



*Gregory R. Smith*



Disability Rights New Jersey

ANNUAL REPORT

*for fiscal year 2015*

## Message from the Executive Director and the Chair of the Board of Directors

Disability Rights New Jersey is a member of the National Disability Rights Network, a web of protection and advocacy systems that spans the continent and continues on as far as Guam almost 8,000 miles from Trenton. DRNJ's access to this network enhances our ability to assist people with disabilities and their families in New Jersey.

Here in New Jersey, DRNJ is part of many formal and informal alliances striving to improve and bring dignity to the lives of people with disabilities.

DRNJ is its own sometimes straightforward, sometimes convoluted, network of teams, units, and committees, advocates, attorneys, and support staff, working together with our partners, families, and self-advocates to leave something a bit better than it came to us.

This report presents a brief sample of who we are, what we do, and what we leave behind.

“To leave the world a bit better, whether by a child, a garden patch, or a redeemed social condition; to know that even one life has breathed easier because you have lived - that is to have succeeded.”

- *Ralph Waldo Emerson*

## Table of Contents

Discrimination .....	4
Intellectual and Developmental Disabilities .....	4
Mental Health.....	6
Healthcare .....	7
Education .....	9
Juvenile Justice.....	10
Employment.....	11
Representative Payee Project .....	12
Assistive Technology.....	14
Intake.....	15
Outreach.....	17
About Disability Rights New Jersey.....	19
Goals and Priorities.....	22
Funding.....	24
DRNJ Board of Directors and Advisory Councils.....	25

*Cover art: Gregory R. Smith, View from Howards, LBI, watercolor on paper.*

*Right: Gregory R. Smith, Stand of Trees, watercolor on paper.*



*“ You did a wonderful job getting the problem solved.”*

## Discrimination

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DRNJ intervened on behalf of a 71-year-old resident of Ocean County who works with his son in an automotive parts business and uses a wheelchair for mobility. He contacted DRNJ because he has attended many concerts and festivals at the PNC Bank Arts Center in Holmdel, and, on this occasion, when he went to see Journey and the Steve Miller Band, the concert officials had roped off the reserved parking for individuals with disabilities. As a result, he had to park far away from the entrance. DRNJ contacted Live Nation, the owner of the venue, to raise the concerns about the lack of accessible parking for those who need it. Following DRNJ’s intervention, the individual attended another concert at the PNC Bank Arts Center and advised that there was a large sign stating “ADA Parking” and that the accessible parking spaces were opened to the public who needed them. When a friend asked if he had anything to do with that sign, he responded, “yes, I did.”

## Intellectual and Developmental Disabilities

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DRNJ assisted a 27-year-old with intellectual disabilities, a hearing impairment, and depression who was living at a residential facility in Florida. The placement had begun eight years before and was funded by the New Jersey Division of Developmental Disabilities. The Florida protection and advocacy system contacted DRNJ to report multiple investigations underway at the Florida facility and requested DRNJ’s assistance to return the client to an appropriate program in New Jersey. While the client had a state guardian, it was also clear that

*“ Thank you! Without your help I would have felt like a victim with nowhere to turn.”*

the client wanted to leave the facility in Florida. DRNJ worked closely with the client's guardian and teams at both the Florida facility and at the Division to determine the client's needs. Disagreements about appropriate placement, including over reliance on old records and concerns about levels of supervision, delayed the move several times. When the client was finally returned to New Jersey, she was placed in an emergency community-based placement, as there continued to be disagreement about a permanent residence. DRNJ has sought multiple evaluations to determine her current needs and is assisting her to vacate the guardianship.

DRNJ intervened on behalf of a 49-year-old man with myositis ossificans (a connective tissue disorder) who resides in his own apartment in Atlantic County. The client contacted DRNJ because his team determined that he can't evacuate himself from his apartment in the event of a fire and recommended he move to a group home. The client wanted to remain in his apartment. Upon investigation, the Division claimed that they could not provide waiver services to the client in his home because it was unsafe. DRNJ filed a complaint with the Office of Civil Rights. DRNJ then facilitated a meeting with the team and determined that the client was fully aware of the risks involved and assumed all the liability. He was assessed in order to determine a budget for services and was referred to support coordination to establish his plan of care and services. DRNJ followed up and determined that the client was receiving the necessary services in his apartment, and he was satisfied with the outcome.

*“ I was very happy with the advocacy DRNJ provided. You didn't judge whether my decisions were right or wrong, and helped others understand I have the right to make my own choices.”*

## Mental Health

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*“ At Ancora Psychiatric Hospital, DRNJ succeeded in securing expanded self-care skills instruction, more community living skills training, behavioral supports, and more, including the discharge of more residents. ”*

DRNJ intervened on behalf of patients on two units at Ancora Psychiatric Hospital that serve a population of individuals dually diagnosed with developmental disabilities and mental illness. DRNJ was concerned that the units were lacking a therapeutically safe environment and the staff training necessary to provide this population with the most appropriate care and treatment. In response to DRNJ's letter, the CEO of Ancora Psychiatric Hospital stated the hospital administration's intent to consult with experts on this dually diagnosed population. DRNJ requested information on any ongoing transitive changes or projected plans following the completion of the consultations. According to the response from Ancora Psychiatric Hospital, several changes were implemented following the consultation. (1) The Rehab Services Department expanded the self-care skills components of programming on the Extended Care Treatment Mall to include bedroom and dining room classrooms. Two new vans were obtained to transport patients twice a week to a program designed to learn and practice community living skills. (2) The Psychology Department provided behavioral support technicians to provide individualized behavioral support programs and services as needed. (3) The treatment teams serving patients with intellectual and developmental disabilities created Master Treatment Plans that fade one-to-one supervision. (4) Special Observation Treatment Plans for patients requiring supervision for assaultive or self-injurious behaviors were improved to outline a detailed crisis cycle to assist the assigned staff in patient-specific de-escalation techniques on all three shifts. (5) Ancora was able to

work successfully with the Division of Developmental Disabilities to discharge into the community a number of long-stay individuals.

## Healthcare

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DRNJ saw a significant increase in the number of health related cases in 2015 resulting from the state's transition of the most medically complex Medicaid recipients to managed care. In prior years, other groups of Medicaid beneficiaries had been switched to managed care, however unlike prior transitions, this transition involved the most medically compromised individuals in the state who would otherwise be at risk of placement in a nursing home.

The state rolled several Medicaid "waivers" or programs into a singular program called Managed Long-Term Services and Supports, or MLTSS. Once eligible for the waiver, Medicaid recipients can receive services such as a home health care aide or skilled nursing in their home. As part of the transition to MLTSS, the state contracted with private insurance companies to administer these services. As with previous groups of Medicaid recipients, the contracted insurance companies are responsible for making determinations as to which services people are eligible for and in what amounts.

When this most medically compromised group was moved to the new program, DRNJ received an influx of requests for assistance involving the reduction or termination of medically based services. The complicated multi-layer appeal process is difficult, if not impossible, for beneficiaries to successfully navigate, and includes two levels of internal appeals with the insurance company, an

“Your agency is very helpful and much needed.”

independent or “external” review by a subcontracted medical expert in some cases, and the right to a hearing before an Administrative Law Judge in the Office of Administrative Law. DRNJ has successfully represented numerous individuals at all levels of the appeal process.

Despite a multitude of complicated medical issues since birth, a 14-year-old has been living with his family and two other beneficiary siblings with disabilities, attending school, and participating in school and community activities. Because he is so medically fragile, this has been possible only with a one-on-one nurse both at school and at home to provide skilled care such as administering his continuous feedings and medications through a feeding tube, venting the feeding tube every two hours to lessen the severe abdominal pressure he experiences and prevent aspiration, assisting with a strict bowel regimen, and monitoring for respiratory and seizure activity.

Despite any lack of improvement to his condition, a decision from the Managed Care Organization (MCO) administering his Medicaid benefits found that he no longer needed the same level of care he has had for the last two years, and attempted to reduce his private duty nursing services from 16 hours a day to just 10 hours. Because of his complex needs, the other children in the household, and the parents’ own health conditions and work schedules, without the continued 16 hours of care, his parents were faced with the difficult decision of having to place him in a medical facility to ensure his safety.

Having already unsuccessfully pursued the internal appeal process with the MCO, the family turned to DRNJ for assistance. DRNJ filed an external appeal through the state’s Department of Banking

“*The help we received was a blessing to our family.*”



and Insurance process. This appeal was decided by an impartial organization comprised of medical professionals who are not affiliated with the insurance company. The external appeal resulted in a finding that the decision to reduce nursing services must be overturned because the services are clinically appropriate and of a skilled nature, and the use of private duty nursing in this instance is “necessary due to the nature of this enrollee’s illness and general aspects of his care. The enrollee’s care has not significantly changed over the recent time period, and the documentation submitted supports the need for the requested skilled care.”

He continues to reside happily with his parents and siblings and attend school.

## Education

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DRNJ intervened on behalf of a 22-year-old resident of Cape May County who has mental illness. The individual contacted DRNJ because her school district wanted to graduate her prematurely at the end of the school year. The individual filed for due process and emergent relief pro se to prevent the graduation. She went to the hearing by herself, and the judge ruled against her on the emergent relief, declared that the due process hearing was not necessary, and issued a final ruling permitting the district to graduate her. DRNJ filed an appeal in United States District Court challenging the judge’s final decision as the individual had no opportunity for a full due process hearing as required by IDEA. The district court judge overturned the ALJ’s decision and remanded the matter back to the Office of Administrative Law for a full hearing. After remand, the

“ *Everyone was kind and professional. I am very grateful.* ”

parties attended a settlement conference and were able to negotiate a settlement in which the individual received additional tutoring services.

## Juvenile Justice

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DRNJ is a member of the New Jersey Juvenile Justice Reform Coalition (NJJJRC). The NJJJRC is a collaborative organization which is led by the New Jersey Institute for Social Justice. Other member agencies include the NJ ACLU, the Rutgers Law School Justice Clinic, the NJ Public Defenders Office, Lowenstein Sandler, the NJ Parents Caucus, and others. The Coalition raises awareness about critical issues in the juvenile justice system, like the school-to-prison pipeline, conditions of confinement, and alternatives to incarceration, and presses policymakers to enact change. DRNJ will participate in two coalition working groups (the school-to-prison pipeline group and the conditions of confinement group) to help outline important issues and formulate plans to address them.

DRNJ intervened on behalf of a 21-year-old with a history of mental illness who had been in the custody of the New Jersey Juvenile Justice System and the New Jersey Department of Corrections (DOC). During a nine-month custody in DOC, he was not provided any educational services, even though he was classified for special education services and was still eligible to receive them. DRNJ filed for due process to secure compensatory services for the educational services that were not provided. DRNJ filed for, and the judge granted, summary judgement. Before the relief hearing, the DOC and the student agreed to a settlement in which the DOC would fund an education

*“The Department of Corrections, failed to provide educational services even though he was classified for special education services and still eligible to receive them.”*

trust fund the individual could use to obtain vocational or educational services in the community, since he was no longer in custody.

## Employment

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DRNJ intervened on behalf of a 42-year-old resident of Middlesex County with dyslexia, apraxia, and central auditory processing disorder. The client worked as a day care assistant for many years and resigned from the position because the work was too physically demanding. She had been having allergy related asthma attacks and her medication was causing her to become dizzy and sleepy around the children. She contacted the Division of Vocational Rehabilitation Services seeking their help to become an administrative assistant at a non-profit organization. DVRS conducted a reevaluation and stated that she needed to go back to being a day care assistant because she had no other skills. The client disagreed and became anxious. A psychological assessment was conducted by DVRS, which indicated that she may have new disabilities impacting her and may require consideration of a new vocational goal, but that an office setting would be difficult for her. Regardless, the client wanted to pursue becoming an administrative assistant, and requested a new counselor. DRNJ assisted the client in amending her Individualized Plan for Employment, and DVRS agreed to the new goal and to providing volunteer employment and career assessments, as well as computer training.

*“I’ve never had anyone more dedicated or who has worked harder for me in my life.”*

## Representative Payee Project

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More than seven million people who get monthly Social Security or Supplemental Security Income (SSI) benefits need help managing their money. Due to a cognitive or physical disability, they are unable to receive and utilize their benefits on their own behalf. As a result, the Social Security Administration (SSA) appoints a representative payee to assume this responsibility. Most organizational payees have a social service relationship with the beneficiaries they serve. Consequently, payees act in good faith and work to meet the needs of the beneficiaries in their care. SSA has an extensive statutorily-mandated program to conduct on-site reviews of organizational and individual representative payees serving large numbers of beneficiaries.

National Disability Rights Network (NDRN) is the non-profit membership organization for federally mandated Protection and Advocacy Systems and the Client Assistance Programs. On September 29, 2009, the Social Security Administration contracted with NDRN to assist in conducting monitoring visits of organizational representative payees that serve more than five, but fewer than fifty beneficiaries. This initiative was created in the wake of an appalling situation in Iowa during the period of 2007 — 2009. This case, in which the payee took advantage of 21 men with severe cognitive disabilities to work in a meat processing plant, received nationwide attention. To prevent further instances like this, NDRN subcontracts with the Protection and Advocacy organizations to conduct reviews on behalf of SSA. During these organizational site visits, investigators from the P&A system help identify employment

conditions, workplace housing safety, and community-based services. Investigators report any possible problems with how the payee is handling its responsibilities. The collaboration between SSA and the P&A system allows SSA to meet its goal of ensuring that payees meet the fiduciary responsibilities they accepted when they applied to act as a payee.

DRNJ is sub-contracted to perform the organizational representative payee reviews in New Jersey.

For FY 2015, DRNJ conducted 26 organizational representative payee site visits. The visits resulted in approximately 115 individual interviews. The individuals resided in group homes, residential health care facilities, boarding homes, and community apartments. The payees interviewed this year did not employ any beneficiaries, but did provide services, such as rehabilitation, counseling, transportation, meal preparation, laundry, and medication monitoring.

## **Findings**

DRNJ staff determined that 87% of the payees visited carried out their duties responsibly. Follow up with SSA was recommended for the few organizations that needed further guidance. Deficiencies found included bank accounts that were financially appropriate but improperly titled and collective bank accounts that were financially appropriate but had not been approved by SSA. In one instance, DRNJ made a referral to the local county health department when a residential provider failed to defuse a potentially violent situation between two residents. The county investigated and required the

agency to take corrective action and ensured that the residents would not lose their housing. Other referrals were made to county health departments to investigate reports of bed bugs.

DRNJ continues to review SSA representative payees, and provides interim and final reports to NDRN on the status of the reviews.

## Assistive Technology

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DRNJ provides assistive technology devices and services to New Jersey residents with disabilities through a contract with the New Jersey Department of Labor and Workforce Development, Division of Vocational Rehabilitation Services. DRNJ works with a network of large and small providers across the state to provide device loan, device demonstration, and device reutilization services. DRNJ also provides training and technical assistance on assistive technology issues. DRNJ, in partnership with Goodwill Home Medical Equipment, outperformed all other states in the provision of used devices to individuals with disabilities in 2015.

- continues

“DRNJ, in partnership with Goodwill Home Medical Equipment, outperformed all other states in the provision of used devices to individuals with disabilities.”

State	Total number of devices reassigned/refurbished/ repaired	Total savings to consumers
<b>New Jersey</b>	<b>7,667</b>	<b>\$1,121,983</b>
Georgia	4,130	\$2,035,055
Washington	3,400	\$1,903,224
Alabama	2,963	\$1,829,028
Missouri	2,728	\$1,234,456
Alaska	2,433	\$1,304,815
New York	2,324	\$1,208,849
Connecticut	2,312	\$1,153,941
Wisconsin	2,241	\$490,431
Tennessee	1,860	\$575,521

## Intake

The Intake Unit is the primary source of contacts for DRNJ, though “taking in” is only part of what happens in this active unit, staffed by an advocate, part-time intake specialist, and the intake coordinator. This is the portal through which all requests for assistance and new cases flow.

The Intake Unit operates from 9 a.m. to 5 p.m. Monday through Friday, and staff responds to requests made via telephone, TTY, on-line through the DRNJ website, by fax, written correspondence, and in-person. By the way, ‘Si, hablamos su idioma’ — ‘Yes, we speak

“ ***In·take*** - /'in·tak/; *noun: the place or opening at which something is taken in.* ”

“The goal is for everyone who contacts DRNJ’s Intake Unit to leave with more than they came for, so they can expand their self-advocacy base.”

- MW,  
DRNJ Intake  
Coordinator

your language’. The Unit has Spanish speaking staff, in addition to a language interpreting service, covering 150 other languages.

The intake staff is charged with making an initial assessment with each contact in order to provide appropriate services, whether it is information and referral, short term intervention, or a case for processing and assignment. In order to accomplish this task, the intake staff is continuously expanding their knowledge and resources of not only disability-related matters, but also of issues that impact daily living and independence. Staff is abreast of the matters directly related to DRNJ’s numerous programs and the span of disability-related services and supports from birth to the aging.

#### Opened Requests for Assistance

	2011	2012	2013	2014	2015
<b>TOTAL</b>	<b>950</b>	<b>1008</b>	<b>834</b>	<b>915</b>	<b>1094</b>
PADD	295	290	303	407	467
PAIMI	209	221	208	197	202
PAIR	243	267	245	218	265
CAP	46	39	35	56	54
PABSS	57	59	16	41	39
PAAT	58	44	33	29	27
PATBI	28	26	26	21	49

The above table reflects the number of new requests for assistance opened during the program year. Because an individual client may have one or more problems assigned to more than one funding source, program totals may exceed the total number of service requests.



## Information and Referral & Website Hits

	2011	2012	2013	2014	2015
<b>I&amp;R</b>	2,421	2,505	2,308	2,532	2,184
<b>Web Hits</b>	958,137	1,191,064	1,221,614	1,586,781	1,566,284

## Outreach

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Every year, DRNJ staff participate in a variety of outreach events including workshops, presentations, and resource fairs. In FY 2015, DRNJ participated in 101 training and outreach events reaching over 15,000 individuals with disabilities, family members, and professionals. More than 1,800 individuals received training on topics that included P&A programs and services, ADA, voting, special education, assistive technology, juvenile justice, advance directives, and employment rights. Information was also distributed to more than 13,000 individuals at conferences, expos, and resource fairs.

DRNJ reached out to the Latino community by participating in numerous outreach events and providing resources in Spanish. DRNJ offers many of its website pages, including online intake form, and numerous brochures and publications in Spanish. Five DRNJ staff members are bi-lingual, including the receptionist and intake staff.

DRNJ consolidated partnerships with veteran affiliated organizations and maintained an active presence at veteran events, including the US Chamber of Commerce, the American Legion, the Department of Military and Veteran's Affairs, the Woodbridge and Lawrenceville

“*Very helpful, very knowledgeable, confident, and sincere.*”

Armories, and the GI Go Fund. For the past five years, staff have participated in the Jeans for Troops campaign. DRNJ also developed a self-advocacy publication titled “Postsecondary Education for Individuals and Service Members with Traumatic Brain Injury.”

DRNJ’s website and social media are constantly updated and include current news and resources. In FY 2015, the website had more than 1.5 million hits and over 23,000 copies of publications were downloaded. DRNJ’s social media followers number over 1,100 strong.

DRNJ was noted in the media including interviews on television stations about the assisted suicide Regulation and accommodations at summer camps. DRNJ was also quoted in newspapers and publications about the closing of state Developmental Disabilities and Mental Illness facilities, the inclusion campaign, and the 25th anniversary of the Americans with Disabilities Act.

## About Disability Rights New Jersey

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Disability Rights New Jersey (DRNJ) is the independent, non-profit organization that has served as New Jersey's designated protection and advocacy system for individuals with disabilities since 1994. Formerly known as New Jersey Protection and Advocacy, the name was formally changed in 2008. DRNJ is a member of the National Disability Rights Network.

### Mission

DRNJ's mission is to advocate and advance the human, civil, and legal rights of persons with disabilities. DRNJ'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.

### To that end, DRNJ:

- Provides individual and systemic advocacy services and legal representation;
- Advises and assists people with disabilities, family members, attorneys, and guardians in obtaining and protecting the rights of individuals with disabilities; and,
- Provides education, training, and technical assistance to people with disabilities, the agencies that serve them, attorneys, professionals, courts, and others regarding the rights of individuals with disabilities; and promotes public awareness and recognition of people with disabilities as equally entitled members of society.

## Goals and Priorities

DRNJ's work focuses on eight program goals and related priorities. These program goals and priorities are intended to ensure that the needs of the most vulnerable populations are served and that the most critical, far-reaching issues are addressed. People with disabilities, family members, service providers, advocates, and the general public are all invited to contribute to and comment on DRNJ's priorities. DRNJ's goals and priorities can be found on page 22.

## Programs

DRNJ currently operates eight federally-funded protection and advocacy programs:

- Protection and Advocacy for Individuals with Developmental Disabilities (PADD)
- Protection and Advocacy for Individuals with Mental Illness (PAIMI)
- Protection and Advocacy for Individual Rights (PAIR)
- Client Assistance Program (CAP)
- Protection and Advocacy for Beneficiaries of Social Security (PABSS)
- Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI)
- Protection and Advocacy for Assistive Technology (PAAT)

- Protection and Advocacy for Voter Access (PAVA)

DRNJ operates two additional non-protection and advocacy programs:

- South Jersey Special Education Project (IOLTA)
- The Richard West Assistive Technology Advocacy Center (ATAC)

# DRNJ's Goals & Priorities

1

## ABUSE & NEGLECT:

People with disabilities will be subjected to or experience less abuse and neglect.

### PRIORITIES:

- Discharge from Institutions
- Individual Rights Violations
- Organizational Representative Payees
- Death Investigations

3

## COMMUNITY-BASED SERVICES:

People with disabilities will have access to community-based supports and services that promote their independence and integration into the community.

### PRIORITIES:

- Community-Based Services and Supports
- Accessible Transportation

2

## DISCRIMINATION:

People with disabilities will be subjected to or experience decreased disability-based discrimination.

### PRIORITIES:

- Housing
- Employment
- Public Accommodations and Government Services
- Voting

4

## HEALTHCARE:

People with disabilities will receive adequate, appropriate, and necessary health care and medical services.

### PRIORITY:

- Disputes with Government and Private Health Care Insurers

5

### DECISION MAKING:

The rights of people with disabilities will be protected through informed, supported individual and/or surrogate decision making.

#### PRIORITIES:

- Supported Decision Making
- Psychiatric Advance Directives
- End-of-Life Decision Making

7

### ASSISTIVE TECHNOLOGY:

People with disabilities will have increased access to assistive technology devices and services.

#### PRIORITIES:

- Access
- Public Awareness
- Device Demonstrations
- Device Loans
- Recycling

6

### CHILDREN:

Children with disabilities will have access to equal educational opportunity and appropriate community-based services and supports.

#### PRIORITIES:

- Education
- Community-Based Services & Supports
- Bullying
- School-to-Prison Pipeline

8

### WORK & VOCATIONAL REHABILITATION

People with disabilities seeking to work will receive assistance, including appropriate services on a timely basis from federally-funded vocational rehabilitation services.

#### PRIORITIES:

- Rehabilitation Services
- Ticket to Work and Work Incentives
- Employment First
- Work-Related Overpayments

**PADD** - Protection and Advocacy for Individuals with Developmental Disabilities

**PAVA** - Protection and Advocacy for Voter Access

**PAIMI** - Protection and Advocacy for Individuals with Mental Illness

**PAAT** - Protection and Advocacy for Assistive Technology

**PATBI** - Protection and Advocacy for Individuals with Traumatic Brain Injury

**CAP** - Client Assistance Program

**PAIR** - Protection and Advocacy for Individual Rights

**PABSS** - Protection and Advocacy for Beneficiaries of Social Security

**ATAC** - The Richard West Assistive Technology Advocacy Center

**IOLTA** - South Jersey Special Education Project

## 2015 Funding

U.S. Department of Health and Human Services, Administration on Community Living, Administration on Intellectual and Developmental Disabilities

**PADD** \$747,718

**PAVA** \$80,928

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

**PAIMI** \$681,414

U.S. Department of Health and Human Services, Administration on Community Living

**PAAT** \$94,317

**PATBI** \$61,317

U.S. Department of Education, Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration

**CAP** \$307,187

**PAIR** \$412,216

Social Security Administration, Office of Acquisitions and Grants

**PABSS** \$100,000

New Jersey Department of Labor and Workforce Development from U.S. Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitative Research

**ATAC** \$437,280

New Jersey State Bar Foundation Interest on Attorneys Trust Accounts

**IOLTA** \$37,740

National Disability Rights Network from Social Security Administration

**Rep Payee** \$102,410

Other Grants and Contributions

**Misc** \$188,695



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