



State of New Jersey

OFFICE OF THE OMBUDSMAN FOR INDIVIDUALS WITH INTELLECTUAL
OR DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

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PHILIP D. MURPHY
Governor

PAUL S. ARONSOHN
Ombudsman

SHEILA Y. OLIVER
Lt. Governor

May 30, 2023

The Honorable Philip Murphy
Governor of New Jersey

The Honorable Nicholas P. Scutari
President, New Jersey Senate

The Honorable Steven V. Oroho
Minority Leader, New Jersey Senate

The Honorable Craig Coughlin
Speaker, New Jersey Assembly

The Honorable John DiMaio
Minority Leader, New Jersey Assembly

The Honorable Christine Norbut Beyer
Commissioner, New Jersey Department of Children and Families

The Honorable Sarah Adelman
Commissioner, New Jersey Department of Human Services

Pursuant to P.L. 2017, c.269 (c.30:1AA-9.1-9.3), I am submitting the attached annual report to you concerning the work done by our office during the 2022 calendar year. I am providing it to you electronically, but if you prefer, I will provide a hard copy version, too.

If possible, I would welcome an opportunity to discuss the details of this report with you.

Regardless, I appreciate your consideration of my observations and recommendations. I also appreciate the support you and your staffs have given to our office. It has been invaluable to the work we are doing and to the people we are serving.

Sincerely,

Paul S. Aronsohn
Ombudsman

NJ Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families

2022 Annual Report

Paul S. Aronsohn
Ombudsman

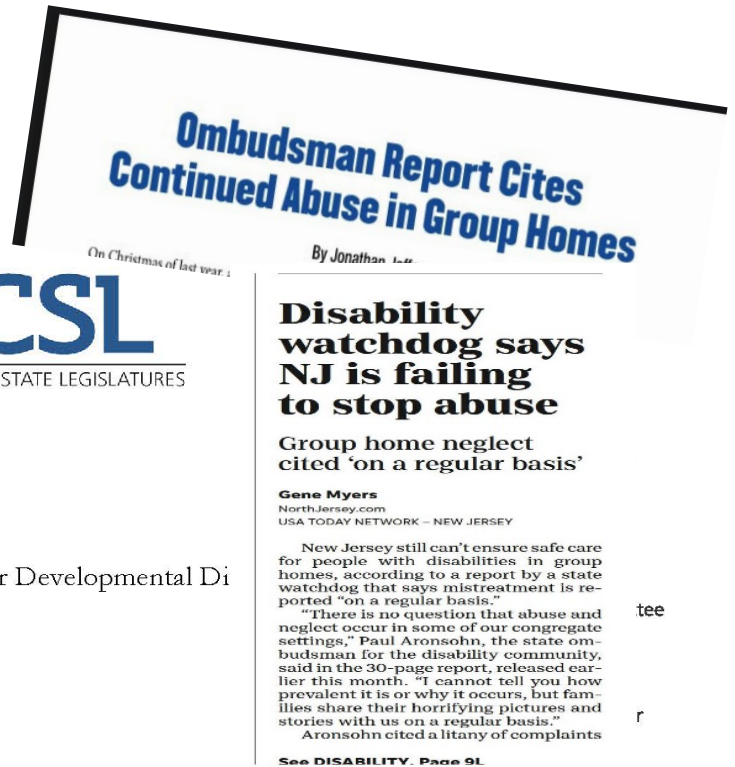


From upper left to lower right: Ombudsman Paul Aronsohn at a Children's Aid and Family Services' event; Deputy Director Christine Bakter and Outreach Operations Manager Charles Dodge at the annual Autism New Jersey conference; the Ombudsman office team at the Abilities Expo in Edison, NJ; the Ombudsman visiting with an individual who self-directs his DDD services.

This report is dedicated to the many extraordinary people with and for whom we serve – the thousands of New Jerseyans with intellectual or developmental disabilities and their families.

We hear you.

Widespread Recognition for Our 2021 Annual Report



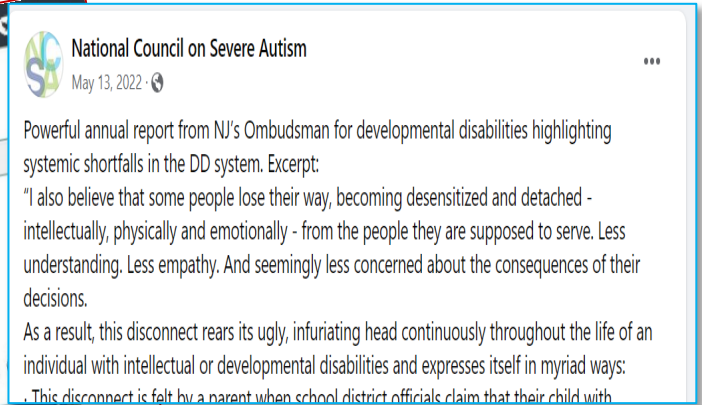
July 15, 2022

Paul S. Aronsohn, Ombudsman
Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families
P. O. BOX 205
Trenton, New Jersey 08625-0221

Dear Mr. Aronsohn:

The Legislative Research Librarians (LRL) Professional Staff Association of the National Conference of State Legislatures (NCSL) is pleased to present a 2022 Notable Document award to you and your staff for the publication of *Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families Annual Report for 2021* (in the category of Social Services). We commend your publication as innovative in providing substantive information on contemporary issues of interest to legislatures.

Both the 2022 Notable Document
NCSL web site at <https://www.ncsl.org>



"When I first saw this report I immediately read it from cover to cover.

To be honest, I became very emotional as I have a 23 year old son who is on the autism spectrum.

What was written in the report is exactly what my family has been going through all these years and I know other families with special needs individuals who are experiencing the same issues."

Ingrid Hernquist,
Manager of Library Services, NJ Office of Legislative Services
August 16, 2022

NJ Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families

2022 Annual Report

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Preface

An Experiment in Human Services

Being NJ's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families is a job unlike any other I have ever had. Every day is full of emotional conversations. Every day is full of difficult, often heartbreaking moments.

On a daily basis, we are brought into the lives of people all across our State – extraordinary lives that have been impacted by lifespan disabilities and are therefore often relentlessly challenging. Through emails, phone calls, virtual meetings and in-person conversations, we work directly with individuals and family members in profoundly personal ways and at profoundly difficult moments. Indeed, people often contact us when they are in crisis.

We also engage regularly with government officials, advocates and provider agency representatives. Sometimes the discussions are specific to an individual or family. Sometimes the discussions are about larger policy issues.

Taken together, we serve as a nexus between those who make and administer policies and those who are impacted by them. We experience both sides of this dynamic, and to the extent possible, we try to bridge any gaps in understanding that may exist. We do this by facilitating communication between individuals, families, government officials and providers. We do this by helping people to navigate and advocate for services they need and deserve. And we do this by speaking truth to power, using this important office as a platform for acknowledging and addressing difficult truths about our system of care in general and people's challenging situations in particular.

Not surprisingly, as people with our own personal connection to disability, our work is a labor of love for us, and we get emotionally invested in the people who turn to us for help. I think that makes us a better resource, but I know others think that makes us unreasonably demanding at times. Regardless, we have worked hard to strike the right balance between being advocates and being government officials. We do not see the roles as mutually exclusive. In fact, we believe they can and should be mutually reinforcing.

The office was conceived as a source of support for people with disabilities and their families. We take that charge very seriously. And we do whatever we can to fulfill that charge, notwithstanding the limitations of our office, including the fact that we do not have the legal authority to make policy decisions or to demand anything of anyone.

That said, we know some individuals and families have expressed frustrations about our office's limited role, suggesting that we should be doing more to change government policies and provider agency practices and that we should have a larger staff to do it all. Conversely, we know others, including some providers, have expressed competing frustrations about our office's spirited approach, suggesting we should not be helping individuals and families with their advocacy and should not be drawing attention to problems – such as abuse and neglect – in our annual reports or with the media.

We take such concerns seriously and do our best with our limited mandate and resources. Clearly, we do not always get it right, but it is certainly not for a lack of trying. We are constantly seeking to do more and to do it better.

Nonetheless, this year marks our office's 5th anniversary – a major milestone for our young, ambitious office – and as such, we have both an opportunity and an obligation to use this moment to reflect on “what” we do and “how” we do it. As discussed elsewhere in this report, we hope and expect many others will join us in this assessment.

Meanwhile, I want to express my appreciation to all with whom we have worked over the past 5 years. You have helped make this experiment in human services both possible and seemingly successful. And, of course, I want to thank all of those for whom we worked – for inviting us into your extraordinary lives and for giving us the opportunity to help in some meaningful way. You make it all worthwhile.



Paul Aronsohn
Ombudsman
May 30, 2023

Introduction

Our 5th Anniversary – Looking Back, Looking Forward

This is our 5th annual report.

Completed on our office's 5th anniversary, this report provides us an important opportunity to reflect on the work of our office as well as its place within New Jersey's larger disability community. What has worked? What should be improved? What role should the office play going forward?

After all, this office has been somewhat of an experiment.

At the time of its founding, this type of Ombudsman office was new and different. Some other States have had similar offices, and here in New Jersey, we have long had non-profit organizations that provide a range of assistance to individuals and families with intellectual or developmental disabilities. But the creation of our office was an innovative attempt by a group of State Legislators and Advocates to put in place a somewhat [independent executive branch office](#) to serve children as well as adults, to serve individuals as well as families, and to serve as a resource as well as an advocate.

Simply stated, they knew that our system of care had significant shortcomings and that they had to do something about it. Something new. Something meaningful. Something to help ensure that New Jerseyans with disabilities were better able to access the supports and services they need and deserve.

Accordingly, they created the office and position of Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families.

Indeed, the newness of this type of office lent itself to seemingly vague language in the enabling legislation that created it – language that made it clear that developing this office was going to be a work in progress. The responsibilities of the Ombudsman were discussed with open-ended language – “shall include, but not be limited to, the following.” Similarly, the [fiscal analysis](#) that accompanied the legislation estimated that the cost of running the office could range from an annual budget of \$150,000 to \$1.9 million, because “the actual cost to implement this bill will largely depend on the design, operation, and implementation of the office.”

When I was appointed to serve as New Jersey's first Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families, I made it a priority to learn about others' expectations of the office. I reached out to my colleagues throughout the Murphy Administration, particularly in the Governor's office, the Department of Human Services, and the Department of Children and Families. I reached out to Members of the State Legislature, particularly the sponsors of the enabling legislation. And I reached out to advocates, providers and the people at the center of it all – the individuals and families who rely on New Jersey's system of care for people with disabilities.

5th Anniversary Reflection

“For far too long, those with intellectual or developmental disabilities and their families have struggled to navigate the state and federal maze of services. The office of the ombudsman was established as a resource meant to provide information and support to these individuals so they may become more self-sufficient and thriving members of society.

Although there is much 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
Primary Sponsor of Legislation to Create the Ombudsman Office
January 2023

5th Anniversary Reflection

“My experience working with constituents caring for a loved one with a disability was the inspiration behind the legislation that ultimately created New Jersey's statewide Ombudsman Office. 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.

Looking forward, the Office must continue to ensure that the disability community is heard and responded to in a meaningful way, so that long-term policy discussions can take place and targeted improvements made to State services.”

Congressman Tom Kean, Jr.
(Former NJ State Senator)
Primary Sponsor of Legislation to Create the Ombudsman Office
January 2023

Not surprisingly, people had different perspectives about the need for this office as well as the role it should play.

- Some thought it should serve as an information and referral resource.
- Some thought it should also be an advocate.
- Some thought it was properly focused on those with lifespan disabilities.
- Some thought it should also serve the broader disability community.
- Some thought it should be subsumed with the Department of Human Services.
- Some thought it should have even more independence and legal authority.
- Some thought it was not needed.
- Some thought it was long overdue.

Now, after a busy 5 years, it is time to revisit questions about the scope and method of this office.

Using this annual report as a starting point, we plan to have just such a conversation throughout the coming year. Through a variety of means – including surveys and small group meetings – we plan to solicit the views of our stakeholders, most notably, individuals, families, advocates, providers, and State and Local government officials.

Moreover, as in previous years, we view this report as an opportunity to highlight issues of importance to the people we serve. In fact, our discussion of these issues is informed by the daily conversations we have with those at the center of our State’s large, robust and diverse disability community: people with disabilities and their parents, siblings, grandparents, aunts, uncles, cousins, spouses, children, and friends.

This report therefore goes beyond the required summary of last year’s work and recommendations. It includes the lessons learned through the lives, experiences and stories of the people for whom we work.

However, whereas previous reports focused primarily on observations about our State’s system of care for people with disabilities, this report focuses more on recommendations – concrete, commonsense suggestions for improving the lives of the people we serve.

Due to its scope and purpose, our office is most often contacted by people seeking assistance. Sometimes they need advice or direction. Sometimes they need an advocate. Often they are in crisis and in need of immediate relief. Our focus therefore is most often on the many challenges faced by individuals and families – their frustrations as well as their unmet needs – rather than on the many success stories.

That said, we have tried to present information in this report in a balanced way, noting both strengths and weaknesses of the system. **This is key, because if we are to provide New Jerseyans with the best system of care possible, we need to recognize and build on what works, while acknowledging and fixing what is broken.** Indeed, there is no intent to finger-point or lay blame, but rather, to highlight and address issues important to the people we serve – providing a snapshot of where we are and a discussion of where we ought to go.

Each of our annual reports has been different in both form and substance. This has allowed us to address a wider range of topics and to discuss them from varying perspectives. We encourage you to read our previous reports, because many of the issues discussed remain relevant today. They are posted on [our website](#).

5th Anniversary Reflection

“The Ombudsman’s Office for Individuals with Intellectual or Developmental Disabilities and Their Families has been a welcome addition to the infrastructure within New Jersey’s system of supports. Individuals with IDD and their families simply don’t know that they don’t know yet they face challenging and life altering situations. Having the Ombudsman’s Office provides a vital resource and safety net for those who find their way to the Office.

The Ombudsman’s Office has made its way into people’s homes and lives in such meaningful ways. The New Jersey Council on Developmental Disabilities (NJCDD) is grateful for the forward thinking policymakers who have prioritized the work of the Ombudsman’s Office. Everyone with a disability deserves to live the life they chose with dignity and supports to reach their goals and dreams. New Jersey is fortunate to offer a support system that assists individuals in achieving their vision of a quality life.

NJCDD is grateful to the Ombudsman’s office for their compassion, knowledge, sensitivity, sense of urgency, guidance, collaboration and sensible role in supporting individuals with IDD and their families.”

Mercedes Witowsky
Executive Director, NJ Council on Developmental Disabilities
January 2023

Background

“Who” and “Why” We Are

The Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families was [established by the New Jersey State Legislature](#) in December 2017 to serve individuals and their families – to help make sure that they get the services and supports they need and deserve.

Signed into law by Governor Chris Christie in January 2018, the Office was made operational when [Governor Phil Murphy appointed me](#) a few months later and has been kept busy by our Administration’s determination - across departments and agencies - to make a positive difference in the lives of the people we serve.

For the first two years, the Office had a staff of one – [me](#). In February 2020, now-Deputy Director [Christine Bakter](#) joined our office, helping me to run our busy, two-person operation. And last year, in March 2022, Operations Outreach Manager [Charles Dodge](#) joined our team.

Together, the three of us have been working to carry out our important mission:

- Serving as a resource for individuals and families;
- Working with individuals and families to improve the system of care for people with disabilities; and
- Ensuring that the voice of individuals and families is heard in a meaningful way in decisions that directly affect them as well as in larger policy discussions.

But since this is a new office, that has meant delivering real-time assistance to the people who need it, while developing a solid foundation for the future – “building the plane while flying it,” as the saying goes.

Indeed, we have taken great care to develop our office in a way that provides a “value added” to the work of our colleagues throughout New Jersey’s system of care and to the lives of the people we serve. Sometimes as advisors. Sometimes as advocates. Always as partners and resources, often sharing information between those who staff our system of care and those who depend on it. And realizing the importance of a personal touch - particularly with human service issues - we have spent as much time as possible working one-on-one with individuals and families and, whenever possible, visiting with them where they live, learn, work and socialize.

The work of our office is 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 to live lives that are safe, healthy and fulfilling.

- This is why we work to ensure that people with disabilities are not abused, neglected, or exploited.
- This is why we work to ensure that people with disabilities have meaningful access to vital supports, treatments, therapies, and medical care.
- This is why we work to ensure that people with disabilities have genuine opportunities to realize their potential.

5th Anniversary Reflection

“The Office of the Ombudsman for Individuals with IDD and Their Families has been beneficial in helping families navigate the complex system for individuals with I/DD including the many state agency silos (i.e., DDD, DVRS, Medicaid).

The Ombudsman is a consistent positive presence in the community and among individual and family advocacy groups.

The Ombudsman brings a unique kind of advocacy to bear on behalf of individuals with IDD, leveraging their relationships with Governor’s Office and the various state departments, in particular the Department of Human Services, and through their efforts bring critical and systemic issues to light.

It is important for individuals and their families to feel they have this office “on their side” and have an independent entity within state government to get the information they need and questions answered.

Disability Rights NJ, the designated protection and advocacy, looks forward to on-going collaboration with the Ombudsman’s Office to complement the services each of our offices offer to people with disabilities.”

Gwen Orłowski
Executive Director, Disability Rights New Jersey
January 2023

Professionally, this has been a tremendous opportunity. Personally, as people with lived disability experience, this has been a labor of love. Through our work, we get invited into the extraordinary lives of some really extraordinary people. The conversations are often emotional. The situations are often complex. Together, we try to find our way through issues important to them and to others.

According to the enabling legislation, the Ombudsman is required to “issue a written report annually to the Commissioner of Human Services and the Commissioner of Children and Families. 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. The ombudsman also shall issue the report prepared pursuant to subsection a. of this section to the Governor, and pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1) to the Legislature.”

This is that report.

5th Anniversary Reflection

“The Ombudsman's office has provided another venue to engage families, gather information, and relay their concerns to policymakers.

Families of people with disabilities continue to express appreciation for the Ombudsman and the opportunity to share their experiences, advocate for more high quality supports and services, and have their voices heard.”

Deborah M. Spitalnik, PhD
Executive Director, The Boggs Center on Developmental Disabilities
January 2023

Summary of 2022 Services Provided

The Year at a Glance

Throughout 2022, our office remained small, but busy with the three of us directly and personally serving thousands of New Jerseyans with disabilities and their families in a variety of ways.

Most of our time was spent troubleshooting situations with people – answering questions, explaining policies, making connections and referrals, strategizing approaches, facilitating communications. This was done through emails, phone conversations, virtual meetings, and in-person visits.

Indeed, whenever possible, we continued to meet with people in their homes and communities – something which allows for a more meaningful conversation without burdening the individuals and families with travel to our office in Trenton.

Moreover, these in-person visits give us a uniquely personal and valuable perspective – one that allows us to better understand their challenges and opportunities, and to better serve them. We have the opportunity to see, hear and feel their life experiences in a way not possible through emails or phone calls.

Similarly, we spent a good amount of time last year working directly with our government, advocacy organization, and provider agency colleagues. Similar to our approach to individuals and families, we worked one-on-one with our colleagues, meeting in person whenever possible – always making ourselves available to answer questions, talk through situations, and engage in policy discussions.

And again, serving as a nexus between decision makers and those impacted by their decisions, we often used our distinct position in the system of care to facilitate communication among individuals, families, government officials and other stakeholders. Sometimes through emails or phone calls. Sometimes through virtual or in-person meetings. We did all we could to encourage and support communication among and between everyone involved in particular situations or policy considerations.

Although our office’s mandate is focused on individuals with intellectual or developmental disabilities and their families, last year – as in previous years – we tried to help anyone with any type of disability. In fact, we have an unofficial workplace edict to try to help anyone who comes our way.

Throughout the year, we worked with individuals and families throughout our State on a wide range of issues, including –

Abuse & Neglect	Adult Services	Children’s Services
Civil Rights	Complex Medical Needs	Criminal Justice
Dental Health	Education	Elections / Voting Accessibility
Employment	Financial Planning	Guardianship
Housing	Long Term Care / Nursing Homes	Managed Care
Medicaid	Medicare	Mental Health
Motor Vehicle Licenses	Physical Health	Private Insurance
Public Safety	Self-Advocacy	Self-Direction
Severe Challenging Behavior	Social Security	State Identification
Transportation	Unemployment	Workforce / Staffing

Most often, this work involved helping them navigate time-sensitive situations.

5th Anniversary Reflection

“The Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families is an effective advocate for people with disabilities in New Jersey, acting on their behalf to help with solving the many challenges they face in their communities.

Their extensive connections in the disability community give individuals with disabilities and their families access to services and resources that they may not have found on their own.

The office’s constant support of people with disabilities and the public entities that serve them is a great example of their genuine commitment to improving the quality of life for people with disabilities in the state of New Jersey.”

Johnesia McKenzie
Chair, NJ Statewide Independent Living Council
February 2023

In addition to our one-on-one work with individuals, families, and other stakeholders, we participated in numerous meetings and events, and we were involved in many initiatives.

Accordingly, throughout 2022 –

- We worked daily with colleagues across the State’s Executive branch, including in the Departments of Children and Families, Corrections, Education, Health, Human Services, Justice, Labor, State, Treasury, and Transportation (including the Motor Vehicle Commission).
- We worked regularly with State Legislators and their staffs, providing support to their constituents and collaborating with them on policy issues.
- We worked closely with the Board and Staff of the [New Jersey Council on Developmental Disabilities](#) (NJCDD) and participated in several meetings and initiatives with them, including weekly phone calls with Executive Director Mercedes Witowsky.
- We worked closely with our colleagues at [Disability Rights New Jersey](#) (DRNJ), including regular communications with Executive Director Gwen Orłowski and her staff.
- We worked closely with the leadership of [Autism New Jersey](#), Executive Director Suzanne Buchanan and former Policy Director Eric Eberman. We also participated in Autism New Jersey’s 40th annual conference.
- We participated in a series of interagency working group meetings to discuss disability issues, which were organized and hosted by the Governor’s Policy Office.
- We participated in regular meetings of the Attorney General’s [steering committee](#) to strengthen coordination between law enforcement officers and members of the mental health and other special needs community.
- We participated in regular meetings of the NJ Group for Access and Integration Needs in Emergencies and Disasters (NJ GAINED).
- We participated in multiple meetings of the [NJ Statewide Independent Living Council](#), including its Public Forum in Atlantic County, and worked closely with several leaders of [New Jersey’s Centers for Independent Living](#).
- We attended the 25th anniversary celebration of the [DAWN Center for Independent Living](#) and participated in the [Progressive Center for Independent Living's](#) annual softball game.
- We attended an Open House event for [Heightened Independence & Progress](#) – the center for independent living for Bergen and Hudson Counties.
- We participated in multiple meetings of the [NJCDD's Regional Family Support Planning Councils](#), and I was a featured speaker at the group’s statewide meeting in the spring.
- We participated in multiple meetings of the NJCDD’s Children and Youth Family Support Service Committee and worked with our colleagues to develop a set of findings and recommendations.

5th Anniversary Reflection

“Working with the Ombudsman’s Office these past five years has been a professional and personal pleasure. It has demonstrated to me how government should work for people with disabilities when the correct people are put in place.

The office has performed its initial mission by listening, advocating, and resolving issues both at the individual and systems levels. No issue seemed to be too small or too huge to take on. At the same time, the office has a broad view of “disability” and approaches issues across the spectrum of disability types and governmental divisions.

This approach is unique for our State where our culture of support has been defined by disability type, yet issues like affordable housing, transportation, employment, and emergency preparedness and planning cannot be addressed disability by disability. That approach has failed time and again, but the Ombudsman’s Office has steered a more inclusive and systematic course on these and other issues.”

Norman A. Smith, HCCP
Former Chair, NJ Statewide Independent Living Council
January 2023

- We participated in multiple meetings of the New Jersey Association of County Disability Services and worked closely with several of its members, many of whom lead their county disability offices.
- We participated in several meetings of the Long-Term Care Stakeholders group organized by [NJ Long-Term Care Ombudsman](#) Laurie Brewer and her staff.
- We participated in quarterly meetings of the [New Jersey Legislative Disability Caucus](#).
- We participated in multiple Special Olympics of New Jersey events, including the Summer Games Opening Ceremony, and I delivered the keynote address at the [SONJ Program Leadership Conference](#).
- We met on multiple occasions with The Arc of New Jersey's [Criminal Justice Advocacy Program](#) team to work through several issues that need attention related to the arrest, detention, incarceration and overall treatment of people with intellectual or developmental disabilities. (We also had several conversations on these topics with families and Administration officials, including NJ's new Ombudsman for Corrections.)
- We met on multiple occasions with groups of Self-Directing families to strengthen the workforce and to plan for the future – working with them to ensure that the resources are in place to make it possible for their loved ones to live safe, healthy, fulfilling lives, and to do so in the least restrictive, most integrated settings.
- We met on multiple occasions with [Autism Speaks](#), a national advocacy and research organization, to discuss severe challenging behavior and other topics.
- We met on multiple occasions with Connecticut's [Independent Ombudsperson for Developmental Disability Services](#), Sharon Jacovino.
- We attended the 16th Annual [New Jersey Self-Advocacy Network](#) spring event.
- We visited – in conjunction with the Office of the Long Term Care Ombudsman - the Woodland Behavioral and Nursing Center [after reports](#) about alleged abuse and neglect of people with disabilities.
- I participated in a "Read Across America" event at the [Children's Aid and Family Services](#) (CAFSNJ).
- I gave a presentation to the [Hunterdon County Aging and Disability Resource Connection Advisory Committee](#).
- I gave a presentation at an information session hosted by [Passaic County Surrogate Zoila Cassanova, Esq.](#)
- I delivered the opening [keynote address](#) at the 2nd Annual Youth and Transition Conference.
- I delivered the closing [keynote address](#) at the 2022 Self-Direction Conference.

5th Anniversary Reflection

"When supporting families of individuals with autism and high behavioral acuity, we frequently learn that they are already involved with the Ombudsman in some capacity or have been referred to our 800.4.AUTISM Helpline by him.

Meeting with one such family, we learned that their son with severe autism was abruptly discharged from an outpatient behavior disorder program due to the severity of his behavior. The Ombudsman and his Deputy Director recognized that this family would be physically unsafe and likely injured and thus took immediate action. They helped the family understand their options and communicated their concerns to decision-makers within both the state and private service systems. Moreover, the Ombudsman stayed involved, following up with the family to address obstacles in their search for safety and stability. The family has now found assessment and treatment services and related therapies to decrease the likelihood that he will pose a danger to himself and his family members and increase the likelihood of learning new skills and improving his basic quality of life.

In the Ombudsman's office, a fundamental commitment to the dignity and safety of every individual meet a collaborative style and systemic know-how. They use their resources efficiently and effectively to help individual constituents, while simultaneously advocating for a "Whole-of-Government" approach to address the many unmet needs of individuals with developmental disabilities."

Suzanne Buchanan, Psy.D., BCBA-D
Executive Director, Autism New Jersey
 January 2023

- I delivered the opening and closing remarks at the 2022 NJ Association of People Supporting Employment First (APSE) [Leadership Link event](#).
- I was a panelist on a virtual disability [information forum](#) organized by Congressman Andy Kim.
- We received a [Notable Document Award](#) from the National Conference of State Legislatures for our [2021 annual report](#) and participated in an event with other award recipients from around the country.
- I received [PLAN NJ's](#) 2022 Public Sector Representative of the Year Award as well as [Inroads to Opportunities'](#) Making Inroads Award and delivered remarks at the respective ceremonies.
- Our office's work was featured in [media stories](#) on a variety of topics, including [our 2021 annual report](#), [abuse and neglect in congregate settings](#), and [The Arc's 75th anniversary](#).
- In addition to the more than 1,000 one-on-one meetings and phone calls with individuals and families, we participated alongside them in numerous meetings with other stakeholders –
 - Child Family Team (CFT) meetings
 - Treatment Team meetings
 - Interdisciplinary Team (IDT) meetings
 - Human Rights Committee meetings
 - NJ Comprehensive Assessment Tool (NJCAT) meetings
 - Meetings with Administration officials
 - Meetings with Legislators and Staff
 - Meetings with Providers
 - Meetings with Educators

Moreover, we made some important changes within our office, including:

- The third member of our team, Charles Dodge, started in March as our Office's Outreach Operations Manager, bringing with him a wealth of personal and professional experience with disability.
- We developed a database that will allow us to track and sort the work we do with individuals and families, making it possible for us to utilize – and share with colleagues – important data about the people we are serving, while helping to uncover gaps in State supports and services.
- We continued to buildout our Office's website into a more of a one-stop resource for individuals and families.
- We developed an [office brochure](#), which is available on our website or in hard copy.
- We began the hiring process for a 4th person in our office, an Intake Coordinator who can help us build our database and support the office more generally.

5th Anniversary Reflection

"In the spirit of truly understanding and connecting to those they are charged with assisting, the Ombudsman and his team have dutifully traveled the state to meet with individuals and families who have concerns about the system.

The Office is compassionate to those experiencing trials and tribulations, and they do all they can to help. In addition, the Office has vocally advocated for both increasing wages for Direct Support Professionals, and bolstering the respect this workforce deserves.

The Arc of NJ looks forward to continuing to work together with the Ombudsman and his team and introducing them to families with varied backgrounds and with different perspectives about the New Jersey disability community and services."

Thomas Baffuto
Executive Director, The Arc of New Jersey
January 2023

5th Anniversary Reflection

"The Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families is not just a good idea; for some of us, it's the disability-services counterpart of life support.

Ultimately, it promotes the safety and well-being of people with disabilities and, in turn, their families, making for happier, more productive citizens, who have one more reason to love New Jersey."

Parent of a Young Adult Who Lives in a State-licensed Residence,
March 2023

OBSERVATIONS

Positive Developments and Persistent Challenges

As I have said in each of our previous annual reports, ours is a tale of two systems – one good, one not good enough.

On the one hand, New Jersey’s system of care for people with disabilities is strong, robust and well-resourced. This is true for children as well as adults. Among the most important resources are the people who staff the system – namely the people who educate our children, the people who treat and provide direct care to our loved ones, and the people who develop and carry out policies that make it possible for others to live safe, fulfilling lives. Many of them are true champions.

And from our perspective, the system has certainly improved over the past 5 years. Some policies have been changed. Some processes have been reformed. And a lot of this good, important work was done against the backdrop of the worst public health emergency in a century.

Indeed, we have witnessed many positive developments, big and small, including –

- **Education:** An additional year of [public education and related services](#) for students with disabilities impacted by the coronavirus pandemic.
- **Employment:** A [new law](#) to eliminate age and income limitations for people with disabilities who work and rely on Medicaid – a new law, once implemented (ideally, without unnecessary premiums/fees), which should help make it possible for more people with disabilities to reach their professional potential.
- **Housing:** A genuine openness to more innovative [housing options](#), including support for intentional communities, and more focus on the residential needs of those – children as well as adults -- with severe challenging behavior and/or complex medical needs.
- **Public Safety:** The establishment of a [statewide framework](#) for improving law enforcement interactions with mental health and other special needs populations.
- **Adult System:** A significant increase in funding for community-based services; the implementation of [The Stephen Komninos Law](#); efforts to improve the incident reporting process; concrete steps to address behavioral crises; the ability to hire family members as self-directed employees; and more regular communication with individuals and families served by the NJ Department of Human Services’ Division for Developmental Disabilities (DDD).
- **Children’s System:** The extension of [Medicaid coverage](#) to applied behavior analysis for children; a subsequent and significant rate increase for that coverage; an increased openness to utilizing out-of-state treatment resources; and a recent effort by the NJ Department of Children and Families to provide intensive mobile treatment services for young people with severe challenging behavior.

Moreover, in the Governor’s office, there has been an increased focus on disability issues in general and on some especially challenging issues in particular. This includes the formation of an interagency disability working group as well as regular engagement with our office. And this includes recent conversations about cross-cutting issues that demand high-level, “whole of government” attention, such as “severe autism” and transitions (childhood to adulthood).

That said, there is a lot of work still to be done.

For many people, the system remains too complex, too rigid, and too inaccessible. Daily, our office is contacted by people falling through the cracks. People going without much needed care. People in crisis.

For many, it is not easy to get the supports and services they need and deserve. For many, it is a never-ending struggle.

To some extent, this is due to the inherent challenges associated with various disabilities. To some extent, however, this is also due to policies and practices that have been kept in place, despite their proven ineffectiveness.

Nowhere is this more apparent than with 4 persistent challenges we have discussed in each of our previous reports.

Workforce Shortage: Many New Jerseyans with intellectual or developmental disabilities - children as well as adults - continue to lack vital direct care supports. This is due, in part, to policies and practices that continue to result in unreasonably low wages/salaries, making it difficult to hire and retain qualified direct care staff – namely, Direct Support Professionals (DSP), Self-Directed Employees (SDE), and Private Duty Nurses (PDN). **(See Appendix A)**

Abuse & Neglect: Many New Jerseyans living in State-licensed residential settings - children as well as adults – continue to be abused and neglected. This is due, in part, to policies and practices that continue to result in many of these settings being understaffed with underpaid and undertrained professionals, who are expected to do very challenging work with minimal oversight and minimal supports for agencies that allow only minimal family involvement.

Autism/Severe Challenging Behavior: Many New Jerseyans with autism – children as well as adults – continue to experience severe challenging behavior involving self-injurious, aggressive and/or destructive behavior. This is due, in part, to policies and practices that continue to make it difficult, if not impossible, for their families to gain access to the right mix of assessments, treatments, supports, and services.

Complex Medical Needs: Many New Jerseyans with complex medical needs - children as well as adults - continue to live in institutional settings. This is due, in part, to policies and practices that continue to make it difficult, if not impossible, for them to live in the community with access to the right mix of assessments, treatments, supports, and services.

These are just 4 examples of serious, crisis-level challenges that persist despite efforts to mitigate, if not eliminate, them. None of these challenges is new. Yet, all of them seem to be growing in both size and significance.

From our perspective, the reason is as simple as it is serious: Many current policies and practices are just not working effectively.

Workforce Shortage in Perspective

To provide direct care staff, many State-licensed provider agencies receive a lot of Medicaid funding through the NJ Division of Developmental Disabilities.

In fact, some home health agencies are paid more than **\$55 per hour** per client. Some residential provider agencies are paid more than **\$43 per hour** per resident.

Yet, these agencies generally pay their direct care staff only \$16-20 per hour – a wage comparable to the starting salary in many supermarkets and retail stores.

Hence, in New Jersey, the estimated Direct Support Professional turnover rate is at least **44%** and the vacancy rate is at least 20%.

Abuse & Neglect in Perspective

“Disability Rights NJ recognizes the prevalence of abuse and neglect against individuals with intellectual and developmental disabilities. All research shows that individuals with intellectual and developmental disabilities are three (3) to ten (10) times more likely to experience abuse. Individuals who live in settings dependent on round-the-clock caregivers are particularly vulnerable.

Disability Rights NJ acknowledges that abuse and neglect must be addressed.”

- Gwen Orlovski
Executive Director, Disability Rights New Jersey
[Testimony before the NJ Assembly Human Services Committee,](#)
December 2020

Autism in Perspective

New Jersey’s autism prevalence is **1 in 34 children** – one of the highest rates in the world.

More specifically, an estimated 220,000 New Jerseyans have autism, including 60,000 children, according to Autism New Jersey.

And it is estimated **1 in 3 children** with autism engage in self-injurious behavior, meaning an estimated 20,000 New Jersey children have likely banged their own head against a wall, punched themselves in the face, bitten themselves or engaged in some other self-injurious aggression – often as a pattern of ongoing behavior.

Complex Medical Needs in Perspective

Over the past 4.3 years, individuals with intellectual or developmental disabilities have been admitted to New Jersey nursing homes on at least 2,268 occasions –

- about 1,587 (70%) of these occasions have involved long-term stays;
- about 1,255 (55%) have involved people under the age of 63 years.

And there are currently more than 1,000 New Jerseyans living in the State’s 6 Intermediate Care Facilities, including the 5 [Developmental Centers](#).

Indeed, current policies and practices are largely the reason that --

- Direct Support Professionals are often paid only about \$17 per hour (only about \$35,000 per year before taxes) just above the State's minimum wage, despite the importance and difficulty of the work expected of them.
- Families often share stories of loved ones - children as well as adults - being physically and emotionally abused, including through improper medicine administration, filthy living conditions and restrictive group home practices.
- Individuals with autism often end up in the back of police cars and in acute care hospital emergency beds for days, if not months, before being discharged on a new mix of psychotropic medicines.
- Individuals with complex medical needs often end up in hospitals, intermediate care facilities, or nursing homes.

Clearly, on these and many other issues, whatever we are doing is just not working.

Following last year's annual report, which included a focus on these and other issues, some people questioned the magnitude of the challenges discussed as well as the system's response to them. This was particularly true with respect to abuse and neglect.

In each of our annual reports, however, we have been clear that our discussion of issues is informed primarily by the daily conversations we have with the individuals and families who reach out to us, many of whom "are in crisis and in need of immediate assistance." They are also informed by our daily conversations with government officials, advocates, and providers. And we have been clear that our lens is limited to those with whom we work – nothing more, nothing less.

With respect to abuse and neglect, we were especially clear on this point:

"There is no question that abuse and neglect occur in some of our congregate settings. I cannot tell you how prevalent it is or why it occurs, but families share their horrifying pictures and stories with us on a regular basis. Sometimes it is in the form of physical injuries. Sometimes it is in the form of locked bedroom doors, withheld food, incorrect medication administration, unsanitary conditions, or some other inhumane treatment. Sometimes it is verbal and psychological, expressing itself in demeaning and degrading behavior toward an individual."

To confirm our understanding, late last year, we sent a survey to the individuals and families with whom we have directly worked over the past few years. Specifically, we sent the survey to about 1,300 people and solicited very high-level responses to 10 questions. It was not scientific. It was not all-inclusive. It was just an attempt to gain additional feedback from the people who have reached out to us for advice and assistance.

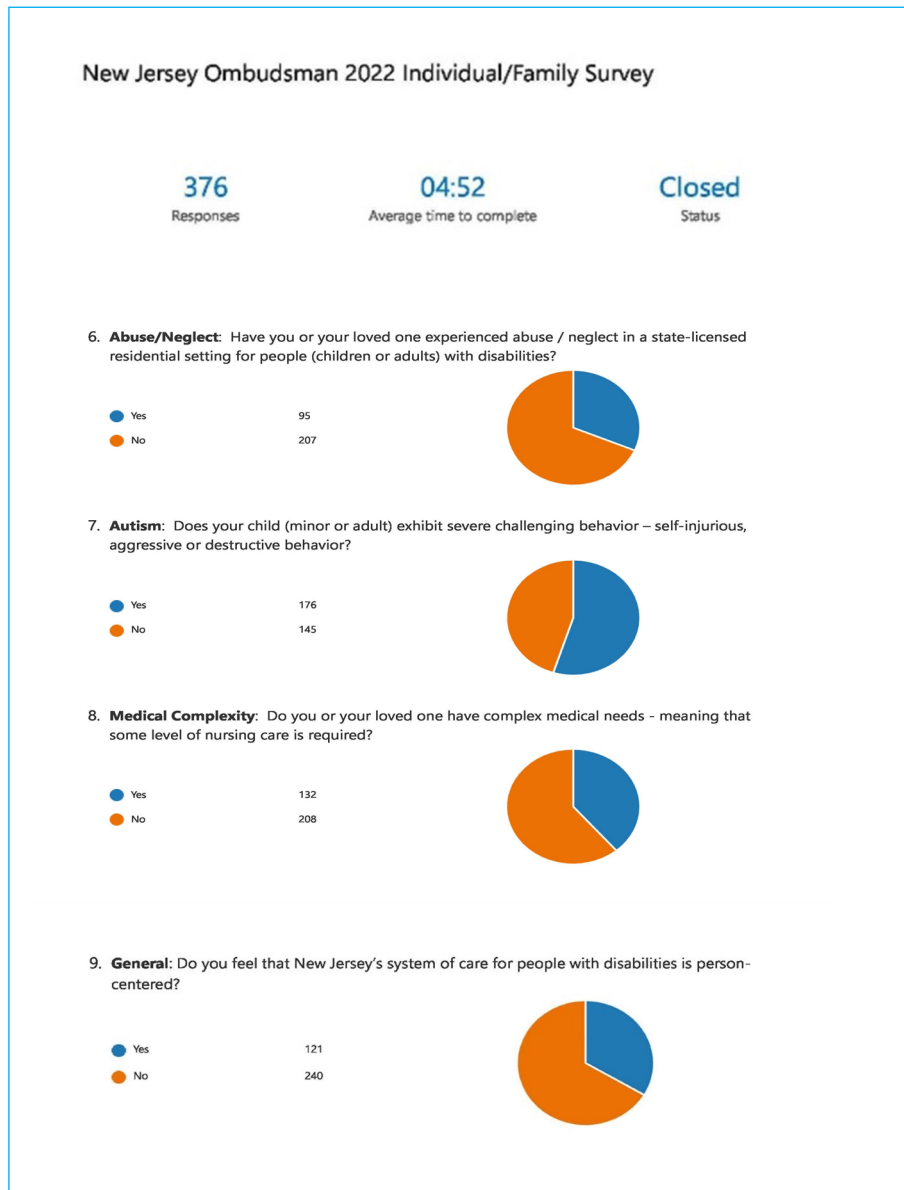
We received 376 responses – a near 30% response rate – in the two-week survey period.

- 95 people (25 percent) said that they or a loved one had been subjected to abuse and neglect in a State-licensed residential setting.
- 176 people (47 percent) said that their loved one has engaged in severe challenging behavior – self-injurious, aggressive or destructive behavior.
- 132 people (35 percent) said that they or a loved one had complex medical needs.

Overall, only 32% of the respondents felt that New Jersey's system of care for people with disabilities was "person-centered" and most gave it a below average rating. In fact, 77 people (21%) gave the system the lowest rating possible, while only 21 people (6%) gave the system the highest rating.

Again, the survey was limited and not scientific. But importantly, it gave us a snapshot of the perspectives and experiences of some of the people who have been in touch with our office over the past 5 years.

In so doing, it confirmed for us a very important point: Despite good faith efforts, many New Jerseyans with disabilities and their families do not feel that they are being well-served by our State’s system of care.



Granted, we know from firsthand experience that a lot of good people have been doing a lot of good, important work over the past few years. This is true in government as well as throughout the larger disability community. But we also know – and we should all acknowledge -- that it is not enough. We should acknowledge that our approach to many of the issues important to the people we serve is not working and that it is necessary to try something new.

Simply stated, we cannot continue the same policies and practices and expect different, better results. History tells us that. Experience tells us that. Something needs to change if we are to address our system’s most serious and persistent challenges.

Again, it was in this spirit that our office was established 5 years ago by government officials and advocates, who had the wisdom and courage to acknowledge the system’s shortcomings and the vision and fortitude to do something meaningful about it. Now, going forward, we must follow their lead – embracing the need for change.

Recommendations

New Policies, Practices, and Approaches

As such, we need to heed the old adage, “When in a hole, stop digging.” This means letting go of policies and practices that have not worked as intended or may even be making a situation worse. This means trying something new - much like the founders of our office did 5 years ago.

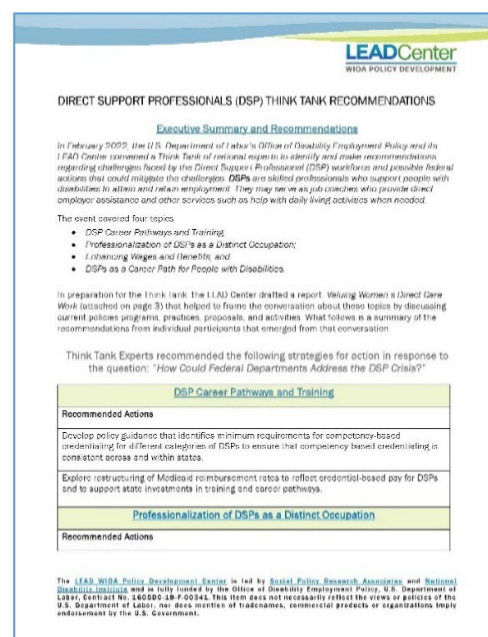
After all, generally speaking, government is a work in progress. Policies and practices that are effective today may not be effective tomorrow. Some may have never been effective at all. It is therefore incumbent upon government officials to know when to try something new - always striving for better outcomes and doing whatever is necessary to get there. This is particularly true with respect to human services - an area of governing that directly and deeply impacts people’s lives.

To that end, we offer the following practicable and straightforward recommendations to the issues discussed above.

Workforce Shortage

To better address the workforce crisis that continues to put people with disabilities at great risk:

- We should consider a requirement that State-licensed residential provider agencies for people with intellectual or developmental disabilities publicly report their revenues and spend a specific percentage of those revenues on direct care staff – similar to the requirement for New Jersey [nursing home providers](#).
 - This would align with a [proposed rule](#) by the US Centers for Medicare and Medicaid Services that 80 percent of all Medicaid payments “be spent on compensation to direct care workers.”
- We should consider a requirement that all direct care staff – Direct Support Professionals, Self-Directed Employees, and Private Duty Nurses – be paid at least a [living wage](#), one indexed annually to account for increases in the cost of living.
- We should consider adopting the recommendations contained in the 2022 [US Department of Labor's Lead Center policy report](#) – recommendations related to training, compensation, and professionalization of the DSP occupation as well as making it more of a career path for people with disabilities.
- We should expand the important effort by the NJ Department of Human Services and [The Boggs Center for Developmental Disabilities](#) to develop DSP “core competencies” by including a meaningful discussion of DSP compensation.
- We should ensure that the rates paid to Self-Directed Employees are based on the needs of the individual and the qualifications of the staff – a calculation that takes into consideration the employee’s familiarity with the individual as well as their overall work experience, placing a premium on the continuity of quality care for the individual.
 - This would align with the spirit of [Executive Order No. 327](#), which was just signed by Governor Murphy and which recognizes the value of practical skills and experience.
 - This would also align with a key principle rooted in the “[budget authority](#)” allowed by the U.S. Centers for Medicare and Medicaid Services (CMS): that Self-Directing families should be able to self-direct the budgets assigned to them – nothing more, nothing less.
 - And this would align with the approach used in [New York](#) where individuals / families “determine the compensation” of their staff.



[NOTE: One parent recently raised an important question to be explored: If the State sets the rate by which SDEs get paid, is the State the employer-of-record and thereby responsible for meeting all relevant labor standards, including those related to benefits, such as overtime compensation?]

- We should consider creating or providing access to an insurance pool for Self-Directed Employees (SDE) – one that covers health and automobile coverage, recognizing that direct care staff need and deserve financial protections.

Abuse and Neglect

To better protect New Jerseyans – children as well as adults – living in State-licensed residential settings:

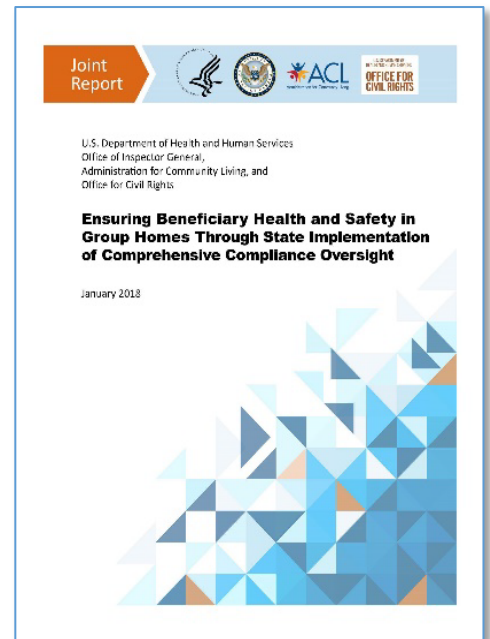
- We should consider a requirement that State-licensed residential provider agencies for people with intellectual or developmental disabilities maintain minimum direct care staff-to-resident ratios – similar to the requirement for New Jersey [nursing home providers](#) – to ensure appropriate staffing levels in congregate settings.
 - We should consider a requirement that State-licensed residential providers use [Electronic Visit Verification](#) (EVV) or some type of monitoring system to ensure adequate staffing levels, actual delivery of services and appropriate use of publicly-funded budgets – similar to the requirement for families and home health agencies providing supports in private homes.
 - We should consider adopting strict rules regarding the administration of medication in State-licensed residences for people with intellectual or developmental disabilities – similar to the strict rules that apply to nursing homes, [assisted living homes](#), [personal homes](#), [schools](#), and State-run prisons . At the very least, we should strengthen oversight, perhaps with some type of Nurse supervision / delegation, such as exists in [New York](#).
 - **[Note: In New Jersey’s 6 intermediate care facilities, including the 5 State-run developmental centers, Nurses administer medication.]**
 - We should consider making video monitoring equipment more readily available in State-licensed residential settings when individuals / families want them. (Already, approximately 25 State-licensed residential provider agencies have applied for and received permission to use such equipment in common areas.). Also, we should ensure individuals and families are made aware of the agencies that utilize video monitoring equipment, so they can make informed choices when choosing a residence.
 - We should consider adopting all of the recommendations outlined in the 2021 NJCDD / Regional Family Support Planning Council subcommittee [Health and Safety White Paper](#) – commonsense recommendations that address staff training, transparency, accountability and family involvement.
 - We should consider using the [Human Rights Committees](#) (HRC) affiliated with the NJ Division of Developmental Disabilities (DDD) and its State-licensed provider agencies for reviewing policies and practices that may be both abusive and human rights violations, thus providing individuals and families a seemingly more accessible, transparent venue for raising such concerns. We should also ensure that the (redacted) minutes of HRC meetings are more readily available to individuals and families and that there is fully transparency regarding committee membership and decisions.
- We should ensure all State-licensed residential provider agencies comply with a key provision of the [Stephen Komminos Law](#) that requires them to facilitate the sharing of contact information among their residents’ families, and we should extend the Law to agencies licensed by the State through the [Children’s System of Care](#).



- We should ensure compliance with the recommendations of a 2018 report by the US Department of Health and Human Services, “Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight,” including the priority it places on family involvement.
- We should ensure greater transparency into the care provided to the residents in State-licensed settings by giving individuals and families read-access to DDD’s iRecord electronic health record system as well as to relevant provider agency notes/logs and billing statements and by compelling State-licensed residential provider agencies to establish advisory boards comprised of family members.
- We should ensure that the federal government’s Home and Community Based Standards (HCBS) are enforced and that a copy of the NJ Department of Human Services’ HCBS Standards and Practices document be posted in every State-licensed residential setting and be given to every individual and family involved in the State-licensed residential program. **(See Appendix B)**
- We should revisit the way in which investigations concerning allegations of abuse and neglect in State-licensed settings are handled, including -
 - We should review the role of provider agencies in the investigations process, taking a hard look at whether it ever makes sense for them to investigate themselves – currently a relatively common practice.
 - We should ensure that letters communicating the results of investigations have the right mix of detail, clarity, sensitivity and professionalism - something often missing from such correspondences.
 - We should make redacted versions of investigative reports concerning allegations of abuse and neglect more readily available to individuals, families, and the general public – using the reports as educational opportunities to improve policies, processes, and approaches as well as to hold agencies accountable.
 - We should ensure investigative reports acknowledge the extraordinary nature of any given situation – acknowledging, for example, that injuries, illnesses or deaths are serious matters not to be taken lightly and not to be taken as a given in congregate residential settings, even when the specifics of the situation are not fully known.
 - We should reconsider the use of the word “unsubstantiated” in investigative reports, particularly when using a word such as “inconclusive” would be more accurate.

[NOTE: As this report was being finalized, our office was working with 6 families, whose allegations of abuse and neglect were recently deemed “unsubstantiated” by the NJ Department of Human Services, despite compelling factors possibly suggesting otherwise.]

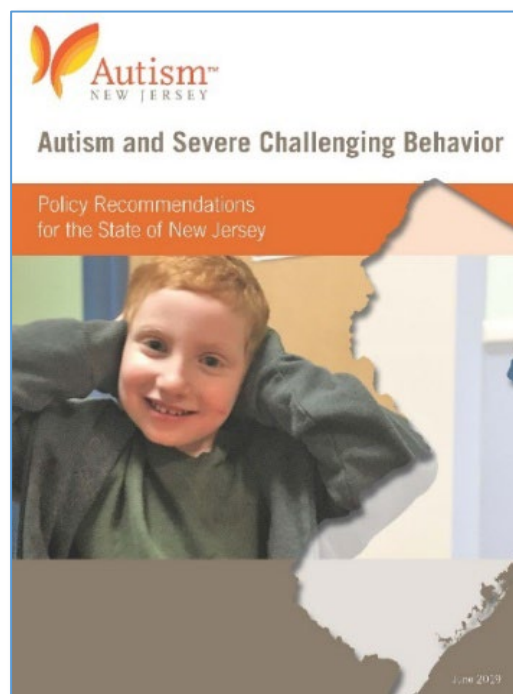
 - We should ensure that every death of an individual under the care of a State-licensed provider is investigated and that the results – in full – are shared with the family in a timely manner.
 - And regardless of other steps taken, we should conduct a 10-year review (2013-2023) of State-licensed residences for children and as well as adults that examines (1) the number of investigations undertaken or overseen by the government, (2) the number of allegations “substantiated,” and (3) the steps taken with those provider agencies to prevent future abuse and neglect, including the imposition of mandatory training or penalties / fees – a review that should be made public upon completion.



Autism / Severe Challenging Behavior

To better support New Jerseyans with autism, including the thousands of children and adults with severe challenging behavior, and to ensure that they are able to live safely and fully in the community in the least restrictive, most integrated environment of their choice:

- We should consider a policy of universal screening for autism spectrum disorder to ensure more and better early intervention – a recommendation included in a [recent study](#) published in the Journal for the American Medical Association (JAMA) seeking to address significant disparities in access to services.
- We should consider adopting the recommendations outlined in 2019 by [Autism New Jersey](#), including the need to place more emphasis on early identification and intervention.
- We should consider establishing an interagency working group on autism and severe challenging behavior, taking a whole-of-government approach that addresses this difficult reality at every stage of life and that involves officials from across government – namely, the Departments of Banking and Insurance; Children and Families; Community Affairs (Housing); Education; Health; Human Services; Law & Public Safety; and Transportation -- as well as individuals, families, advocates, behavior analysts, medical professionals, hospital officials, first responders, and providers.
- We should consider developing “best practices” for responding to a severe challenging behavioral crisis – putting an end to a crisis response cycle that often causes more trauma and more harm. (See Appendix C)
- We should ensure children in behavioral crisis get the supports they need when they need them, making intensive in-home supports more readily available, particularly when out-of-home placement is not immediately possible.
- We should ensure better access to healthcare by actively promoting integrated approaches, using the [Rowan Integrated Special Needs Center](#) as an example, and by ensuring more meaningful network adequacy by our [5 Medicaid Managed Care Organizations](#) (See below).
- We should encourage the development of more intentional communities – independent, yet fully supportive communities for people with the full range of behavioral needs.
- We should urge public officials – at every level of government – to become more educated about autism and severe challenging behavior, including through important films, such as “[A Voice for Severe Autism.](#)”



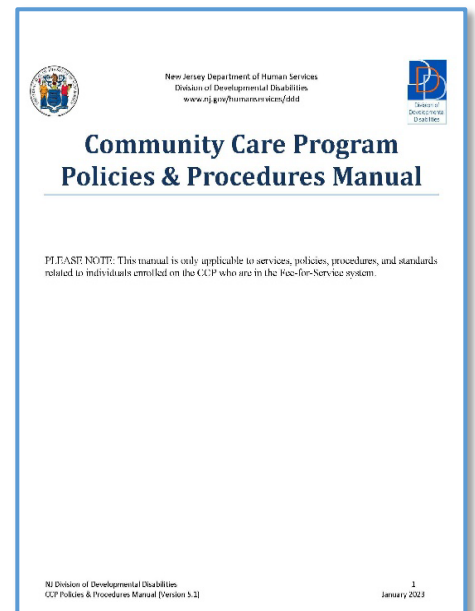
Complex Medical Needs

To better support New Jerseyans – children as well as adults -- with complex medical needs and to ensure that they are able to live safely and fully in the community in the least restrictive, most integrated environment of their choice:

- We should ensure Private Duty Nurses (PDN) are more readily available by paying them a more reasonable salary. The current average Medicaid rate of \$28 per hour, which has apparently not increased in more than a decade, does not necessarily reflect the PDN’s level of training, nor the individual’s required level of care.

[Note: Although provider agencies are paid \$61 per hour for Registered Nurses and \$49 per hour for Licensed Practical Nurses – which represent recent increases - there is currently no requirement regarding the amount agencies must pay the actual Nurses.]

- We should ensure more meaningful network adequacy by our [5 Medicaid Managed Care Organizations](#) (MCO) by –
 - ✓ ensuring our Medicaid rates are reasonable and more aligned with Medicare and private (commercial) insurance rates;
 - ✓ ensuring that more medical, mental, and dental health professionals accept Medicaid;
 - ✓ ensuring that these medical, mental, and dental health professionals are trained to treat people with intellectual or developmental disabilities and are willing and able to extend the length of time for appointments, as needed; and
 - ✓ ensuring that MCOs extend coverage to “border providers” (healthcare professionals and hospitals) in adjacent States – similar to the coverage offered to [New Jersey State government employees](#).
- We should ensure that individuals enrolled in DDD’s [Community Care Program](#) (CCP), like those enrolled in the [Supports Program](#), have access to Private Duty Nurses – something currently precluded.
- We should explore ways to make adult day programs more accessible for people with complex medical needs, ensuring that nurses are either available in such programs or allowed to accompany individuals enrolled in them.
- We should explore ways to make medical group homes more readily available and encourage the development of medical intentional communities – independent, yet fully supportive communities for people with complex medical needs.



Fundamental Change in Approach

This is clearly not an exhaustive list of issues that could benefit from new policies and practices. The diversity of people within our community and the persistent challenges facing them is extensive, and it involves everything from housing to education to employment to transportation to healthcare access.

Indeed, despite years of good faith efforts and well-intentioned policies and practices -

- Many people with disabilities are still not living in appropriate settings of their choosing.
- Many students with disabilities are still deprived a free appropriate public education.
- Many adults with disabilities are still unemployed or underemployed.
- Many adults with disabilities still go without the transportation that makes work and community living possible.
- Many people with disabilities still do not have meaningful access to medical, mental, and dental health professionals.

Moreover, many people with disabilities still do not, in fact, have access to basic supports and services. For whatever reason – cultural barriers, language barriers or socio-economic barriers – many New Jerseyans with intellectual or developmental disabilities have been effectively shut out of our system of care.

Taken together, all of this speaks to the need for change – not only a change in policies and practices, but also a change in overall approach, recognizing that “what” we are doing and “how” we are doing it is clearly not working for many of those we are supposed to serve.

To that end, we should make fundamental changes to the way we make decisions, develop policies, and engage the disability community more generally.

- **This means changing the way we staff government offices and committees, ensuring that people with lived disability experience are in meaningful decision-making positions throughout State and Local government.**
 - ✓ Offices that make policies for people with disabilities should be largely staffed, if not also led, by people with lived disability experience – a standard widely applied to any office making policy regarding a specific segment of the population.
 - ✓ Diversity in the workplace – including positions at the most senior levels of government – should include people with lived disability experience.
 - ✓ All offices and committees - not just those focused on disability issues - should have meaningful representation from the disability community, recognizing all issues affect people with disabilities.
- **This means changing the way we make decisions and policies, ensuring that we engage people with disabilities and their families before decisions and policies are made, using their real-world experience as a guide.**
 - ✓ All State government public meetings and personal assessments/evaluations should be offered in hybrid fashion, providing individuals and families the option of participating by video or in-person.
 - ✓ All disability policy offices should have advisory bodies that include people with lived disability experience.
 - ✓ All draft policies and legislative bills, particularly those directly impacting people with disabilities, should be reviewed by people with lived disability experience before they are finalized.
- **This means changing the way we view and treat people with disabilities by eliminating terms and policies that not only devalue and discriminate against them, but that also reinforce harmful economic and cultural barriers.**
 - ✓ The concept of “rehabilitation” - as used with respect to disability employment policies and practices - should be eliminated, because it wrongly suggests the need to fix someone. People with disabilities are not broken and do not need to be fixed. Although “rehabilitation” is a widely-used concept, dating back to the post-World War I era and rooted in good intentions as well as Federal and State laws, we should discontinue its use by following the lead of the [US Department of Veterans Affairs](#). Indeed, we should mark the 50th anniversary of the [Rehabilitation Act of 1973](#) by ending the use of this offensive “R” word.
 - ✓ The “marriage penalty” imbedded in multiple Federal and State programs should be eliminated, because it precludes many people with disabilities from getting married. For example, [Supplemental Security Income \(SSI\) and Medicaid](#) penalize married couples with uneven asset and income eligibility requirements. This is a matter of civil and human rights.
 - ✓ People with disabilities should be able to live and work where they choose. That means ending policies and practices that preclude them from being treated like every other segment of society. Indeed, we would never tell someone of a particular gender, race, or ethnic group where they can live or work. This, too, is a matter of civil and human rights.

Again, there are a great many challenges facing people with disabilities and their families. Many are significant. Many are persistent. As such, many could certainly benefit from new policies, new practices and new approaches.

And while I cannot promise that the above recommendations would solve all that needs to be solved, I can promise that “the hole” we have been digging – with respect to many of our system’s most persistent challenges - will only get bigger unless we change course and try something new.

Simply stated, for many people with disabilities and their families, the need for change is real; the time for change is now.

Postscript

An Important Milestone for Children's Services

As noted, this year marks our office's 5th anniversary, and we believe that presents us – all of us – with both an opportunity and an obligation to assess the role of our office. What has worked? What needs to be improved? What should we do going forward? And again, we invite everyone to join us in that assessment.

Similarly, this year also marks another important milestone – the 10th anniversary of the NJ Department of Children and Families (DCF) assuming responsibility for providing supports and services to children and young adults (up to age 21) with intellectual or developmental disabilities.

Prior to 2013, this responsibility resided in the NJ Department of Human Services' Division of Developmental Disabilities (DDD). In his 2012 budget address to the Legislature, Governor Christie explained his decision to move these supports and services to DCF:

So with this budget, I am proposing to create a new division focused on children within the Department of Children and Families. This division will be the point of entry for all families with children with developmental disabilities – allowing them to benefit from a battery of services without having to be shuttled from agency to agency.

The concept is to treat the whole child and the whole family – in one place. The division will develop an integrated set of services – and for these families, make government work smarter and better. It will also provide a transition process through adolescence to adult services.

Not surprisingly, this decision was met with mixed reactions. Some supported it. Some opposed it. Some had questions.

Since becoming Ombudsman, this decision has been regularly raised in conversations with our office. Specifically, many people – families, providers and advocates – have questioned whether DCF is the right place to house supports and services for young people with intellectual or developmental disabilities. We noted this concern in our first two annual reports:

[From 2018 Report] *“However, families have often complained that DCF – although completely well-intentioned -- seems to approach their children's situation through a mental health prism and with a focus on “fixing” behavioral issues, rather than with an appreciation for the life-span nature of the disability.”*

[From 2019 Report] *“More generally, parents continue to express concern that DCF does not seem to understand their children with intellectual or developmental disabilities -- that the Department seems to approach their children's situation through a mental health prism and with a focus on “fixing” behavioral issues, rather than with an appreciation for the life-span nature of their disabilities. Many have also pointed to the system's contracted partners – the Care Management Organizations (CMO) and PerformCare – for sometimes taking short-term approaches to their family's long-term situations.”*

To be sure, although we have had similar concerns, we can state emphatically that there has been an improvement over the past few years – that DCF has demonstrated an increasing understanding, sensitivity and commitment to young people with intellectual or developmental disabilities. As a result, DCF has taken important steps forward.

However, we can also state emphatically that more needs to be done - that despite a seeming surge in children with autism and severe challenging behavior, there remains an unacceptable scarcity of intensive in-home supports and out-of-home treatment options.

As with the other persistent challenges discussed in this report, we should therefore acknowledge the need for change – the need to revisit current policies, practices, and approaches for young people with intellectual or developmental disabilities, making sure we are doing everything possible to provide them with the safest, healthiest, most fulfilling childhood experiences.

Fortunately, this year's milestone provides us – all of us – with both an opportunity and an obligation to assess the role of DCF's Children System of Care. What has worked? What needs to be improved? What should we do going forward?

Clearly, we need to have this important conversation. Children's lives literally hang in the balance.

Acknowledgements

Once again, throughout the year, the work of our office benefitted from the partnership and leadership of so many people throughout New Jersey's disability community, including –

- Many of our colleagues across the Murphy Administration, particularly in the Governor's front office and in the Departments of Banking & Insurance, Children & Families, Community Affairs, Education, Health, Human Services, Labor and Workforce Development, Law and Public Safety, Transportation, and Treasury with whom we worked on a regular – sometimes daily – basis. In this context, we are especially grateful to the leadership and staff of the NJ Division of Developmental Disabilities (DDD) and the NJ Children's System of Care (CSOC) with whom we have worked most often and most closely.
- Our fellow New Jersey Ombuds colleagues with whom we continued to work closely and collaboratively –
 - Corrections Ombudsperson Terry Schuster
 - Long-Term Care Ombudsman Laurie Facciarossa Brewer
 - Mental Health Ombudsman Susanne Mills
 - Special Education Ombudsman Cynthia Hoenes-Saindon
- Members of the State Legislature and their staffs, particularly in the offices of Senate President Scutari, Senate Republican Leader Oroho, Senator Bucco, Senator Corrado, Senator Gopal, Senator Lagana, Senator Schepisi, and Senator Zwicker as well as Assembly Speaker Coughlin, Assembly Republican Leader DiMaio, Assemblyman Conaway, Assemblywoman Dunn, Assemblywoman Murphy, Assemblywoman Swain, and Assemblyman Tully.
- Many organizations and providers across the State, particularly Autism New Jersey, Disability Rights New Jersey, New Jersey's Centers for Independent Living, The Arc of New Jersey, The Boggs Center on Developmental Disabilities, the New Jersey Association of County Disability Services, the New Jersey Council on Developmental Disabilities, the Regional Family Support Planning Councils, and the New Jersey Statewide Independent Living Council,
- And most importantly, individuals and families from communities across our State with whom we had the opportunity to work – extraordinary people living extraordinary lives who inspire us in profoundly important ways.



A screenshot of the Indeed website's salary page. At the top, there are navigation links for 'Jobs', 'Company reviews', and 'Find salaries'. The main heading is 'Build a career you'll love'. Below this is a search bar with 'What' set to 'Direct support professional' and 'Where' set to 'New Jersey'. A 'Search' button is to the right. Below the search bar are tabs for 'Overview', 'Salaries', 'Skills', 'Jobs', 'Companies', 'Questions', and 'Articles'. The 'Salaries' tab is selected. The page content shows the breadcrumb 'Home > Career Explorer > Direct Support Professional > Salaries' and the title 'Direct support professional salary in New Jersey'. Below the title is a question: 'How much does a Direct Support Professional make in New Jersey?'. A salary card displays 'Average base salary' as '\$17.72 Per hour', which is '11% above national average'. A horizontal bar chart shows the salary range from 'Low \$14.51' to 'High \$21.65', with the average salary marked at \$17.72. Below the card, it lists a 'Non-cash benefit: 401(k)' and a 'View more benefits' link. At the bottom, a yellow highlight contains the text: 'The average salary for a direct support professional is \$17.72 per hour in New Jersey. 12.6k salaries reported, updated at March 21, 2023'. There is also a 'Is this useful?' section with 'Like', 'Maybe', and 'Dislike' buttons.

A starting salary at one of our State’s largest supermarket chains is comparable to the salary paid by many of our State-licensed residential provider agencies.

Simply stated, Direct Support Professionals should be treated as professionals and paid a salary that reflects the importance and difficulty of their responsibilities.



HCBS Settings Rule Standards & Real Life Examples

<p>Community Integration</p> <p>Members are able to join in community life, participate in scheduled and unscheduled activities, and access public transportation, among other things.</p> <p>Cindy can meet a friend for coffee in town before she goes to a job interview.</p>	<p>Choice</p> <p>Members choose their living arrangements and day services from several options.</p> <p>Chuck can choose from appropriate services and providers based on his person-centered care plan.</p>	<p>Independence</p> <p>Members must have autonomy, physical access to all parts of the setting, and the ability to decide what to do each day, how to decorate their unit, and with whom they wish to socialize.</p> <p>Inez can decorate her living space in her personal style. She can get a snack with her friend at any time.</p>	<p>Rights</p> <p>Members have the right to keep their health information private, to be spoken to with respect and dignity by staff, to have their individual needs and preferences known, and to have their requests for services and supports accommodated.</p> <p>Robyn is feeling reflective today. They are not pressured to participate in social activities.</p>
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Additional Requirements for Provider-Owned and/or Operated Residential Settings

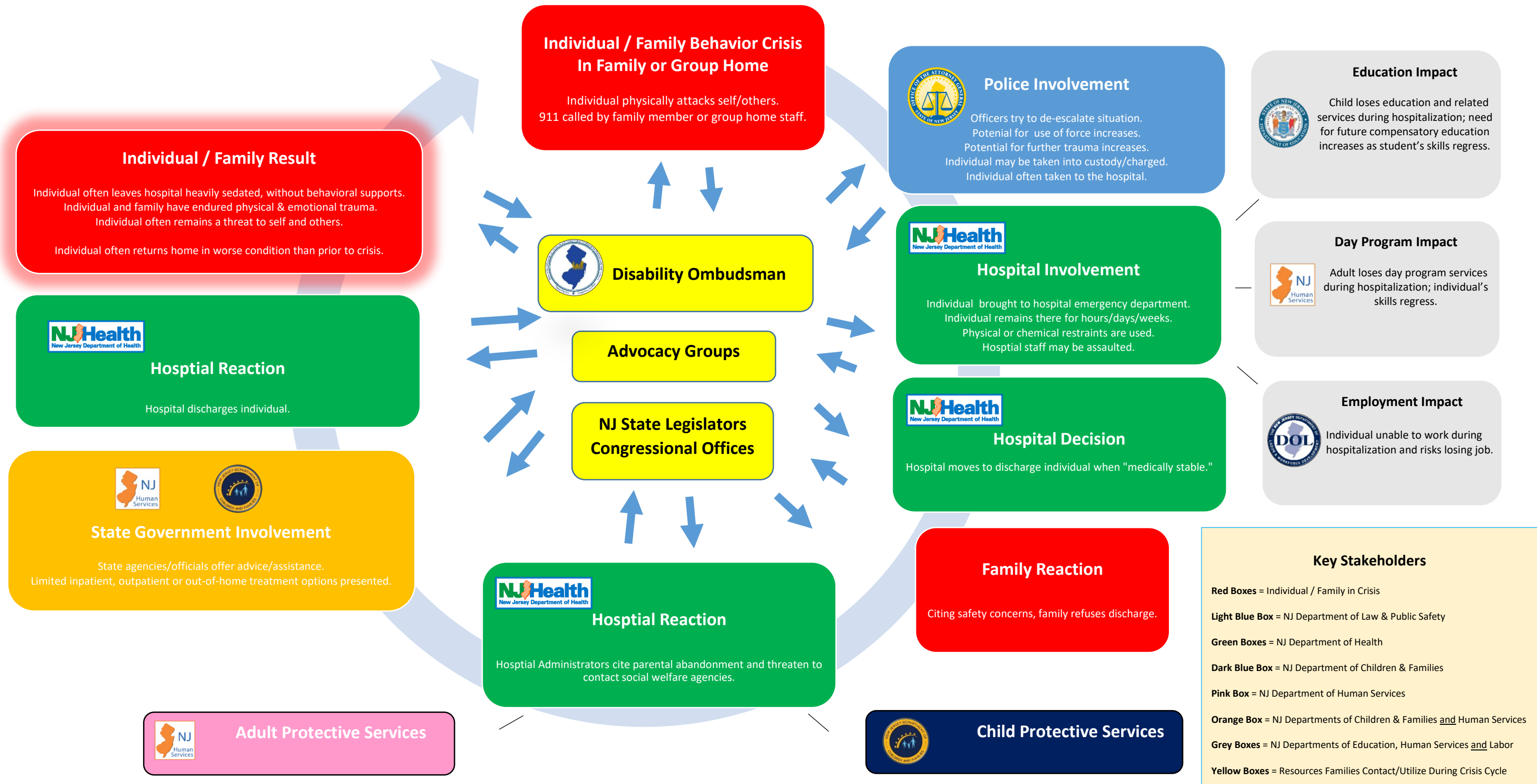
CMS has set additional requirements for settings where services and supports are bundled, like provider-owned residences. These protections include:

<p>Protection from eviction</p> <ul style="list-style-type: none"> • Legally enforceable agreement like a lease • Resident has same protections as renters in landlord/tenant laws 	<p>Rights to privacy</p> <ul style="list-style-type: none"> • Resident has a door with a lock • If they do not or cannot hold their own key, they get to decide on who does • In group homes, there can be a master key with limited access to the key 	<p>Freedom of choice</p> <ul style="list-style-type: none"> • Resident has control of their schedule • They have access to food at any time 	<p>Right to receive visitors at any time</p> <ul style="list-style-type: none"> • Resident can choose visitors to visit at any hour • The setting must have comfortable places for private visits with family and friends 	<p>Physical access to all parts of the setting</p> <ul style="list-style-type: none"> • Resident has needed supports, like grab bars and seats in bathrooms • They have access to appliances, tables, and chairs they can use
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The purpose of Home and Community Base Services is to make it possible for people with disabilities to live in the community in the least restrictive, most integrated environment.

These graphics outlining HCBS standards were developed by the NJ Department of Human Services and should be posted in every State-licensed residential setting and made available to every resident and family member.

Severe Challenging Behavior Crisis Cycle



When individuals and their families experience severe-challenging behavior, the crisis often follows a predictable path – one that is traumatic, dangerous and damaging.

This is a "whole-of-government" challenge that requires a "whole-of-government" response.