

2018 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. The plan includes Targets.

What Is a Target?

Our targets are the goals we work every day to reach. To achieve full equality and justice for people with disabilities, we need to accomplish many different goals. But we do not have the resources necessary to tackle all of the issues facing people with disabilities at one time.

Through public input and our work with clients, we identify problems that are widespread or pose the greatest threat to 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. We receive most of our funding from the federal government. Targets guide the work of our legal teams and provide the structure within which we spend our limited resources.

Does Disability Rights NC Do Work Outside of the Targets?

Yes! We provide self-advocacy tools and trainings to help people with disabilities learn about and enforce their rights. We also conduct investigations and monitoring of facilities where people with disabilities live or receive services, and we engage in public policy advocacy. Find out more about those areas of work on pages 11 and 12.

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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Keep students with disabilities in school.

Students with disabilities are excluded from school more often than students without disabilities. This happens through schools' use of suspensions, homebound placements, modified day schedules, and other exclusionary practices. These exclusions often result in months and sometimes years of lost academic progress for students with disabilities, effectively segregating these students from the community.

The data on exclusionary practices in our state is stark and telling. In 2013, for example, more than 35% of the long-term suspensions and removals to alternative schools were given to students with disabilities, yet students identified as having disabilities comprise less than 13% of the total student population. In December 2016, more than 1,000 students with disabilities in the state were on homebound placements and thus were not allowed to attend school. Most of these students were placed on homebound for reasons related to their disabilities, such as challenging behaviors, and not for legitimate medical reasons, such as being severely immune-compromised.

These practices occur despite federal and state laws that prohibit schools from suspending students for behaviors related to their disabilities. They also violate laws that require schools to appropriately educate students with disabilities in the least restrictive environment, regardless of the severity of their disability, behaviors, or the services they require to make progress.

Our Goals for Systemic Change

- Schools will change their practices and support inclusion for all students with disabilities.
- Schools will follow the laws that prohibit and regulate out-of-school exclusions and that require legally appropriate special education services, including behavioral support, in the school setting.
- Pursue formal administrative complaints or litigation against eight school systems and/or charter schools in order to deter future illegal exclusions.

Our Work in 2018

- Help 25 students with disabilities who have been excluded from school for reasons related to their disabilities return to school, and ensure that they receive appropriate compensatory education and special education services.
- Prevent future illegal exclusions by educating schools about laws that prohibit and regulate out-of-school exclusions and about resources for high-quality behavioral services.

Target Population

Students with disabilities who are excluded from school for reasons related to their disability will benefit from work on this Target.

A student served by this Target is likely to be minority, low-income, and/or living in a rural area. This is because schools with high populations of students with those characteristics are more likely than schools in higher-wealth areas to suspend and exclude students with disabilities and not provide required services due to limitations on resources. Furthermore, families with those characteristics have more limited access to services and resources that support self-advocacy.

Funding: PAIDD, PAIR, PAIMI, PAAT, IOLTA

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

Many students with disabilities are subject to abuse at school. This includes physical and emotional abuse by school staff, the use of seclusion and restraint, and the use of aversives. 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 challenges. In addition, the abuse goes undetected and unreported because the students attend school in segregated settings, including separate schools and self-contained classrooms.

Our Goals for Systemic Change

- Prone (face-down) restraint will be banned in all public schools.
- Segregated classrooms and segregated schools for students with disabilities will have appropriate and adequate monitoring and oversight to prevent and address physical and emotional abuse by school staff.
- School staff will be required to document all instances of seclusion or restraint.

Our Work in 2018

- Support ten school systems in adopting new policies prohibiting the use of prone restraint.
- Investigate five allegations of abuse in segregated classrooms or schools, and assist

one law enforcement agency, child welfare worker, and/or licensing entity to substantiate the allegation and pursue recourse.

Target Populations

This Target—particularly implementation of a statewide ban on prone restraint—will benefit all children with disabilities in North Carolina’s public schools. The main beneficiaries will be the students who are placed into segregated classrooms or schools, and the students who are subjected to the use of restraint, seclusion, and other abusive interventions. These are students with more involved needs, particularly students with significant autism or with multiple disabilities, and students in racial/ethnic minorities.

Funding: PAIDD, PAIMI, PAIR

What It Means to be a P&A

The federal government mandates that every state have a protection and advocacy (P&A) system. 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

Congress gave P&As extraordinary investigative authority so we can prevent and address the abuse and neglect of people with disabilities. For example, we have routine access to all individuals with disabilities who receive services from a facility or provider. Under certain circumstances, the facility/provider must give us access to all records of individuals with disabilities as well as any records relevant to our investigation. A facility/provider also must give us immediate access to records related to the death of an individual or in a case where we have found there is “probable cause to believe that the health or safety of an individual is in serious and immediate jeopardy.”

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

Our monitoring activities reveal the continued reliance on sheltered work and the subminimum wage as a default for many workers with disabilities. We receive a steady stream of calls from people with disabilities who face barriers to finding work and staying on the job. When we discuss the underemployment of people with disabilities with coalition partners and stakeholders, we continually hear that people with disabilities are discouraged from working or earning higher wages for fear of losing benefits.

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

Our Goals for Systemic Change

- People with disabilities will be employed in meaningful, integrated careers with all reasonable accommodations necessary to do their jobs.
- People with disabilities will work free from disability-based discrimination.
- North Carolina will recognize that its reliance on segregated, subminimum-wage employment and training is failing to adequately prepare people with disabilities for competitive, integrated careers.

- Enforce the right of individuals to receive employment training in competitive, integrated settings through individual representation, training, outreach, and education of policymakers.

Target Populations

- People with disabilities who desire competitive, integrated employment.
- People with disabilities who lack adequate information about work incentives and other resources for finding and maintaining employment.

Our Work in 2018

- Enforce the right of employees or potential employees to be free from disability-based workplace discrimination through individual representation, training, and outreach.

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

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

Through calls from individuals and meetings with collaborators who work on housing issues, Disability Rights NC has found that discrimination due to disability in housing is widespread. People with disabilities are living in homes that are not accessible for their needs, or they cannot find accessible, affordable housing that would allow them to transition to living independently in the community of their choice.

Addressing this issue requires long-term planning and ultimately an increase in supply of appropriate housing. It also requires increased awareness of the rights of people with disabilities to reasonable accommodations and modifications in housing.

Our Goal for Systemic Change

People with disabilities in North Carolina will have access to accessible, integrated, affordable housing in the communities of their choice, and they will have full use and enjoyment of the physical features of their homes.

Our Work in 2018

- Provide representation to individuals with disabilities in cases involving housing and discrimination.
- Advocate for an increased supply of accessible, affordable housing and quality permanent supportive housing programs for people with disabilities.

- Increase awareness of the rights of people with disabilities to reasonable accommodations and modifications in rental housing and Home Owner Association communities through presentations and factsheets.

Target Population

Our individual clients will benefit from our representation, and many more individuals with disabilities will benefit from the systemic policy changes we will achieve.

Funding: PAAT, PAIMI, PAIR, PAIDD, PATBI

Protect the right of people with disabilities to self-determination.

Guardianship allows for the substitution of one person's decision-making for someone else's, and this can be the most egregious denial of self-determination. Promoting self-determination—the ability to make decisions and take actions to shape one's own life—is fundamental to our purpose as a P&A. We need to design systems that support, rather than supplant, the decision-making capabilities of people with disabilities.

Our Goals for Systemic Change

- North Carolina will join a growing number of states with legislative recognition of supported decision-making as an alternative to guardianship.
- Individuals petitioning for guardianship will be provided information and education about alternatives to guardianship.
- Existing guardianships will be reviewed on a regular basis to identify individuals who are candidates for restoration.

- Train private attorneys to handle restoration of competency cases for our clients *pro bono*.
- Educate policymakers and others about how to improve our guardianship system to preserve self-determination.

Target Population

This work will benefit individuals with any kind of disability under guardianship who desire increased self-determination and/or restoration of competency.

Funding: PAIDD, PAIMI, PATBI, PAIR, PAAT

Our Work in 2018

- Represent individuals seeking restoration of competency.

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

North Carolina's health and human services system is biased toward institutionalization over home and community-based services. We receive many requests for assistance from people with disabilities who are stuck in institutional settings but who could successfully live in the community with sufficient services and supports. In addition, we get calls from people currently living in the community who are at risk of unnecessary institutionalization and segregation due to cost-cutting measures and flawed implementation of the service delivery system.

We also have found that the State frequently fails to comply with the provision in the federal Medicaid law known as EPSDT (Early and Periodic Screening, Diagnostic, and Treatment). EPSDT requires North Carolina to provide children who are eligible for Medicaid with all medically necessary services to correct or ameliorate their conditions in their home and communities. Callers and coalition partners tell us many children and adolescents are being denied these services.

Our Goals for Systemic Change

- People with intellectual and developmental disabilities (I/DD) and significant mental illness will live and engage with their communities in the least restrictive environment.
- Individuals with disabilities who are at risk of unnecessary institutionalization and segregation will receive appropriate supports and services to allow them to remain in their homes and participate in their communities.
- Children and adolescents will receive medically necessary services in their homes and communities to correct or ameliorate their complex medical conditions.

Our Work in 2018

- File and defend a complaint to address the State's reliance on institutional settings to serve the I/DD community and its failure to adequately plan to transition people out of institutional settings.
- Appeal select cases to the Office of Administrative Hearings to affirm the rights of children with complex medical needs under EPSDT and to enforce the rights of people with I/DD and mental illness to due process.
- Provide technical assistance to coalition partners to assist members of the I/DD and mental health communities.

- Visit institutional settings to identify and provide advocacy to individuals who want to transition out of institutional settings and into the community with appropriate supports.
- Monitor changes in the Waiver programs and engage in public comments to ensure the State's compliance with state and federal Medicaid laws and the U.S. Supreme Court decision known as *Olmstead*.

Target Populations

- People with disabilities in institutions who could be more appropriately served in home and community-based settings.
- People with disabilities whose community placements are in jeopardy and who face an increased risk of institutionalization.
- Children and adolescents whose rights to receive medically necessary services in their homes and communities to correct or ameliorate their conditions are being violated.
- People without adequate information to enforce their rights to transition from a facility into the community and receive needed services.

Funding: PAIDD, PAIMI, PAIR, PAAT, PATBI

Funding Acronyms

The funding for most of our work comes from seven federal grants and one grant from the NC State Bar. At the end of each Target section in this document, you will see acronyms for the grants that fund the work.

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

PAAT — Protection and Advocacy for Assistive Technology

PABSS — Protection and Advocacy for Beneficiaries of Social Security

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

The grant amounts in fiscal year 2017 ranged from \$36,400 to \$1,062,747. Each year, we carefully plan the expenditure of the grant funds across the Targets and our Investigations and Monitoring work.

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 services offered by businesses, local municipalities, and the State because of physical barriers or policies that do not take people with disabilities into account.

Our Goals for Systemic Change

- People with disabilities will be integrated and welcomed in all parts of our communities.
- Individuals with disabilities will enjoy equal access to programs and services in their communities.
- Students with disabilities will receive the accommodations necessary to complete community college, university, and other post-secondary education programs.

Our Work in 2018

- Enforce the right of students with disabilities in higher education to accommodations.

- Enforce the rights of individuals with disabilities to equal access in their communities.

Target Populations

- People with disabilities who have been denied equal access to public places, programs, or services.
- Higher education students who are unable to demonstrate their academic aptitude because the school refuses to provide auxiliary aids and services or make reasonable modifications for their disability.

Funding: PAIDD, PAIMI, PAIR, PATBI, PAAT

Monitor the safety of North Carolina jails for people with disabilities and advocate for implementation of best practices.

Jails are neither designed nor funded to provide mental health treatment, yet they have become *de facto* mental health facilities because of the erosion of public mental health services. The North Carolina Jail Regulations are outdated and have minimal requirements regarding the care and treatment of inmates with mental health needs. Many North Carolina jails are not equipped to provide the support and services that this population needs. Without appropriate treatment, inmates with mental illness decompensate, are vulnerable to abuse, and are disproportionately segregated in solitary confinement.

Our research reveals suicide is the leading cause of death of NC jail inmates, and the percentage of deaths due to suicide in NC jails exceeds the national average (46% of the deaths in NC jails from 2013 to 2016 were suicides; the national average is 33%). National experts say every jail should screen inmates for mental health needs upon admission and should operate a robust suicide prevention program.

Currently there is nationwide attention on the treatment of people with mental illness in jails. In August 2017, Disability Rights NC issued a report on the dangers of jail confinement for people with mental health disabilities and called on all levels of government in North Carolina to respond. We are positioned to lead the advocacy effort to increase public awareness of the problem and improve the responses of jails, service providers, state agencies, and policymakers.

Our Goals for Systemic Change

- People with mental health needs in NC county jails will receive humane care and treatment.
- Incidents of abuse and neglect of people with mental health needs in jail will be reduced.

Our Work in 2018

- Inform stakeholders of our report and recommendations.
- Encourage training in suicide prevention programs at the state level and by sheriffs and jail administrators.
- Encourage coalition partners to join our efforts to improve the treatment of people with disabilities in jails.
- Research and report on jail deaths in 2017 and 2018 and recommend best practices.
- Monitor updates from the NC Division of Health Service Regulation to state

administrative rules impacting jails and advocate for strong rules that incorporate national best practices.

- Advocate with policymakers for enforcement of best practices in jails and for increased funding at the state and county levels.
- Respond to calls from jail inmates and family members. These communications keep us abreast of operations in jails and the daily impact of the inadequate services on individuals with disabilities in jails and their families.

Target Populations

Our work will benefit people with mental illness who are or become confined in jails in North Carolina, as well as their families and their communities. It will also benefit sheriffs, sheriffs' deputies, and people who work in jails.

Funding: PAIMI

Ensure appropriate treatment for people with disabilities in North Carolina prisons and enforce their rights 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. For those with mental illness in prison, the outcome can be harmful and even tragic. Prisoners with intellectual/developmental disabilities (I/DD) often are not identified or accommodated, placing them in situations where they are vulnerable. Currently there is no routine screening for traumatic brain injury in NC prisons.

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 ongoing advocacy and monitoring, we have learned that the prison system fails to identify and accommodate prisoners with disabilities, which is a violation of the Americans with Disabilities Act (ADA).

By monitoring and investigating to identify and address suspected 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 correctional facilities and increase the chances that they can be successful upon release. Constant advocacy by us and our coalition partners has contributed to significant advancements, and more advocacy is necessary to secure additional reforms.

Our Goals for Systemic Change

- Inmates with mental illness in NC prisons will be identified upon admission to prison and appropriately treated while incarcerated.
- NC prisons will no longer subject inmates with serious mental illness or I/DD to prolonged periods of isolation.
- NC prisons will abide by the ADA 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.

Our Work in 2018

- Advocate for implementation of the new prison disciplinary policy so that it accommodates an inmate's mental disabilities instead of imposing additional punishments.
- Monitor the operation of three Therapeutic Diversion Units to assess the quality of treatment and fidelity to the goal of the units.
- Monitor the Youth Unit to ensure the Youthful Offender Program is implemented.
- Advocate for effective screening for I/DD and TBI upon admission to prison and for adequate

treatment and support services.

- Monitor prison facilities to assess accessibility of programming and services to people with disabilities.
- Advocate for individual inmates seeking accommodations in prison.
- Advocate with prison officials regarding the implementation of video relay services in prisons.
- Advocate for improvements to the ADA prison policy.
- Gather and evaluate information regarding the identification and classification of inmates with disabilities and the implementation of ADA policies.

Target Population

Our work will benefit people with mental health disabilities in prison who are not identified and who are not receiving appropriate treatment, and 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, PAAT, PAIR

Promote the right of children and adolescents from the ages of five to 21 with complex mental health needs and co-occurring intellectual and/or developmental disorders to receive medically necessary, high-fidelity, community-based mental health services and supports in their homes, family setting, or the most home-like setting appropriate to their needs.

Hundreds of children and adolescents who are Medicaid-eligible and who have developmental disabilities and chronic mental health conditions/behavioral problems are not receiving the treatments and services they need. As a result, they are being removed from their homes, losing educational opportunities, experiencing cyclical hospitalizations, facing segregation in school settings, and getting involved with the juvenile justice system.

These children and adolescents need adequate, effective, and appropriate services to correct or ameliorate their conditions. Currently, the State fails to provide these children with appropriate behavioral health services to screen, diagnose and/or treat their conditions as required by the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions of the federal Medicaid Act.

A Disability Rights North Carolina investigation concluded that administration of the State's existing policies, procedures and service delivery system for children with complex needs is deficient. We further determined that the deficiencies are the result of lack of effective case management, an over-reliance on institutional care, and a failure to invest in effective community-based services and supports. We filed a lawsuit against the State because of these deficiencies, which resulted in a settlement agreement. The goal of this agreement is to make sure that every child and adolescent with complex needs in North Carolina has access to the full scope of services required under EPSDT.

Our Goal for Systemic Change

North Carolina will build the capacity of its service system to meet the needs of individuals with complex needs who do not fall neatly into existing silos.

- Provide EPSDT rights training to parents, advocates, LME/MCOs, and other community stakeholders.
- Provide training on the settlement agreement to parents, advocates, providers, and other community stakeholders.

Our Work in 2018

- Monitor implementation of the settlement agreement by the State, LME/MCOs, and service providers.
- Monitor psychiatric residential treatment facilities to ensure that they are implementing the settlement agreement.
- Provide technical assistance and, if resources allow, direct representation and advocacy to children who are dually diagnosed and who have been denied medically necessary services.

Target Population

Our work will benefit all Medicaid eligible children and adolescents under the age of 21 who have complex mental health needs and co-occurring intellectual and/or developmental disorders who are having problems accessing or have been denied medically necessary mental health services to keep them in the community and out of institutions.

Funding: PAIMI

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 are 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.

Our Goals for Systemic Change

- People with disabilities will receive appropriate services in a safe environment.
- Individuals with disabilities will have opportunities to participate in activities and work that are important to them.
- People with disabilities will receive the proper supports that will allow them to live in their community.

Our Work in 2018

- Monitor at facilities, including large adult care homes and state-operated facilities. The state-operated facilities include three psychiatric hospitals, three Intermediate Care Facilities for Individuals with I/DD, three neuromedical centers (also known as nursing homes), two residential schools for students who are deaf, and one residential school for students who are blind.
- Inform our work by regularly attending the Human Rights Committee or Residents' Rights Council meetings at facilities to empower committee/council members and their work, and in the case of state-operated facilities, to hear executive and advocacy staff report on

their work for the previous month.

- Monitor at psychiatric residential treatment facilities (PRTFs) statewide. PRTFs serve children from ages 6 to 17. Our work in these facilities will focus on ensuring that:
 - Educational services, including special education, are provided;
 - A judicial review of each child's initial and continued placement in the PRTF occurs;
 - Restrictive interventions, such as seclusion and restraint, are not used excessively and are used in accordance with proper techniques and the law; and
 - All serious occurrences in PRTFs are reported to Disability Rights NC and to the State as required by law.

Target Population

Our work will benefit hundreds of people with disabilities living in facilities whose rights must be identified and protected.

Funding: PAIDD, PAIMI, PAIR, PATBI

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.

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 the risks of abuse and/or neglect. The continuation of cuts in services in the community 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 that residents receive, increasing the risks of abuse and neglect.

Our monitoring efforts can and do reveal the need to conduct 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 except by adjusting and modifying other investigations and other team work so that we can take on the extremely compelling case even when we are at full capacity.

Our Work in 2018

Investigations in facilities are opened in response to specific reports of abuse, neglect, and/or death. Each year, we investigate as many reports as our resources will allow. We use the following criteria to determine which reports we will investigate:

- Nature and pervasiveness of the problem, including location, whether there is a death or serious injury, what triggered the allegation, how long the problem has persisted, the impact on other people with disabilities in the same or similar environments (whether the problem is indicative of a larger systemic problem), and whether accepting the case for investigation presents the opportunity for systems reform.

- Description of the individual(s) about whom the allegations are made.
- Whether this is a primary or secondary investigation, potential policy violations and implications, and the potential relief sought.

Target Population

Our work will benefit hundreds of 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



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