

2019 Targets and Monitoring Work

Each year, Disability Rights North Carolina adopts a plan to focus its work on the greatest threats to the independence of people with disabilities and the most prevalent violations of disability rights laws. This plan includes Targets.

What Is a Target?

To achieve full equality and justice for people with disabilities, we need to accomplish many different goals. But we do not have the resources to tackle all of those goals at one time.

Through public input and our work with clients, we identify problems that are widespread and threaten the independence of people with disabilities. Then we develop Targets to address those problems.

Why Do We Need Targets?

Disability Rights NC is the federally mandated protection and advocacy (P&A) system in North Carolina. Most of our funding comes from the federal government, which requires Targets. Our Targets guide the work of our legal teams and provide the structure within which we spend our limited resources.

What Other Work Does Disability Rights NC Do?

We provide self-advocacy tools to help people with disabilities learn about and enforce their rights. We conduct investigations and monitoring of facilities where people with disabilities live or receive services. We conduct reviews of representative payees' records to protect people with disabilities who receive Social Security benefits. We engage in public policy advocacy.

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Keep students with disabilities in school.

Students with disabilities are susceptible to being excluded from school when they exhibit challenging behaviors, even when those behaviors are related to their disabilities. Students with disabilities are excluded from school more often than students without disabilities through suspensions, homebound placements, modified day schedules, and other exclusionary practices.

During the 2015-16 school year, more than 22% of the long-term suspensions and more than 24% of the short-term suspensions were given to students with disabilities, yet students with disabilities are less than 13% of the total student population. These exclusions often result in months and sometimes years of lost instructional time for students with disabilities. In 2015-16, the average length of a long-term suspension was 76 school days—that's more than 40% of the school year.

Students with IEPs are, in effect, suspended when the IEP team changes their placement from the school setting to homebound or to a modified day schedule. With homebound placement, the student is not allowed to come to school and usually receives two to four hours of instruction per week. With a modified day placement, the student is allowed to come to school for only part of the school day. We receive many calls from parents whose children have been on homebound or modified day schedules for most or all of a given school year.

Target Populations:

- Students with disabilities who have received a lengthy homebound placement or modified school schedule who can be served in a less restrictive setting if the school provides an appropriate placement, supports and services.
- Students with disabilities who have received long-term suspensions or multiple short-term suspensions without the benefit of the disciplinary safeguards in the Individuals with Disabilities Education Act..
- Students with disabilities who are, in effect, suspended because the principal has asked their parents to pick them up from school for more than 10 days.

Funding: PAIDD, PAIR, PAIMI, PAAT

Go to page 9 for an explanation of the funding acronyms.



Ensure that students with disabilities attend school free from abuse, including abusive interventions.

Many students with disabilities are subject to abuse at school, including physical and emotional abuse by school staff and the use of restrictive interventions, such as seclusion and restraint. Students with disabilities are particularly vulnerable to mistreatment. One study concluded that one in three children with an identified disability receiving special education services is a victim of neglect, physical abuse, or sexual abuse.

This problem is compounded by reporting and exclusion issues. Many children with disabilities are unable to report abuse because of communication issues related to their disability. In addition, they may attend school in segregated settings, including separate schools and self-contained classrooms, that allow the abuse to go undetected and unreported.

This year, Disability Rights NC received a new grant from the Governor's Crime Commission. This grant enables us to monitor in self-contained classrooms and separate schools designated for children with behavioral or intellectual disabilities. We will look for signs of abuse, including the inappropriate use of seclusion and restraint, and we will investigate allegations of abuse. We will also educate school staff about how abuse happens and best practices for working with children with disabilities.

Students with disabilities should attend school in a safe environment, free from traumatic experiences from abuse and abusive interventions. The work of this Target will focus on systemic changes to school-system practices in order to prevent abuse and abusive interventions from occurring or remaining undetected.

Target Populations:

- Students with disabilities with communication challenges.
- Students with disabilities in separate classrooms and separate schools.
- Students with disabilities with significant behavior challenges.

Funding: PAIDD, PAIR, PAIMI, PAAT, GCC



Address North Carolina over-reliance on psychiatric residential treatment facilities (PRTFs).

Since 2010, the number of PRTF beds in the state has increased by 119% to 1,081. This does not include the children and adolescents who North Carolina sends to PRTFs in other states. Rather than increasing these institutional beds, North Carolina should be ensuring that children get the services they need in their communities. Medicaid Transformation and the State's development of Tailored Plans must include community services that will dramatically reduce reliance on PRTFs.

A 2013 report to Congress detailed a five-year demonstration project to determine whether children and adolescents could be better served in the community through Medicaid Waiver services than in PRTFs. That study found:

- 1) "Children and youth generally maintained or improved their functional status when receiving services in the community"; and
- 2) "Waiver services cost about a third (32 percent) of comparable services provided in PRTFs."

In other words, the children in the demonstration project fared better or the same when receiving the right services in the community, and those services saved 68 percent compared to the cost of PRTFs.

Many children and adolescents in NC's PRTFs cycle in and out of psychiatric hospitals, PRTFs, and the community. Through our monitoring work, we have seen children who have cycled through numerous PRTFs throughout the state, often times far away from their families and other natural supports for weeks, months, and even more than a year. We know through our monitoring efforts and regulatory surveys that some children are abused and neglected in these settings. Some PRTFs fail to recognize and address children's trauma histories, thereby perpetuating the underlying trauma. PRTFs are potentially setting up generations of North Carolina's children and adolescents for a lifetime of misdiagnoses and mistreatment.

This Target proposes to reduce NC's reliance on these institutional settings by developing and making available information to policy makers and the public that will demonstrate the need to shift resources back to the community for our youth.

Target Populations: Students with disabilities who are under the age of 18 and residing in a PRTF.

Funding: PAIDD, PAIMI



Advocate for the employment of people with disabilities in competitive and integrated jobs.

People with disabilities continue to face barriers to finding work and staying on the job. Some choose not to work more hours or earn higher wages for fear of losing benefits. Sheltered, subminimum wage workers are denied full inclusion in our workforce.

Work is the foundation for economic stability. Our clients must have information about work incentives programs and access to competitive employment, free from discrimination.

Target Populations:

- People with disabilities who receive vocational training in segregated settings.
- People with disabilities facing employment discrimination or other barriers to employment, including lack of reasonable accommodations or lack of transition services.
- People with disabilities without adequate information about work incentives and other resources to help them find and maintain employment.

Funding: PAIDD, PAIR, PATBI, PABSS, PAAT, PAIMI



Enforce the right of people with disabilities to have equal access to their communities.

People with disabilities are regularly denied the full and equal enjoyment of the services offered by businesses, local municipalities, and the State.

Target Populations:

- People with disabilities who have been denied equal access to public places, programs, or services.
- People with disabilities who have been denied accommodations/modifications by colleges and universities.

Funding:

PAIDD, PAIR, PATBI, PAAT



Reduce unnecessary institutionalization of individuals with disabilities and advance home and community-based healthcare services and support

The current health and human services system is biased toward institutionalization over home and community-based services. Often, people with disabilities who could successfully live in the community with sufficient services and supports are stuck in institutional settings. Others currently living in the community are put at risk of unnecessary institutionalization and segregation due to cost-cutting measures and a flawed implementation of the service delivery system.

This system violates the rights of individuals with disabilities to receive services in the least restrictive environment under the Americans with Disabilities Act and the *Olmstead* decision. Additionally, the State fails to comply with federal Medicaid law regarding the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions of Title XIX of the Social Security Act (Medicaid Act).

We will take a holistic approach to address these issues in order to reduce institutionalization, promote community integration, and promote access to medically necessary services. We will work to ensure that adults and children with disabilities can live where they want and have the services they need to have fulfilled and integrated lives.

Target Populations:

- Adults and children with disabilities in institutions who could be more appropriately served in home and community-based settings.
- Adults and children with disabilities in integrated settings whose rights to community-based services have been denied.
- Adults and children with disabilities who face an increased risk of institutionalization because of inadequate home and community-based service systems.
- People without adequate information to enforce their rights to transition into the community and receive needed health care services.

Funding: PAIDD, PAIMI, PATBI, PAIR, PAAT



Increase access to accessible, affordable housing for people with disabilities in the communities of their choice.

Disability Rights NC receives numerous calls from individuals who are being discriminated against in housing due to disability. They are living in homes that are not accessible for their needs, or they simply cannot find accessible, affordable housing so they can live independently in the community of their choice.

We are committed to increasing access to housing so people with disabilities can live independently in the community and have full use and enjoyment of their homes. We will utilize Protection and Advocacy tools—including targeted individual representation, education and training, and systemic advocacy—to increase access to and funding for safe, affordable, accessible housing.

Target Populations:

- People with disabilities who have been denied equal access to fair housing.
- People with disabilities who want to live in safe and accessible housing in communities of their choice.

Funding: PAAT, PAIMI, PAIDD, PATBI, PAIR



Promote the right of self-determination.

Self-determination is the fundamental right to make decisions and shape one's own life. Guardianship permits an individual, a corporation, or the government to stand in the shoes of a person with a disability and make decisions on their behalf. Guardianship almost always results in the loss of some or all decision-making authority belonging to a person with a disability. Advocating for the right of people with disabilities to self-determination is fundamental to our purpose as a P&A.

Target Populations:

- People with disabilities who would like to restore their competence.
- People with disabilities who have public or corporate guardians and would like to live in the community.

Funding: PAIDD, PAIMI, PAIR, PATBI, PABSS



Monitor jail deaths, advocate for improved treatment, and advocate for improved jail rules, including mandatory suicide prevention programs.

Jails are neither designed nor funded to provide mental health treatment, yet with the erosion of public mental health services, they have increasingly become de facto mental health facilities. Recently, two people died in NC jails after they were placed in single cells to prevent self-injury. One suffocated himself with toilet paper, using a blanket to shield his actions from a camera (December 30, 2017). The other hung himself in the “watch” cell when officers failed to conduct the required 15-minute observation (January 14, 2018). To date in 2018, five people have died by suicide in North Carolina jails. Advocacy is needed to ensure jail administrators appropriately respond to an inmate in a mental health crisis.

The NC Department of Health and Human Services is currently considering updates to the North Carolina Jail Regulations. Among the proposals are mental health and intellectual/developmental disabilities (I/DD) screening and treatment and mandatory suicide prevention programs. These updates are critical to improving the treatment of people with disabilities incarcerated in our local jails. Advocacy will be needed to press the proposals through the rule-making process.

There are few organizations monitoring conditions in NC jails. Disability Rights NC can have a meaningful impact of the quality of care for people with disabilities.

Target Population: People with disabilities confined in North Carolina jails.

Funding: PAIMI, PAIDD, PAIR



Ensure appropriate treatment for people with mental health disabilities in NC prisons and enforce the right of prisoners with disabilities to accommodations required by the ADA.

There are more North Carolinians with severe mental illness in our prisons and jails than in our psychiatric hospitals. Prisoners with I/DD often are not identified or accommodated, placing them in situations where they are vulnerable to abuse and neglect. Currently there is no routine screening for traumatic brain injury (TBI).

Through Protection and Advocacy system monitoring and investigation of abuse and neglect, and by collaborating with other advocacy groups, Disability Rights NC

can impact how people with mental health disabilities are identified and treated in our prisons and increase the chances that people can be successful upon release.

Prisoners with disabilities also face discrimination in access to programs and services and suffer hardships additional to the loss of freedom. Through Disability Rights NC's on-going advocacy in the prison system, we have learned that the prison-ADA system fails to identify and accommodate prisoners with disabilities. Our goal is to remedy the ADA system in NC prisons so that inmates with disabilities are no longer discriminated against and are able to access programs and services while in prison and as part of their preparation for successful reentry upon release.

Target Populations:

- People with mental health disabilities in prison who are not identified and who are not receiving appropriate treatment.
- People with disabilities in prison who are not receiving accommodations and who are denied equal access to prison programs and services.

Funding: PAIMI, PAIDD, PATBI, PAIR, PAAT

Funding Acronyms

The acronyms at the end of each Target show you what grants fund that work. The Protection and Advocacy grants come from the federal government.

PAAT — Protection and Advocacy for Assistive Technology

PABSS — Protection and Advocacy for Beneficiaries of Social Security

PABRP — Protection and Advocacy for Beneficiaries with Representative Payees

PAIDD — Protection and Advocacy for Individuals with Developmental Disabilities

PAIMI — Protection and Advocacy for Individuals with Mental Illness

PAIR — Protection and Advocacy for Individual Rights

PATBI — Protection and Advocacy for Traumatic Brain Injury

PAVA — Protection and Advocacy for Voting Access

IOLTA — North Carolina State Bar Plan for Interest on Lawyers' Trust Accounts

GCC — Governor's Crime Commission



Keep people safe in facilities through monitoring efforts.

Consistent with our federal mandate, Disability Rights NC monitors facilities where people with disabilities live or receive services in order to prevent, detect, and address instances of abuse, neglect, or exploitation. We also want to ensure appropriate services are provided, that the environment is safe for the individuals, and that individuals are provided opportunities to participate in activities and work that is important to them. Finally, we want to identify people who could live in the community if they had the proper supports. In short, we monitor to ensure legal compliance with respect to the rights and safety of residents.

Target Population: People with disabilities living in facilities whose rights must be identified and protected.

Funding: PAIDD, PAIMI, PAIR, PATBI



Keep people safe in facilities by investigating deaths and allegations of abuse and neglect.

The protection and advocacy system was created in the 1970s as a result of systemic, horrific abuse and neglect of people with intellectual and developmental disabilities in a New York state-operated facility called Willowbrook.

People with disabilities who live in facilities are particularly vulnerable to abuse or neglect. Cuts to community-based services results in more institutionalization of people with disabilities at a time when providers are paid less for those services. This impacts both the quality and level of care, increasing the risks of abuse and neglect.

Our monitoring efforts can and do reveal the need for investigations, but we also initiate investigations based upon complaints we receive. This means investigations are more reactionary, providing us less ability to predict or control the work. When a compelling cases arises, we must adjust and modify other investigations and other team work so that we can take it on, even when we are at full capacity.

Target Population: People with disabilities living in facilities whose rights must be identified and protected to ensure they are safe and free from abuse, neglect or exploitation.

Funding: PAIDD, PAIMI, PAIR, PATBI



Monitor and investigate how representative payees administer Social Security funds for beneficiaries.

A representative payee is a person who acts as the receiver of Social Security Disability or Supplemental Security Income for a person who is not fully capable of managing their own benefits. Unfortunately, multiple investigations have uncovered representative payees who have stolen or misused funds and exploited, neglected, and even abused the people with disabilities they were supposed to be helping.

In 2018, the federal government authorized the nation's Protection and Advocacy system to monitor and investigate how representative payees administer Social Security funds. Under the new Protection and Advocacy for Beneficiaries with Representative Payees grant program, Disability Rights NC will conduct periodic onsite reviews of representative payees' financial records, as ordered by the Social Security Administration. We will also conduct reviews at our discretion. If we find that a representative payee is not fulfilling his duties, we will notify the Social Security Administration and create a corrective action plan.

Target Population: People with disabilities who receive Social Security benefits and have representative payees.

Funding: PABRP

What It Means to be a P&A

Congress created the nation's Protection and Advocacy (P&A) system in 1975 to stop the abuse and neglect of people with disabilities. The government mandates that every state have a P&A agency. We are the P&A for North Carolina. As a P&A, our responsibilities include the following:

- Ensuring that people with disabilities live in safe and humane conditions
- Informing individuals about their legal rights and how to enforce them
- Ensuring that people with disabilities are not unnecessarily institutionalized
- Enforcing the rights of all North Carolinians with disabilities under federal and state law

Our work covers the entire range of disability, including physical impairments, visual and hearing impairments, intellectual and developmental disabilities, mental illness, and traumatic brain injury. More than 4,000 people call our office every year seeking assistance.

Public Policy and Legislative Advocacy

In addition to our legal advocacy, monitoring, and investigations work, we pursue system change through policy advocacy, including lobbying. We cannot and do not use federal funds to conduct lobbying activities.

Legislative and regulatory advocacy is a critical piece of our work. Laws and regulations are often the underlying cause of the problems people with disabilities face. We also focus on public benefit programs because they are often the only way people with disabilities can get the services they need.

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.

We are an independent 501(c)(3) nonprofit organization. Our team of attorneys, advocates, paralegals, and support staff provide advocacy and legal services at no charge for people with disabilities across North Carolina.



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