

# The N.J. Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families



# Presentation Outline

-  Who We Are
-  Why We Are
-  What We Do
-  How We Do It
-  With Whom We Do It
-  Observations
-  Issues
-  Persistent Challenges
-  Recommendations
-  Looking Forward
-  Contact Information



# Who We Are



**Paul Aronsohn**  
Ombudsman



**Christine Bakter**  
Deputy Director



**Charles Dodge**  
Outreach Manager



**Suhani Purohit**  
Intake Coordinator





# Why We Are

*“For far too long, those with intellectual or developmental disabilities and their families have struggled to navigate the state and federal maze of services...Although there is more work to be done, the disability community now has a voice that will continue to fight for each and every one of these residents.”*

Former Assemblywoman Valerie Vainieri Huttle  
Legislative Sponsor  
January 2023

*“...It was clear to me that individuals with disabilities and their families required a central point of contact that would help them navigate and access the resources they needed not just to survive but to thrive.*

*Over the past five years, the Ombudsman’s office has fulfilled its role as a vital one-stop source of information and most important, has lent its expertise to advocating for individuals and their families in a timely and compassionate manner...”*

Former NJ State Senator Congressman Tom Kean, Jr.  
Legislative Sponsor  
January 2023

*“The work of our office is premised on and driven by the understanding that while many of us have special needs, all of us – each and every single one of us – has special gifts and that we all deserve the opportunity to be safe, to be healthy and to reach our full potential.”*

Paul Aronsohn  
Ombudsman  
Annual Reports

ASSEMBLY, No. 3824  
**STATE OF NEW JERSEY**  
217th LEGISLATURE

INTRODUCED MAY 26, 2014

Sponsored by:  
Assemblywoman VALERIE VAINIERI HUTTLE  
District 37 (Bergen)  
Assemblywoman PAMELA R. LAMPITT  
District 6 (Burlington and Camden)  
Assemblywoman ANGELA V. MCKNIGHT  
District 31 (Hudson)  
Assemblyman JAMEL C. HOLLEY  
District 26 (Union)  
Assemblyman RAJ MUKHERJI  
District 33 (Hudson)  
Assemblyman ANDREW ZWICKER  
District 16 (Hampden, Mercer, Middlesex and Somerset)  
Assemblyman BENJIE E. WIMBERLY  
District 35 (Bergen and Passaic)  
Senator THOMAS H. KEAN, JR.  
District 21 (Morris, Somerset and Union)  
Senator BRIAN P. STACK  
District 33 (Hudson)

Co-Sponsored by:  
Assemblywoman Monique A. Castiglia, Benson, Mazzes,  
Gasler, Assemblywoman Jasey, Senators A.R. Bucco and Madden

SYNOPSIS  
Establishes Office of Ombudsman for Individuals with Intellectual or  
Developmental Disabilities and their Families.

CURRENT VERSION OF TEXT  
As introduced.

(Sponsorship Updated As Of: 12/19/2017)





# What We Do

The legislation creating the Office outlines specific responsibilities, which can be grouped into 3 categories:

- 1. Advising / Supporting / Troubleshooting**
  - Information & Referral
  - Options Counseling
  - Communications Coaching
  - Advocacy
- 2. Recommending Improvements**
- 3. Ensuring the Individual/Family's Voice is Heard**



# How We Do It

**We work closely & directly with all of our partners.**

➤ **Individuals and Families**

➤ **Advocates**

➤ **Government Officials**

➤ **Providers**

**We participate in every possible meeting by phone, by video or in person.  
When possible, we meet people where they live, work or socialize.**





# How We Do It

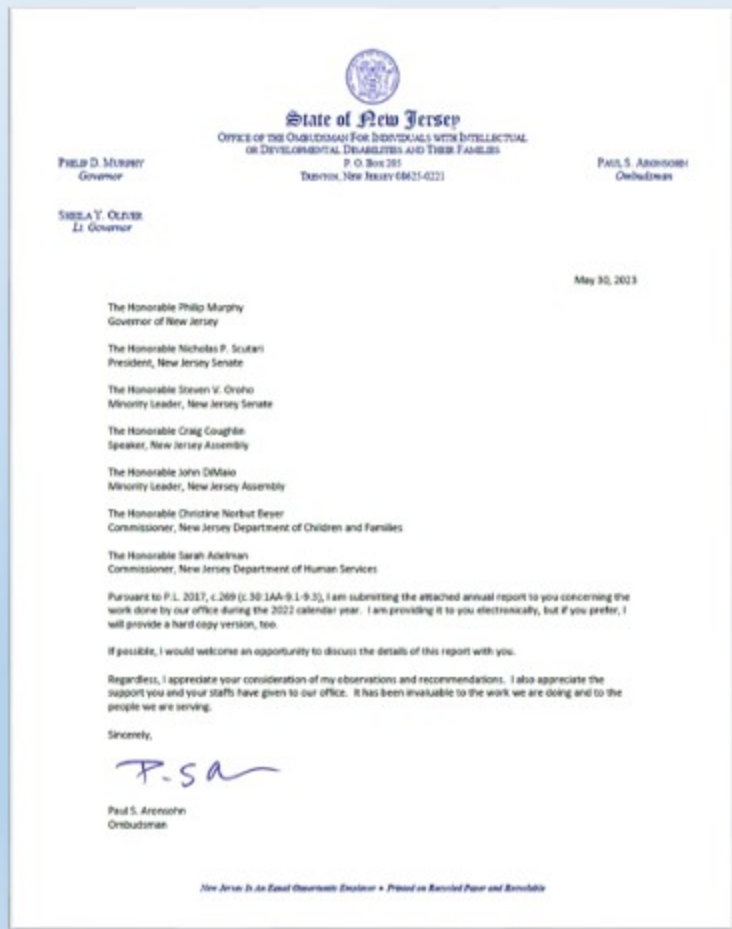
## We Participate in Public Events...





# How We Do It

## We Issue an Annual Report...



**3. a. The Ombudsman ... shall issue a written report annually ...**

***The report shall include a summary of the services the ombudsman provided during the year, and any specific recommendations the ombudsman deems appropriate and necessary concerning the State's implementation of procedures with respect to providing individuals with intellectual or developmental disabilities with services and supports.***







# How We Do It

## We Testify, Speak with Reporters, and Write Opinion Pieces...

### NJ residents with disabilities ‘in crisis,’ report says

**Gene Myers**  
NorthJersey.com  
USA TODAY NETWORK - NEW JERSEY

The state’s disability ombudsman released a report Tuesday that highlighted more losses than wins in the way New Jersey cares for people with disabilities.

The annual report by the ombuds-

man called the state programs for people with disabilities “a tale of two systems.”

On one hand, dedicated people achieved a number of recent wins, such as securing additional education and therapy for disabled students thrown off course by the pandemic. They also managed to get a bill passed that did away with age and income limits placed

on people with disabilities in the workforce that were tied to Medicaid benefits.

But while an increased interest in disability issues in the governor’s office has led to advancements in some areas, like an additional \$1 billion in funding going to community and care programs, a lot of work still needs to be done, said Ombudsman Paul Aronsohn.

The report is chock-full of examples of the toll an inflexible system plagued with ineffective policies can have on people’s lives.

“For many people, the system remains too complex, too rigid, and too inaccessible. Daily, our office is contacted by people falling through the cracks.

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### Media

### Americans with disabilities must have their voices heard

**Your Turn**  
Paul Aronsohn  
Guest columnist

This week, at the United Nations, representatives from around the world are meeting to discuss the human rights of people with disabilities. The overarching theme of the meeting is “Build Back Better,” and while the focus will be on the global response and recovery to the COVID-19 pandemic, there will be other discussions significant to people with disabilities, including those concerning independent living and educational rights. In all, representatives from about 180 countries are expected to participate.

Yet there will be an important voice missing from these proceedings — the voice of the more than 60 million Americans with disabilities and their families.

Simply stated, the United States is one of only nine countries that have not yet ratified the U.N. Convention on the Rights of Persons with Disabilities. As such, our country is not permitted to officially participate in this week’s 14th session of the Conference of State Parties to the CRPD.

Clearly, this doesn’t seem right. It doesn’t seem

right that we have not yet ratified this landmark treaty. Nor does it seem right to have such a meeting without the U.S., which is certainly one of the most inclusive, most accessible countries in the world. We should be sitting at that table.

Clearly, too, this needs to change. Americans with disabilities deserve to be represented in this high-level forum, and with a president and congressional leadership who have demonstrated their commitment to people with disabilities, now is the time to make that change.

The CRPD, which is observing its 15th anniversary later this year, is not only the first human rights treaty of the 21st century; it is also a compelling expression of the world community’s determination to do right by people with disabilities and their families. It commits governments “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” It also provides an invaluable forum for exchanging ideas, raising questions and building a more accessible future.

Without question, there is absolutely no good rea-

son for us to be sitting on the sidelines. The United States remains the global leader on human rights, and as I know from my work over the years, disability is a nonpartisan issue.

Granted, as an advocate for people with disabilities, I am clearly biased on this subject. And as a family member, this is obviously personal. But even looking at this somewhat objectively — as an American — there is no reason not to make this the year when the U.S. takes its rightful place at the global disability table.

After all, the U.S. signed the CRPD in 2009, during the first year of the Obama administration. It now only makes sense for us to ratify it during the first year of the Biden administration and to do so with overwhelming bipartisan support. Doing so would be a wonderful, powerful way to underscore the president’s message to the world that “the United States is back.”

Paul Aronsohn, who comes from a family with disabilities, is New Jersey’s Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families. Previously, he worked for several years at the U.S. Mission to the United Nations.

### Opinion Pieces



### Legislative Testimony



# With Whom We Do It

## In Government...



Department of Human Services



Department of Children & Families



Department of Education



Department of Labor & Workforce Development



Department of Law and Public Safety



Department of Health



Department of Community Affairs



Department of Transportation



Department of the Treasury



Department of Banking & Insurance

New Jersey Department of Banking and Insurance



The New Jersey State Legislature



Department of Corrections



Department of State









# Observations

## A Tale of Two Systems

### Strengths

- ✓ Good, hardworking, dedicated people
    - ✓ Person-Centered Approaches
  - ✓ Significant resources in some areas
- 

### Shortcomings

- ✓ Overwhelmingly complex system
    - ✓ System-Centered Approaches
  - ✓ Inadequate resources in some areas
-



# Issues

## A Wide Range of Issues

- Abuse and Neglect
- Autism
- Basic Needs
- Bathrooms
- Blindness/Vision Impairment
- Budget/Funding
- Bureaucracy
- Care Organizations
- Communications Management
- Disabilities
- COVID-19
- Deafness/Hearing Loss
- Direct Support Professionals
- Education
- Employment
- Families
- Fee-For-Service
- Government Websites
- Guardianship
- Healthcare
- Housing
- Individuals with Severe Challenging Behaviors
- Medically Fragile/Complex Individuals
- NJ Comprehensive Assessment Tool (NJCAT)
- Personal Care Assistance
- Private Duty Nurses
- Public Meetings
- Public Safety
- Self-Direction
- Stephen Komninos Law
- Support Coordination Agencies
- Transitions
- Transportation
- WorkAbility



# Persistent Challenges

## Workforce Shortage

Many individuals with ID/DD lack vital direct care supports due to policies and practices that continue to result in unreasonably low wages/salaries, making it difficult to hire and retain qualified direct care staff – Direct Support Professionals (DSP), Self-Directed Employees (SDE), Private Duty Nurses (PDN)

## Abuse & Neglect

Many individuals in state-licensed residential settings are abused and neglected due to policies and practices that result in many of these settings being understaffed with underpaid & undertrained professionals, who must do challenging work with minimal oversight and supports.

## Complex Medical Needs

Many individuals with complex medical needs live in institutional settings due to policies and practices that make it difficult/impossible for them to live in the community with access to the right assessments, treatments, supports, and services.

## Autism/Severe Challenging Behavior

Many individuals with autism experience severe challenging behavior involving self-injurious, aggressive and/or destructive behavior due to policies and practices that make it difficult/impossible for families to gain access to the right assessments, treatments, supports, and services.





# Recommendations

**Need to Appoint More People with Disabilities and Family Members to Boards and Committees**

**Need to Hire More People with Disabilities and Family Members in Government Offices**

***“Nothing about us, without us.”***

**Need to Make Sure that People with Disabilities and Family Members Always Have a Seat at the Decision-Making Table**

**Need to Engage People with Disabilities and Family Members in Meaningful Ways**



# Looking Forward

Develop and Grow Staff

Strengthen Online Presence

Build & Leverage a Case Management Database  
(Files/Metrics)

Grow Relationships with Individuals and Families &  
Other Stakeholders



# Contact Information

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