 months of death (had been 6 months of death), and who pose little or no risk to public safety. DRNC has long advocated with policy makers to expand the eligibility criteria as the prison population becomes older and sicker, which reduces government spending.
- The recently passed State budget created funding for two additional full time jail inspectors, a change strongly supported through DRNC's research, analysis and advocacy to increase safety in NC jails.

Below is a sampling of groups with which DRNC collaborates to protect and promote rights and choice for people with disabilities:

#### ACLU-NC

Association of Mexicans in NC, Inc.

- Autism Society of NC
- Brain Injury Association of NC
- Carolina Institute for Developmental Disabilities
- Center for Public Representation
- Charlotte Center for Legal Advocacy
- Coalition on Aging and its Health Equity Committee
- Council for Children's Rights
- DD Consortium
- **Disability Rights Advocates**
- Ed NC
- **Equal Justice Alliance**
- Exceptional Children's Assistance Center (PTC)
- Friends of Residents in Long Term Care
- Home and Community-Based Services Stakeholders
- HOPE NC
- Legal Aid of NC
- Long-Term Care Ombudsman
- Meals on Wheels
- Meet The Need NC Advisory Council
- Mental Health Coalition
- National Disability Rights Network (NDRN)
- National Federation of the Blind
- National Health Law Program (NHeLP)
- NAMI NC
- NC Assistive Technology Grant Advisory Council
- NC Center for Intellectual and Developmental Disabilities Consumer Advisory Committee
- NC Child
- NC Council on Developmental Disabilities
- NC Equal Access to Justice Commission
- NC Equal Access to Justice Foundation

NC FASD

NC IOLTA

NC Institute of Medicine

NC Justice Center

NC Mental Health Block Grant Planning and Advisory Council

NC Pro Bono Resource Center

NC Reading Service

NC Statewide Independent Living Council

NC Traumatic Brain Injury (TBI) Advisory Council

North Carolina NAACP

Pisgah Legal Services

Unlock the Box

#### IN THE WORDS OF PEOPLE WE SERVE



- DRNC assisted a disabled older gentleman in obtaining a federal grant to remove mold and make repairs to his home that was damaged in a hurricane. The process was lengthy but successful and all the repairs were completed to his satisfaction. "I thank you so very much for all you have done to make this grant possible for me. It took a lot off me to know the mold is gone. I have a very nice place to live now and to help (his wife) raise our grandchildren."
- A US military veteran who relocated to NC from another state reached out to DRNC for information about Emotional Support Animals (ESA) and housing. DRNC staff provided him a fact sheet and sample accommodation assistance letters. DRNC staff also encouraged him to call us for a full intake if he is denied his housing accommodation. "I am HAPPY," he wrote to us. "She (DRNC staff) talked to me, didn't act like a robot. As a Veteran I need help (but) so many times I get shoved to the side. Thank you!"
- A woman recovering from a stroke sought DRNC's assistance to obtain reasonable accommodations at her workplace. Staff provided her information on reasonable accommodations and the Equal Employment Opportunity Commission process. "The entire experience was exceptional," she reported. "I sense a genuine effort to assist every case, even though I understand limitations exist. I truly hope for your expansion, enabling you to offer assistance to more people in the impactful capacity you strive for."
- A woman called with concerns that her landlord might evict her because the service dog she has for a seizure disorder was being aggravated by a neighbor's dog. She sought DRNC's assistance drafting a letter explaining the situation to the landlord. She subsequently decided to move out of the apartment complex and DRNC staff helped her draft a letter that enabled her to move out without penalty. "Your input and resources were tremendously helpful. Empathetic and competent staff at all levels." She wishes DRNC had more funding "to hire more staff to do more of the great work you do."

- A mother of a disabled child living in an institution sought DRNC's assistance in successfully advocating for specialized testing for her son. "I am so glad I called DRNC, his medical team at (the facility) is very responsive and his care team has been advocating on his behalf and keeping me informed. Thank you!!!!!"
- A case manager called DRNC seeking community resources and services for children with disabilities. DRNC staff provided her information about various kinds of services, as well as rights to Medicaid services. "My experience was great," she wrote. "I needed information for children's resources to give to the parents whose children are disabled. I really was helped a lot. (The DRNC staff person) went out of her way to help me and I really appreciate it! She obviously cares about helping the disabled. I received incredibly helpful information. Thank you so much!"
- A young adult was hospitalized for a Traumatic Brain Injury (TBI) that happened when he was away from home on vacation. From there, he was transferred to a nearby nursing home, then bounced several times between the hospital and the nursing home. The young man requires total care. His family called DRNC concerned about the kind of care he was getting at the hospital and the nursing home, and to see if DRNC could help him get appropriate services and supports to move back home. DRNC staff helped secure services and home modifications so the client could return home. "(DRNC staff) went above and beyond to assist my family and I with my son. They listen to our needs and took over where was necessary in order to get (the son) better treatment but most importantly getting him home. I cannot say enough nor put into words how these ladies advocated for my son like it was one of their children in which we are forever grateful to them both. THANK YOU and you are AWESOME and AMAZING!!"