

**DISABILITY RIGHTS** NEW JERSEY

ADVANCING JUSTICE. ADVOCATING INCLUSION.



2021

# ANNUAL REPORT

**A RENEWED VISION**

# *A letter from Gwen Orlowski, Executive Director and Mitch Friedman, Board Chair*



This annual report, our first in several years, and nearly 2 years into the COVID-19 pandemic, is an appropriate time for us to reflect on all we have achieved amid true adversity. And to thank all who generously support our work.

In January 2019, Disability Rights NJ, under new leadership, moved to elevate the work of the state's Protection and Advocacy agency from its excellent person-centered individual advocacy to include a laser focus on solving a broad array of system issues that had plagued New Jersey's disability community for too long.

As 2020 began, Disability Rights NJ's efforts were already underway with a reorganization that included a separate Investigations and Monitoring Unit, a new Policy Director, a new team approach and plans for a new website...

And then COVID-19...

Since March 2020, we could not be prouder of the Disability Rights NJ staff and the expansion of their many accomplishments to ensure that people with disabilities were free from abuse and neglect during the pandemic, that their rights were protected and advanced, thus ensuring self-determination, independence, productivity, and integration into all facets of community life for the people we serve.

On every level, the monitoring of abuse and neglect, both virtually and in-person, to the work of our legal teams, to engaging in ongoing advocacy and policy efforts with our county, state, and federal partners, holding Town Halls designed to capture the voices of people with disabilities, to the creation of a broad and unprecedented number of self-advocacy tools, Disability Rights NJ was again and again at the forefront....and at almost all times remotely.

The work of Disability Rights NJ has never been more important, nor has the leadership and staff been more committed to not only continuing our good core work but enhancing it to ensure that the most vulnerable of us are both protected and empowered.

As you read this report about the important work we have accomplished this year, we hope you will be inspired to help us expand our work. We encourage you to renew or begin your commitment today to Disability Rights NJ with a recurring or one-time gift. Your support ensures that Disability Rights NJ will continue to address any challenge we encounter, while still providing excellence in all we do for today's — and tomorrow's — disability community in our families, our neighborhoods, and throughout New Jersey.

Thank you for investing in Disability Rights New Jersey. Together, there's no limit to what we can accomplish.

*Gwen Orlowski & Mitch Friedman*



# OUR MISSION

Disability Rights NJ's mission is to protect, advocate for, and advance the rights of persons with disabilities in pursuit of a society in which persons with disabilities exercise self-determination and choice, and are treated with dignity and respect.

Disability Rights NJ's activities are grounded in its belief in the inherent value and worth of all individuals and their right to equality of opportunity and full participation in their communities.

# OUR PROGRAMS

ATAC	Richard West Assistive Technology Advocacy Center
CAP	Client Assistance Program
IOLTA	Interest on Lawyers Trust Accounts
PAAT	Protection and Advocacy for Assistive Technology
PABRP	Protection and Advocacy for Beneficiaries with Representative Payees
PADD	Protection and Advocacy for Persons with Developmental Disabilities
PAIMI	Protection and Advocacy for Individuals with Mental Illness
PAIR	Protection and Advocacy for Individual Rights
PABSS	Protection and Advocacy for Beneficiaries of Social Security
PATBI	Protection and Advocacy for Persons with Traumatic Brain Injury
PAVA	Protection and Advocacy for Voting Access

# HIGHLIGHTS OF OUR WORK

*Removing barriers and providing critical access to the COVID-19 Vaccine – through education and collaboration*

Disability Rights NJ and all protection and advocacy agencies nationwide received a grant from the Administration for Community Living to assist individuals with disabilities to access the COVID-19 vaccines, recognizing not only the impact of the pandemic on this particularly vulnerable population, but the barriers that might be present to their accessing the protections of the vaccine. A vaccine team was established and quickly began discussions with our sister agencies and other stakeholders on both the state and local level to identify those barriers.

We became especially concerned about people with disabilities who are unable to travel to a vaccine site and contacted the county and local departments of health to determine their plans for ensuring that the needs of people with disabilities were being addressed, including transportation options and outreach efforts. We compiled a questionnaire to gather information about the county plans and made the data available to anyone seeking vaccine assistance.

We included COVID-19 vaccine questions during the monitoring of institutions and learned that individuals in the psychiatric hospitals had a relatively low rate of vaccination. We began discussions with the Department of Health regarding a collaboration to increase vaccination rates and planned a Day of Action at Trenton Psychiatric Hospital where we visited individually with unvaccinated patients and answered questions and concerns that each individual had. As a result of their trust in Disability Rights NJ, 26 individuals were vaccinated.

Disability Rights NJ successfully advocated vaccine availability in all the Juvenile Justice and detention centers.

We hosted a vaccine webinar that included experts in the areas of infectious diseases, public health, and emergency preparedness, providing information about the vaccine, dispelling myths, and addressing access issues, including requesting accommodations at vaccine sites. We also established the Vaccine Assistance and Resource Center which contains informational videos and resources.



# INSTITUTIONS

## *Building freedom from abuse, neglect, and exploitation*

COVID-19 brought both challenge and opportunity to our investigations and monitoring activities. We were successful in negotiating virtual access to institutional settings along with regular and ongoing formal and informal access to administrators and policy makers in the state. This allowed us to be “boots on the ground” with residents and clients, to participate in discussions about not only shifting COVID-19 situations and consequential policy changes, but matters arising during our regular monitoring of abuse and neglect allegations. We were able to seamlessly move from virtual to in-person monitoring as COVID-19 dictated.

The spotlight of COVID shone its brightest on New Jersey’s long term care settings, such as nursing homes, and prompted us to expand our reach into these facilities. We initially targeted special care nursing facilities that provide services to those with traumatic brain injuries in order to understand the scope of those services and how they were being provided. During this exploration we uncovered large swaths of people with serious mental illness and I/DD who were also housed in these facilities. How these individuals came to be segregated in nursing homes and whether there should have been more appropriate home and community-based settings available to serve their needs has become a renewed focus to expand our monitoring efforts and collaborate with long term care advocates, including the Long-Term Care Ombudsman.



Disability Rights NJ initiated an extensive monitoring of sheltered workshop settings that began in 2019 but was halted due to COVID shutdowns. At that time, it was abundantly clear from our interviews that participants were not aware of the service delivery system available to assist in finding employment in the community at competitive living wages. As soon as these sites reopened, we began a series of monitoring visits that included presentations to participants that educated them on the services available through state systems that could help them find, secure, and maintain jobs that paid at least a minimum living wage. We were able to present this information live to over 270 workshop participants and authored several self-advocacy materials we disseminated at later outreaches and webinars.

Serious allegations of child abuse, including the death of a child in Michigan, have been brought nationally against Sequel, a for-profit corporation that runs congregate care facilities for children in foster care, prompting us to engage in an investigation at the NJ facility and participation in a national investigation with the National Disability Rights Network. Disability Rights NJ contributed research on the historical context of youth residential care, the financial structure of Sequel, implications for treatment equality and national policy recommendations. This year, NDRN released the report, *Desperation without Dignity*, to national attention and acclaim that spurned federal legislative efforts addressing abuses at for-profit residential psychiatric facilities.

**“I was surprised and pleased with the swift action and results to my issue. Everyone involved was amazing and persistent with our issue.”**

**“Excellent service and support. A great helpful resource. Thank you.”**

# COMMUNITY INCLUSION

**People with disabilities should be able to live, work, play, and go where they choose**

Disability Rights NJ has long been at the forefront of ensuring that people with disabilities can have the opportunity to live fully in their communities, using all approaches available to us including litigation, policy, and legislative actions as well as individual advocacy and legal representation. The renewal of the NJ Family Care Comprehensive Waiver, which will guide the state's efforts in supporting people with disabilities to live and thrive in the community is an opportunity that arises every five years.

Because of our recognized expertise, we met regularly with leadership in the Division of Medical Assistance and Health Services to discuss issues of concern, including the discharge of people with disabilities segregated in nursing homes, services in the waiver that have yet to be implemented, specifically enhanced services to children, and "one door" access to eligibility for Medicaid services. Many of the items that we raised were included in the draft Renewal Proposal. In addition, we followed up with formal written comments to the draft proposal regarding other issues that affect our constituents including new proposed behavioral health services and the new Medicaid infrastructure to address housing issues. To ensure that the voices of people with disabilities and their families were heard, we collaborated with our sister agencies, the NJ Council on Developmental Disabilities and the Boggs Center on Developmental Disabilities, and held virtual community town halls to seek the perspective of those impacted by the Waiver services.

## **Extra funding, extra opportunity**

As part of the American Rescue Plan legislation, New Jersey received significant extra funding for disability related services to compensate for the damage caused by COVID-19. With a very short turnaround for the state to submit its plan for spending this money, Disability Rights NJ made sure that the most pressing weaknesses in the home and community-based service delivery system received the attention they deserved. For example, the state adopted our request for workforce development and fee raises to ensure adequate, well trained staff to meet the staffing needs of people living in the community. The state also proposed funding to smooth transitions from nursing homes back to the community, a direct boon for increased community inclusion. Most remarkably, the state dedicated funding for dramatic expansion of affordable, accessible housing stock that is one of the most pervasive barriers for people living in institutions in finding a home of their own.

**"Attorneys were outstanding with providing assistance and advice for our daughter."**

**"Our case was handled with such compassion and professionalism. Very grateful."**



# JUVENILE JUSTICE & SPECIAL EDUCATION

## DECRIMINALIZING DISABILITY



New Jersey has the highest black/white youth incarceration disparity rate in the nation, with black youth twenty times more likely to be detained or committed than white youth, and where 100% of girls in detention have a mental health diagnosis. Disability Rights NJ, with the help of a grant from the Ford Foundation and support from our national network, implemented an ambitious project in Mercer County aimed at addressing the tragic matter of "misincarceration," the placement of youth with disabilities in the juvenile or adult criminal legal system due to the lack of services in the community to meet their needs, rather than due to a need for punishment. Discipline issues in school result in law enforcement involvement and increased court cases, where courts are unprepared to provide proper accommodations to youth with disabilities. Effective education advocacy and training in court and out of court can be a tool for preventing misincarceration. Youth facing juvenile charges or who are court involved are referred to us by public defenders and other court personnel in Mercer County for special education advocacy with issues including behavior supports, re-enrollment, assessment and evaluation, abuse and neglect, transition plans, and ensuring that educational services are being provided in the least restrictive and integrated environments. Through attendance at juvenile court and participation in weekly multi-disciplinary meetings, we were able to assist in sentencing mitigation during plea negotiations and to argue dismissals or reductions in charges. We also attend monthly Youth Services Commission meetings and the Mercer County Juvenile Detention Alternatives Initiative committee with a focus on county-wide detention alternative barriers for court involved youth.

We forged a relationship with the state Juvenile Justice Commission, participating in quarterly meetings to problem solve state level concerns. This relationship led to an invitation to become part of the state-wide School/Justice Partnership. Disability Rights NJ presented on our project and encouraged a renewed focus on re-entry to schools following detention. The School/Justice Partnership has now adopted that focus for its 2022 working group.

Disability Rights NJ established a national presence by presenting at two national conferences on "Decriminalizing Disability." The first presentation was at the National Disability Rights Network's annual conference for P&As across the nation and focused on strategies and advice for piloting this work. The second presentation was at the National Juvenile Rights Defender Center, which was geared towards defense attorneys, probation officers, and other court advocates and focused on the applicable law, as well as suggestions for advocating more holistically for their clients with disabilities. Both presentations were collaborations with attorneys from Illinois, Massachusetts, and Washington, D.C.

We hope to expand the program to additional counties in NJ, to monitoring for abuse and neglect in juvenile facilities, and to provide enhanced self-advocacy tools for youth and their families.

# COMPENSATING FOR COVID-19

Disability Rights NJ strongly supported and provided technical expertise to legislation introduced by the state legislature who recognized the severe impact of COVID-19 on students with disabilities aging out of special education. The legislation automatically provides for one additional year of services to a student aging out of special education in the years 2021, 2022, and 2023. The bill was passed and signed into law.



**“**.....  
*I hope more people realize what a resource DRNJ can be and reach out for support.*  
.....**”**

**“**.....  
*He worked tirelessly and expeditiously to resolve the matter to full satisfaction within a limited window of time.*  
.....**”**

**“**.....  
*Excellent service and support. God Bless – Keep Safe.*  
.....**”**



# BRINGING NEEDED REFORM TO THE MOST VULNERABLE



One of the earliest and most tragic consequences of COVID-19 was its spread throughout the long-term care facilities in NJ resulting in a large number of deaths. In response to these deaths, and the subsequent fear, sadness, and outrage, the state of NJ hired an independent consultant to review policies and procedures in long-term care facilities and to make recommendations to improve their functioning. The State legislature held a joint session to discuss the report with the author, and to hear from other stakeholders about ways to improve conditions. Disability Rights NJ testified during that hearing about the failure to have a centralized system in the Department of Health, similar to that in the Division of Developmental Disabilities, to track and address cases and ongoing issues during the pandemic. Following that hearing, legislators introduced a package of bills designed to address problems identified in the report and improve the care of residents in long-term care facilities.

Disability Rights NJ advocated for a key reform, signed into law, requiring the establishment of a Long-Term Care Emergency Operations Center in the Department of Health to serve as a centralized command and resource center during a declared public health emergency that is likely to affect long-term care facilities.

Disability Rights NJ was appointed to the New Jersey Task Force on Long-Term Care Quality and Safety, established by law and responsible for developing recommendations to improve person-centered care, resident and staff safety, quality of care and services, workforce engagement, and other aspects of the long-term care system.

A third bill signed into law set forth minimum staff ratios in nursing facilities including one certified nurse aide to every eight residents for the day shift, one direct care staff member to every ten residents during the evening shift, and one direct care staff member to every 14 residents for the night shift.



The final bill signed into law raised the minimum wage for direct care workers and required the first in the nation establishment of a direct care ratio, which requires that each long-term care facility expend 90% or more of their annual revenues on direct care of residents. Disability Rights NJ has done considerable research about the benefit of this bill and has drafted multiple comments to the proposed implementation regulations. Other states are now proposing similar measures. Although the final regulations weakened the provisions of the direct care ratio, Disability Rights NJ continues to advocate for the full benefit of this law.

# CREATING A ROBUST, ACCESSIBLE AND EXPANSIVE COLLECTION OF SELF-ADVOCACY RESOURCES

COVID-19 necessitated creativity and collaboration to empower and engage people with disabilities who have been isolated from activities and dealing with service providers and systems reeling from the pandemic. We used this time to develop a new and fully accessible website with easy navigation, a myriad of new resources, and a visually compelling expression of the new Disability Rights NJ, as well as a multi-faceted Self-Advocacy Resource Center.

We are particularly proud of the new Self-Advocacy Resource Center born of a grant from the NJ Council on Developmental Disabilities where we provided a series of self-advocacy materials including webinars, issue briefs, toolkits, newsletters, FAQs, and informational videos as well as other written materials. Our staff drafted the documents which were then reviewed by people with disabilities and their families to ensure that they were accessible, readable, and meaningful. We also welcomed input from individuals living those specific experiences. These resources covered current, relevant topics such as compensatory education, employment first and getting a job, reasonable accommodations in the workplace, Medicaid, stimulus payments impact on recipients of SSI/SSDI, nursing home transition, and special education.

Our new resources are listed in our Resource Library, which also includes The Advocate Oak, a newsletter and blog site to keep the disability community informed about current and timely issues.



# STATISTICS

## OUTREACH TRAINING EDUCATION:

**142** events  
reaching **12,075**  
individuals

## SOCIAL MEDIA FOLLOWERS:

**4,241**

 1,022  
 3,129

INDIVIDUAL CLIENTS SERVED: **1,525**

HITS TO WEBSITE: **431,034**

## RECIPIENTS OF NEWSLETTERS AND EBLASTS:

**5,014** contacts on  
distribution list

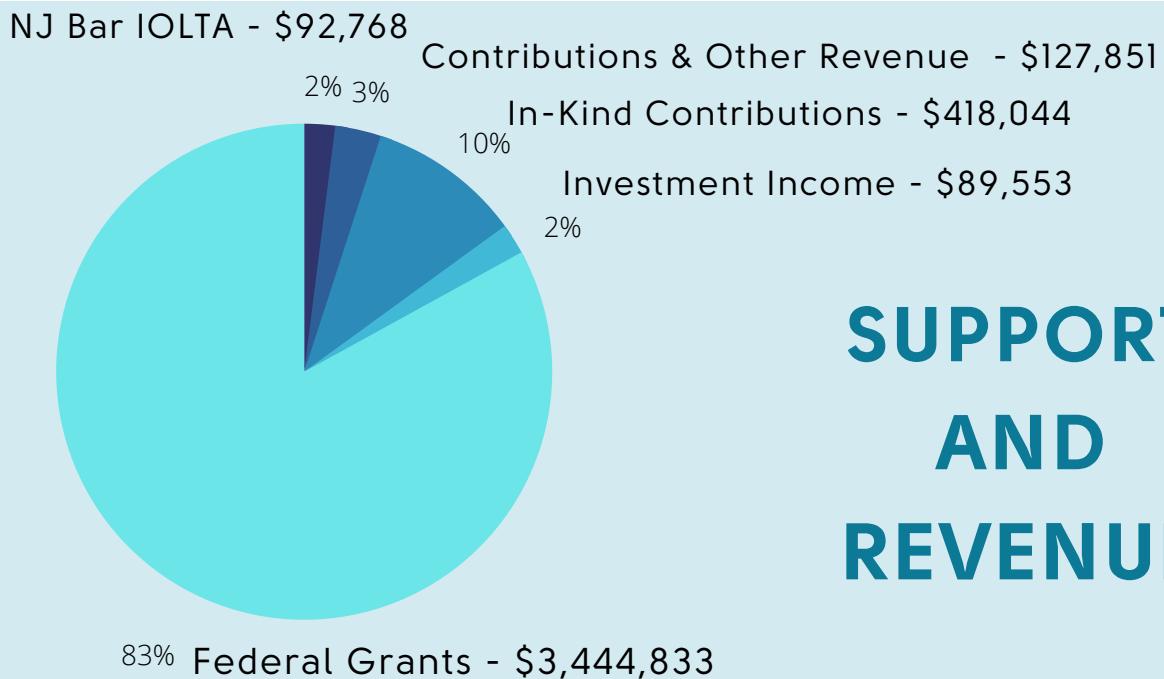
## INVESTIGATION AND MONITORING ACTIVITIES TO:

**3,128**  
individuals in  
**21** facilities

Submitted administrative comments,  
testimony, and advocacy letters to impact  
**38** pieces of legislation



# FUNDING

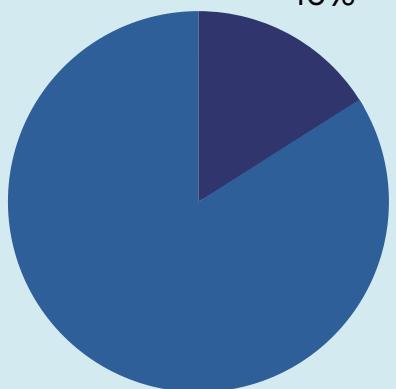


## SUPPORT AND REVENUE



## EXPENSES

Program Services - \$3,505,246  
84%



# DONORS

## FOUNDATION CONTRIBUTION

Harold Wetterburg Foundation

## INDIVIDUAL CONTRIBUTIONS

Nicholas Attanasio  
Beth Barnhard  
Alexander & Alexa Barrera  
Jill & Al Bernstein  
Ken Boydan  
Marie Bozzi  
Elaine Buchsbaum  
Dana Burzymowski  
Ellie Byra  
Jose Caro  
Pericles Castillo  
Jeanette Castro  
Barbara Ciccone  
Barbara Coppens  
Catherine Coryat  
Marie Davis  
Kevin Deutsch  
Nancy Feldman  
Judith Florio  
Daniel Florio  
Jim & Denise Fowler  
Mitch Friedman  
James Gui  
Ellyn Hill

Michael & Kristi Illum  
Tasha Jones  
Suzanne Kreie  
Elizabeth Manzo  
Muo-Perozo  
Gwen Orlowski & Chris Scherer  
Samir Papal  
Verlina Reynolds Jackson  
Nancy Richardson  
Robert Robinson  
Robin Robinson  
Francine Roby  
Patricia Rogers  
Margarita Rosario  
Ryann Siclari  
Heather Simms  
Linda Soley  
Spataro  
G Stilts  
Dharmendra Surati  
Savannah Voorhees  
Jay Yudoff  
Leah Ziskin