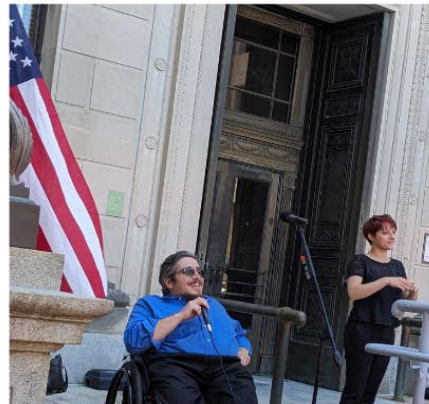




NJ Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families

2023 ANNUAL REPORT



From upper left to lower right: New Jersey State Capital Building at night; Outreach Operations Manager Charles Dodge and an American Sign language Interpreter outside the State Annex Building for "Rev Up New Jersey" voter turnout event; Self Advocate Patrice Jetter with Ombudsman Paul Aronsohn at the NJ Council on Developmental Disabilities' Community Building Awards ceremony; Ombudsman Paul Aronsohn speaking with an individual at the Autism New Jersey Annual Conference; group photo of the Ombudsman office team outside of the NJ State Capital Building; Deputy Director Christine Bakter, Colonel Patrick Callahan (Superintendent, NJ State Police), and Suzanne Buchanan (Executive Director, Autism New Jersey) at the Arrive Together press event.

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 see you. We hear you.

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

2023 Annual Report

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“Nothing about us without us.”

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Preface

- The Fierce Urgency of Now -

In 1963, during his “March on Washington” speech, the Rev. Dr. Martin Luther King, Jr. spoke of “the fierce urgency of now” - a call to action to end racial injustice without further delay. No more complacency. No more excuses. No more waiting. “Now is the time,” King explained.

I often think of that clarion call in the context of our work, because many of the people we serve embody that “fierce urgency of now.” Children engaging in self-injurious behavior. Adults being abused and neglected. Individuals struggling with dangerous behavioral or medical conditions. Families being torn apart – physically, emotionally and financially. Parents laying their children to rest.

Indeed, many of the individuals and families who reach out to us do so with a sense of urgency. Some are dealing with a time-sensitive matter. Some are trying to find their way through a crisis. Most of them need immediate assistance - not next week, next month or next year. They need help now.

We do our best to meet that need, knowing that too often their pleas go unanswered, their concerns disregarded, their sense of urgency dismissed. Too often, they are told to be patient and just “wait.”

- Wait for the next Individualized Educational Plan (IEP) meeting.
- Wait for a “crisis bed” or a group home placement.
- Wait for a therapist or doctor or dentist who accepts Medicaid.
- Wait for an opening in an adult day program.
- Wait for a late paycheck for direct care staff.
- Wait for the results of an investigation.
- Wait for a court date with a local school district or any number of government offices seemingly more inclined to fight you, rather than serve you.
- Wait for a change of policy.
- Wait for the next meeting.
- Wait for a return phone call.
- Wait to be placed on a waiting list.

All of us in government, particularly those of us in human services, must realize that this problem needs to be fixed - now. Our responsibility is not only to recognize peoples’ sense of urgency, but also to understand, embrace and share it. And our responsibility is to do everything possible to “get to yes” when approached with time-sensitive requests.

For the child in crisis. For the adult in danger. For the family under siege. There is no time to wait. There is no room for delay. For many of these individuals and families, “wait” is the most dispiriting, if not dangerous, four-letter word, because time is not a resource available to them.

For them, the fierce urgency is now. For us, the call to action is real.



Paul Aronsohn
Ombudsman
July 22, 2024

A Sense of Urgency in Perspective

A Sample of Subject Headings from Emails Sent to Us in 2023

"Urgent: Request for Emergency Assistance and Documentation"

November 15, 2023

"XX Abuse Call"

August 25, 2023

"Seeking urgent help for a Special Needs resident"

December 28, 2023

"Emergency oxygen and medication"

June 22, 2023

"meeting asap please!!"

November 28, 2023

"emergency student matter" "

July 28, 2023

"Help-urgent ***"**

May 26, 2023

"Personal aid URGENT"

May 19, 2023

"URGENT!! PLEASE READ ASAP!!!"

June 8, 2023

"Please call tomorrow this is urgent!!!"

July 12, 2023

"Medical Mismanagement"

February 6, 2023

"XX - Abuse case info"

March 10, 2023

"... was taken without my consent to Trinitas Hospital"

March 7, 2023

"Fwd: Your Advice URGENT TIME SENSITIVE"

May 25, 2023

"FW: Autism: We Need Your Help"

March 1, 2023

"... in two hospitals yesterday"

October 12, 2023

"The Urgency of Immediate and Complete WorkAbility Implementation"

January 10, 2023

"Burlington Abuse"

April 27, 2023

"ACTION ALERT !!! Person served in need of help"

September 18, 2023

"A plea for help for disabled sister"

December 13, 2023

"Immediate Need"

September 14, 2023

"Institutional Abuse"

June 7, 2023

"Emergency IDT Meeting for"

March 8, 2023

"Urgent Help with the FDA"

May 23, 2023

"Emergency Medication Neglect..."

January 29, 2023

"... Still Hospitalized 8+ months"

August 21, 2023

"Please help!"

August 8, 2023

"Immediate assistance"

October 13, 2023

"Help with patient - urgent"

February 24, 2023

"Healthcare heroes act potential abuses"

May 31, 2023

"URGENT: Request for assistance."

March 24, 2023

"Hi Paul we need to talk urgently they denied me again under the new authorization"

June 7, 2023

"Everyone knows we are being Physically abused, we need help"

July 12, 2023

"More Abuse"

July 11, 2023

"*URGENT!- NO LONGER HAVE SERVICES FOR MY DISABLED BEHAVIORAL BROTHER*"

May 1, 2023

"Report of multiple bite incidents in my son's daycare"

October 20, 2023

"...Urgent issues- follow up needed"

March 24, 2023

"Need some help please ... Before 1/24/2023"

January 13, 2023

"Please help me!"

November 19, 2023

"Urgent concern"

February 16, 2023

"Wrongful denial please help"

July 28, 2023

"Urgent Plea for Assistance: My Son's Life Hangs in the Balance"

October 18, 2023

"Please Help My Father - 84 yrs old - Army Veteran"

June 29, 2023

Introduction

- Government Letterhead -

In 2019, after the release of our first annual report, a parent offered me some important feedback. “I read your report,” she explained. “I liked it. I didn’t learn anything, but it was good to see it on government letterhead.”

To me, that was the best feedback I could have received. The statement was and remains both instructive and valued. It suggested that I got it right – that after about a year of talking with individuals and families about their experiences, I not only understood what was being shared with me; I was also able to convey it in a way that honored them and validated their concerns. They were not alone, and yes, we heard them.

Since then, I have thought often about that parent’s feedback. It reminds me about the need to “keep it real” – the need to use this annual report as an opportunity to speak truth to power in a very straightforward way. It also underscores the need to demonstrate that we are, in fact, listening, and that we do, in fact, understand what it is being said.

Indeed, that feedback has guided the drafting of every subsequent annual report by this office. Although some of the recommendations offered are our own, everything in these reports is rooted in the stories shared with us over the previous year – personal, compelling stories that reflect the often challenging lives of the people who turn to our office for assistance. For many, it is a story of unmet needs, missed opportunities, unimaginable loss. For many, it is a story often told, but rarely heard.

We therefore take great care to tell the story in a way that effectively highlights the many challenges faced by individuals and families throughout our State. We also take great care not to unfairly point fingers or lay blame for the shortcomings in our State’s system of care for people with disabilities. We realize it is not just “what” we say, but “how” we say it. Substantive. Authentic. Balanced. And yes, with an appropriate sense of urgency.

To that end, each year, we have taken a somewhat different approach. Different themes. Different emphases. And yes, different lengths. This allows us to address a larger mix of issues and to do so in a more impactful way.

- Our first two reports focused on a wide range of issues, making our new office’s first attempts at identifying and discussing the challenges faced by so many New Jerseyans with disabilities and their families.
- Our third report took a more high-level approach, focusing on systemic challenges faced by individuals and families, including those in crisis and those living in underrepresented communities. It also included a discussion of our State’s response to the COVID-19 public health emergency.
- Our fourth report explored the “disconnect” that often exists between decision-makers and those impacted by the decisions – the “disconnect” that is responsible for many of the well-intentioned, yet misguided policies and processes that make it more difficult for individuals and families to get the supports and services they need and deserve.
- Our report last year focused, in part, on our office’s 5th anniversary and the opportunity it presented for all of us to step back and take a good hard look at the work of our office – our short, busy history as well as our way forward. More generally, the report also underscored the need for new approaches to old, persistent challenges.

This year’s report is a call to action with respect to some of the most serious, most persistent challenges affecting the lives of New Jerseyans with intellectual or developmental disabilities – issues that embody “the fierce urgency of now.”

- Abuse and Neglect
- Autism/Severe Challenging Behavior
- Complex Medical Needs
- Housing
- Student Transportation
- Transitioning

Clearly, this is not an exhaustive list of priority issues. For example, it does not include Criminal Justice, Employment, and Transportation, just to name a few other serious, persistent challenges that also demand immediate attention. Rather, the 6 issues listed above reflect the conversations we had with individuals and families on an almost daily basis last year.

To be sure, we have addressed each of these issues in previous reports. Some we have addressed in all of our reports. And there have been many important efforts undertaken with respect to each of these issues by other government officials, advocates, and providers. New policies have been put in place. New task forces and committees have been established. New studies have been funded.

But despite all of these good faith efforts and progress, the challenges clearly remain.

- The abuses continue.
- The behavioral crises continue.
- The medical emergencies continue.
- The housing shortages continue.
- The bus tragedies continue.
- The transition challenges continue.

Through this report, we hope to inform the conversations taking place on each of these time-sensitive topics – offering observations, making recommendations, and underscoring the need for a sense of urgency in our approach to them. We then offer a recommendation that gets at the heart of these and other issues – a recommendation that speaks to the need for more accountability, particularly on the part of the organizations/agencies at the center of our system of care.

And by putting it all on government letterhead, we hope it gets the attention it needs and deserves.

A Note for All Readers

As discussed, this report reflects the information brought to our attention by individuals and families over the past year. And while many people with disabilities are well-served by New Jersey's system of care, our office is most often contacted by people who don't know where else to turn and who are trying to find their way through challenging situations.

They share their stories. They share their questions and concerns. They share their documents, pictures, and recordings. And through this report, with their permission, we are sharing some of this with you.

This has resulted in a report longer than our previous reports.
This has also resulted in an emotionally-charged report that may be difficult to read.

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 supports and services 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 over the past couple of years, we have grown to be a team of five with the addition of Operations Outreach Manager [Charles Dodge](#) (2022), Intake Coordinator [Suhani Purohit](#) (2023), and Constituent Relations Coordinator [Amanda Reece](#) (2024).

Together, we 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 in other State government offices 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.

Our Number of Meetings and Phone Calls with Individuals and Family Members

2020	2021	2022	2023
462	707	996	1,149

(estimate)

Professionally and personally, our work is a labor of love for us. The issues are often hard. The situations brought to our attention are often emotionally charged. But we feel a deep sense of mission, and we share the sense of urgency felt by the individuals and families who come our way. This is what helps make us effective. This is what keeps us moving forward.

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.

Summary of 2023 Services Provided

- The Year at a Glance -

Throughout 2023, the work of our office continued to be driven by and guided by the “fierce urgency of now” referenced earlier. Most of the people who contacted our office needed something in a hurry. Answers to time-sensitive questions. Advice on time-sensitive matters. Assistance navigating time-sensitive situations. And to the best of our ability, we responded in kind.

Our team remained small, but busy with all of us directly and personally serving thousands of New Jerseyans with disabilities and their families.

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

“We really need the help of the state of New Jersey right now to navigate this crisis.”

Parent of Young Adult with a Dual-Diagnosis of
Developmental Disabilities and Mental Illness
July 2023

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 talk face-to-face. We meet other family members. 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 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/Student Transportation | Elections / Voting Accessibility |
| Employment | Financial Planning | Guardianship |
| Hospitals/Acute Care | Housing | Long Term Care / Nursing Homes |
| Managed Care | Medicaid/Medicaid Unwinding | Medicare |
| Mental Health | Motor Vehicle Licenses/ID Cards | Physical Health |
| Private Insurance | Public Safety | Self-Advocacy |
| Self-Direction | Severe Challenging Behavior | Social Security |
| Transportation | Unemployment | Workforce / Staffing |

And again, most often, this work involved helping them navigate time-sensitive situations.

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 2023 –

- We worked daily with colleagues across the State’s Executive branch, including in the Departments of Children and Families, Corrections, Education, Health, Human Services, Labor, Law & Public Safety, State, Treasury, and Transportation (including the Motor Vehicle Commission).
- 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 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 communications 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 her team. We also participated in Autism New Jersey’s 41st annual conference as well as two new initiatives led by the organization – one focused on [law enforcement](#) and one focused on [access to healthcare](#).
- We worked closely the leadership of the Arc of New Jersey’s [Criminal Justice Advocacy Program](#) and, among other things, facilitated a relationship between that organization and the [NJ Office of the Corrections Ombudsperson](#).
- 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. I also participated in related meetings of the Prosecutor-led Special Needs Working Groups in Bergen, Gloucester, and Passaic counties.
- 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](#) and worked closely with several leaders of [New Jersey’s Centers for Independent Living](#).
- We participated in multiple meetings of the [NJCDD’s Regional Family Support Planning Councils](#), and we participated in multiple meetings of NJCDD’s Developmental Disabilities Advocacy Network (DDAN) – the Children & Youth Family Support Service Committee, the System Funding Committee, and the Person-Centered and Self-Directed Services Committee.
- 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 meetings of the The Arc of New Jersey’s [Statewide Self-Advocacy Network](#).
- We participated in the Special Olympics of New Jersey Youth Leadership Conference.

- We participated in the annual [Spring Carnival for Special Needs Children](#), which is held at the Governor’s official residence in Princeton.
- 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 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 worked closely with advocates on a range of employment issues, including the implementation of the 2022 law to expand the [NJ WorkAbility](#) program, which makes it possible for people with disabilities to work while maintaining their Medicaid eligibility. (We were not successful, however, in our efforts to advocate against the imposition of a new [schedule of fees](#) on many working people with disabilities enrolled in the program – fees that are budgeted to raise [more than \\$14 million](#) for the State over the next year.)
- We visited with a New Jersey family at the [Anderson Center for Autism](#) in Staatsburg, NY.
- We visited the Children’s Specialized Hospital’s [RUCares Severe Behavior Program](#) in Somerset.
- We visited the Rowan-Virtua [Regional Integrated Special Needs Center](#) in Sewell.
- We attended a “commitment ceremony” at [Montclair University](#) for people with disabilities, who are sometimes financially penalized for getting married due to provisions in certain Federal or State programs.
- We attended The Boggs Center on Developmental Disabilities’ [40th Anniversary Colloquium](#).
- We attended [REED Autism Services’](#) Grand Opening of their campus in Franklin Lakes.
- We attended two events related to the [ARRIVE Together](#) program – one announcing the expansion of the initiative, one celebrating its 2nd anniversary.
- We participated in multiple resource fairs, including the [Phoenix Center Annual Transition and Recreation Fair](#) in Nutley, the [Annual Camden County Mental Health Resource Fair](#) in Voorhees, and the [NJ Special Education Administrators Association Transition Fair](#) in Paramus. I also spoke at the Ocean County Library’s [Sixth Annual Autism Resources Fair](#) in Toms River.
- We participated in the annual [Abilities Expo](#) at the New Jersey Convention & Expo Center in Edison.
- We participated in two conferences organized by [Cooper University Health Care](#) and [Bancroft](#) – one focused on “Integrated Health Care” in Mount Laurel and one focused on “Compassionate Communication” in Cherry Hill.
- I delivered remarks and responded to questions at an information session for Social Workers hosted by [Passaic County Surrogate Zoila Cassanova, Esq.](#) in Wayne.
- I delivered the opening [keynote address](#) the 3rd Annual Youth and Transition Conference.
- I delivered an opening [keynote address](#) at the 2023 Self-Direction Conference.
- I delivered an opening [keynote address](#) at the Felician Autism Collaboration in Teaching (FACT) Conference in Rutherford.
- I delivered remarks and responded to questions from the NJ Office of Legislative Services’ Continuing Legal Education course participants in Trenton.

- I delivered remarks at the 5th Anniversary of the [Passaic County Parents of Adults with Disabilities](#) celebration in Haledon.
- I was interviewed for a [podcast](#) for the National Council of Severe Autism.
- I received a New Jersey Council on Developmental Disabilities' [Community Building Award](#).
- Our office was included in [media stories](#) on various topics, including our [2022 annual report](#), the [work of our office](#), the [unmet needs for disability services](#), and the "marriage penalty" imbedded in some Federal and State programs,
- And again, we had more than 1,100 meetings and phone calls with individuals and families, often participating alongside them in numerous meetings with other stakeholders –
 - Individualized Education Program (IEP) meetings
 - Child Family Team (CFT) meetings
 - Treatment Team meetings
 - Interdisciplinary Team (IDT) meetings
 - Human Rights Committee meetings
 - Eligibility Appeal Conferences
 - 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:

- We on boarded the fourth member of our team, Suhani Purohit, as our Office's Intake Coordinator, who brought with her a valuable mix of energy, perspective, and commitment.
- We implemented and operationalized our customized database, which will soon allow us to share meaningful data with colleagues and the general public. Indeed, during this first year of operations, we devoted time and resources to refine our intake process, to further build a taxonomy of concerns brought to our attention by individuals and families, and to refine our service definitions. Unfortunately, limited staffing and budget constraints, combined with an increase in requests for our assistance, resulted in less progress on this front.
- We launched social media presences on [Facebook](#) and [LinkedIn](#).
- We continued to buildout [our office's website](#) into a more of a one-stop resource for individuals and families.
- We moved to a new office location to accommodate our team's growth in size and workload.

OBSERVATIONS / RECOMMENDATIONS

- Urgent Issues, Urgent Responses -

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

On the one hand, our system of care for people with disabilities is strong, vibrant, and well-resourced. Lots of good people - in and out of government - doing lots of good, important work for the many thousands of New Jerseyans with disabilities. Educators. Providers. Advocates. Direct care professionals. Government officials at all levels and of all political affiliations.

This is a very important point that I fear sometimes gets lost in the conversation. Indeed, New Jersey's system of care benefits from the hard work, passion, and unwavering commitment of many, many people who have dedicated their professional lives to serving others. And it also benefits from the availability of significant resources – funding, supports, services and programs – that make it possible for people with disabilities to live safe, fulfilling lives.

However, this is not the case for everyone. Many people are not safe. Many people are not able to live their full lives. For them, the system is too complex, too rigid, and too inaccessible. For them, the system is not person-centered. In fact, for many of them, the system is broken.

This is also a very important point that I fear sometimes gets lost in the conversation.

To help remedy this, we are once again using our government letterhead to tell the story. This year, we have chosen 6 issues to discuss in this section – issues most often brought to our attention last year and that demand immediate action.

Abuse & Neglect

Throughout New Jersey, we have about 9,500 individuals with intellectual or developmental disabilities – children as well as adults – living in State-licensed, community-based residences. Many are having a good, safe, fulfilling experience. Many, however, are not. In fact, for many individuals and families who contact us, their living situation is absolutely terrible.

In each of our annual reports, we have spoken about the abuse and neglect brought to our attention. Again, I cannot estimate the overall prevalence, but I can tell you that individuals and families approach us daily with heartbreaking stories and horrifying pictures. Physical abuse. Emotional abuse. Sexual abuse. Improper medicine administration. Improper food practices. Questionable visitation policies. Questionable house practices. Unexplained injuries. Unexplained deaths.

Through our reports and through our regular conversations with colleagues throughout the system, we have offered suggestions for mitigating, if not eliminating, the abuse and neglect.

Staffing: We all know the importance of a well-trained, professional direct care workforce – that with the right staff and the right number of staff, individuals in State-licensed residences can and do live good, full lives without abuse and neglect. And we also know the opposite is true. We know that without the appropriate number of trained direct care staff, abuse and neglect happens.

"I was just informed that (my son) is being taken to the ER due to ... double dosing of medication.

This is the second hospitalization due to (group home) staff. I am in fear for the safety of my son's health. I need him placed where he (will) get the proper care."

Parent of 19 Year Old Son,
Living in a State-Licensed Group Home
February 2023

Indeed, direct care staff play an absolutely critical role in the lives of many people with disabilities whether they live in a State-licensed setting or in a private home. Direct Support Professionals. Self-Directed Employees. Private Duty Nurses. Whatever the title, these are the folks who are on the frontlines everyday helping to ensure people with disabilities live safe, fulfilling lives.

Anyone with lived disability experience or with on-the-ground professional experience knows this indisputable fact. Yet, the State continues to allow many direct care staff to be paid low wages, to receive minimal training, and to work with minimal supports – a questionable approach that seems to lead inevitably to high job turnover rates, high job vacancy rates, and continued abuse and neglect.

We have discussed this serious, persistent challenge in every annual report, and while there have been important steps taken to increase some salaries and to revisit some training requirements, much more needs to be done.

In fact, many within the disability community believe that the workforce crisis has never been worse – that the shortage of qualified, trained direct care staff is putting unprecedented strains on our system of care. However, too few are willing to acknowledge that it is largely a crisis of our own making – one that could be mitigated, if not eliminated, with some very reasonable changes in policy.

After all, some provider agencies already receive a lot of taxpayer money, but choose not to spend it on direct care staff salaries or training. As discussed in the “Systemic Recommendations” section below, some choose to spend their money on executive salaries or to save it in their reserves, and the State allows them to do so.

Moreover, with respect to State-licensed residences, some agencies have an “organizational culture” that results in substandard work environments – a culture that prioritizes earnings at the expense of safe, supportive, clean residential settings. Clearly, this is no way to treat direct care staff, not to mention the residents they serve.

Going forward, we need to take steps to ensure a solid, professional workforce. That means living wages. That means meaningful, ongoing training. That means higher standards enforced by the NJ Department of Children and Families and the NJ Department of Human Services. And that means making clear to all provider agencies that our system of care has no room for organizations with the wrong organizational cultures.

Among the recommendations offered in last year’s report –

- We should consider a requirement that all provider agencies for people with 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](#) and aligned with a recent [final rule](#) by the federal Centers for Medicare and Medicaid Services (CMS).
- 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 a requirement that agencies that provide supports in State-licensed residences for adults with disabilities maintain minimum direct care staff-to-resident ratios – similar to the approach taken for children and similar to the requirement for New Jersey [nursing home providers](#) – to ensure appropriate staffing levels in State-licensed residences.
- We should consider a requirement that State-licensed residences use [Electronic Visit Verification](#) (EVV) or some type of monitoring system to ensure adequate staffing levels and appropriate use of publicly-funded budgets – similar to the requirement for families and agencies that provide in-home supports in private/family homes.
- We should consider adopting strict rules regarding staff administration of medication in State-licensed residences for people (children as well as adults) with intellectual or developmental disabilities – similar to the strict rules that apply to nursing homes, assisted living homes, private/family homes, schools, State-run prisons, and the five State-run Developmental Centers. At the very least, we should strengthen oversight, perhaps with some type of Nurse supervision / delegation, such as exists in [New York](#).

“You don’t have any family. If your family loved you, they wouldn’t have put you in this house. They would’ve taken care of you.”
(from audio recording)

State-Licensed Group Home Staff Member,
Speaking to a 22-Year-Old Resident
October 2023

“Upon entering the home, she saw (my son) eating raw, frozen meat. Staff were with (him) and never attempted to take it from him or tell him no. They just let him eat the frozen, uncooked meat. (He) was in a good mood, yet staff seemed clearly afraid of him and never attempted to redirect him.

She also says that they allow (him) to engage in unsafe behaviors with kitchen appliances.

Staff are not even trying at this point.”

Parent of 22 Year Old Son,
Living in a State-Licensed Group Home
March 2024

Simply stated, without urgently needed reform – without higher salaries, higher standards, more training, and better work conditions – the abuse and neglect will continue.

Investigations: We all know the importance of investigations – that when we examine allegations of abuse and neglect in a thorough, credible way, we strengthen our system of care for people with disabilities. We help ensure accountability. We help ensure the abuse and neglect does not happen again.

However, we also know that the opposite is true - that when we do not conduct thorough, credible investigations, we are setting the system up for failure and endangering the lives of the people at the center of it.

Here, in New Jersey, allegations of abuse and neglect in State-licensed residences are sometimes investigated by either the NJ Department of Children and Families or the NJ Department of Human Services. More often than not, however, the provider agencies that run these residences investigate themselves, and their reports are reviewed by the respective Departments.

This is a problem. Not only is this a questionable practice, but the agency investigative reports – unlike those undertaken by the Department – are **not** readily available to the individuals or families involved. Although the Department of Human Services has taken steps to improve the communication of the results of agency-led investigations, individuals/families are usually required to obtain a court order to see the actual redacted reports.

“I am (young woman’s) mother and legal guardian. (She) has been interviewed twice and neither time was I notified nor asked I wish to be in attendance.”

Parent of 20 Year Old Daughter,
Living in a State-Licensed Group Home
April 2023

On top of all of this, there is a concern about quality control. Here, we have concerns about both the process and the substance of investigations. Many of the investigative reports we have been able to review are inconsistent, incomplete and somewhat incoherent. Often, we have been told that individuals/family members themselves have not been interviewed during investigations involving them, and often, we have been told that they have not even been notified that an investigation was being conducted, which is inconsistent with [The Stephen Komminos Law](#). And sometimes the results of investigations are communicated in emails or letters without letterhead – communications that are often vague, grammar-challenged, and much too informal.

Last year, we also learned that the NJ Department of Human Services does not investigate all deaths that occur in State-licensed residences for people with intellectual or developmental disabilities. Department staff report the deaths. They do cursory “mortality reviews.” But they do not necessarily investigate. Indeed, the Department does not automatically investigate even the unexpected deaths of individuals, who were healthy prior to passing.

We learned this disturbing and seemingly inexplicable policy when working with the family of a 39-year-old man who died unexpectedly in a State-licensed group home. It took the Department over a year to agree to conduct an investigation, despite repeated requests from the family and despite the fact that the young man’s cell phone displayed multiple attempts to call 911 the evening of/before his death. (Incidentally, since August 2023, I have been asking the Department for the number of unexpected deaths in State-licensed group homes and its reason for not automatically investigating them. I have not yet received an answer.)

We stand by our recommendations from last year’s annual report, including the following:

- 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.
- We should ensure that every death of an individual living in a State-licensed residence is investigated and that the results – in full – are shared with the family in a timely manner.
- 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 reconsider use of the word “unsubstantiated” in investigative reports, particularly when using a word such as “inconclusive” would be more accurate, and the reports should, at a minimum, acknowledge the injury (physical or emotional), even if they cannot ascribe specific blame or cause.

- Regardless of other steps taken, we should conduct a 5-10-year review of State-licensed residences for children as well as adults that examines the (1) number of investigations undertaken, (2) number of allegations “substantiated,” and (3) responses of the provider agencies found culpable.

Moreover, we should consider establishing an organization similar to New York’s [Justice Center for the Protection of People with Special Needs](#) – a 10 year old, 500 employee organization that “investigates, reviews, and makes findings in allegations of abuse and neglect by staff against individuals receiving services.” The Center also “reviews all deaths that occur in settings under Justice Center jurisdiction and investigates those involving allegations of abuse and neglect.”

Simply stated, without urgently needed reform – without making the investigation process more thorough, more credible, and more consequential - the abuse and neglect will continue.

“Unsubstantiated neglect?! That is your finding after a yearlong investigation?!”

My child was starved, locked in her room, locked in the basement, drugged, denied medication, lost all her hair and teeth, has been thrown into a psych ward where she was restrained unable to communicate that she was in excruciating pain from dental decay and an infected vulvar abscess, developed Rhabdomyolysis, ended up in a coma on a ventilator, has been made homeless illegally and without cause, had her MARS records falsified, body bruised ... and this is the best conclusion DHS can produce after wasting a year to “investigate”?

Parent of 19 Year Old Daughter,
Who Had Lived in a State-Licensed Group Home
February 2023

Agency Accountability: Last year, we learned that neither the NJ Department of Human Services nor the NJ Department of Children and Families ever imposes financial penalties on agencies providing residential supports, even when they violate policies related to abuse and neglect. Indeed, the only financial penalties imposed are for violations of “Danielle’s Law,” which requires direct care staff to call 911 in potentially life-threatening situations. Significantly, however, those penalties are only levied against direct care staff, not the agencies.

Unlike the NJ Department of Health, which maintains and publicizes a detailed [schedule of financial penalties](#) as well as corresponding [enforcement letters](#) and unlike most every other industry or sector, the two State government departments responsible for the safety and well-being of individuals with intellectual or developmental disabilities do not impose any financial penalties on provider agencies that violate policies. Short of a temporary halt on admissions or the loss of an agency’s license, which rarely happens, there are no financial consequences for bad behavior.

As one senior official recently noted with respect to a provider agency seemingly trying to circumvent a State policy, “Unfortunately, I don’t have any real sticks” to ensure their compliance.

This must change.

Without financial penalties or any such meaningful consequences, bad actors will continue to act badly. That is true in any industry. That is especially true if a bad actor stands to benefit financially through non-compliance – for example, by understaffing a group home. We therefore need to adopt a zero-tolerance policy that holds agencies directly accountable for abuse and neglect through meaningful financial penalties. At the very least, doing so would help compel a change in an organizational culture that exists in some agencies – a culture that has allowed deplorable behavior to be perpetuated against people with disabilities.

To be sure, it has been suggested that financial penalties would “hurt” some of the provider agencies that run the group homes and supervised apartments, potentially putting them out of business. For that reason, they argue, we should maintain the status quo.

But that makes no sense. We impose financial penalties on nursing homes. We impose financial penalties on hospitals. And we should be willing – when necessary - to impose financial penalties on the provider agencies that operate State-licensed residences, many of whom receive millions of New Jersey taxpayer dollars.

Regardless, punishing bad behavior is not just the right thing to do; it is also the smart thing to do. Done correctly, it would probably save money, and more importantly, it would probably save lives. And I am confident that the good agencies providing residential supports – those who strive to do the right thing – would welcome a systemic change that roots out the bad actors.

Simply stated, without urgently needed reform – without the possibility of consequential financial penalties – we are setting the system up for failure, and the abuse and neglect will continue.

“These investigations are extremely important since this (provider agency) really needs an incentive to get their act together.”

Parent of a Young Man,
Living in a State-Licensed Group Home
February 2023

Abuse and Neglect in Perspective

- * Note that this is a police report about a young man who eloped from a State-licensed group home.
- * Note that the young man typically required 1:1 staffing, but reportedly, no one noticed that he left the premises.
 - * Note the Police Officer's comments about the group home's logs.
 - * Note the Police Officer's comments about the young man's window.

Incident Details

Agency: [REDACTED] Police Department
Print Date/Time: [REDACTED] 2023 09:24
Agency #: [REDACTED]

On [REDACTED] 23 at approximately 1218 hrs, I was dispatched to the area of [REDACTED] for a report of a nude male running in the area. Upon my arrival, I observed a nude male who I recognized from prior encounters as, [REDACTED] crouching in the bushes in the area of [REDACTED]. I am aware from past encounters that [REDACTED] is a non verbal autistic who is wary of emergency responders and may become agitated by their presence. As I exited my vehicle [REDACTED] attempted to run away from my vehicle and into the roadway. I was able to push [REDACTED] against my vehicle and with the arrival of [REDACTED] as backup we were able to handcuff [REDACTED] (adjusted and double locked) and secure him in the rear of patrol vehicle 1703 for his safety. We then transported [REDACTED] back to his residence of [REDACTED]. It should be noted that [REDACTED] is a group home operated by the [REDACTED].

Upon arrival, I made contact with the staff on location, [REDACTED] both advised that they were unaware that [REDACTED] had left the location and advised that he typically needs 1 to 1 supervision. They advised that they had believed he was napping and stated that under such circumstances they were allowed to check on him every 15 minutes. I then requested to see any logs that they might have of such checks but initially they were unable to produce such logs. [REDACTED] eventually produced what he said was the log for this date, however I observed that the date was for the previous day and the log was incomplete. I then attempted to ascertain how [REDACTED] had exited the property. While walking the exterior I observed on the side of the building what appeared to be human feces smeared on the siding of the residence under an exterior window. [REDACTED] was advised of the same and immediately attempted to be cleaning it. I observed that the window where [REDACTED] resided was damaged and appeared to have been repaired with plastic sheeting. I observed a large screw in the bottom portion of the window which I believe would have prevented [REDACTED] from exiting the window without injuring himself.

[REDACTED] was checked by [REDACTED] EMS and turned over to the custody of the [REDACTED] Staff. After clearing I contacted DDD and advised [REDACTED] of the incident.

On the same date at 1325 hrs, I responded back to [REDACTED] due to [REDACTED] mother calling and requesting he be taken to the hospital for evaluation due to the above incident. I responded with [REDACTED] EMS. I was then able to assist them with preparing [REDACTED] for transport. During this transport due to his agitated state he was secured with cravats. I then rode with BLS and assisted in turning him over to hospital staff. Nothing further to report.

[REDACTED]

Question: Was this dangerous situation due to understaffing or undertraining ... or both?

Staffing in Perspective

* Note this is a job advertisement by an agency that provides residential and in-home supports.

* Note the high end of the salary range for the Direct Support Professional, \$40,600 per year (\$19.50 per hour).

* Note the ad ran on at least two job hiring sites, SimplyHired and Indeed.

SimplyHired.

Direct Support Professional (DSP) - NJ, NJ

New Jersey - 2.7 ★

New Jersey - 2.7 ★

Quick Apply

Job Details

Part-time | Full-time

Estimated: \$32.1K - \$40.6K a year

Benefits

Health insurance Dental insurance Paid time off Vision insurance

Qualifications

CPR Certification High school diploma or GED Driver's License
First Aid Certification Organizational skills Home health 1 year
Communication skills

Full Job Description

URGENTLY Hiring FT & PT DSPs- NJ, NJ

About

NJ is a premier provider in the Social Services industry and a great place to work! provides services, resources and support for adults with intellectual, developmental and physical disabilities in Central New Jersey. Founded in 19 as a leading nationwide provider of specialized adult foster care, intermittent services crisis respite services, and assisted senior living services. has been recognized as a leader in its field for the past 59 years, offering proven experience and a commitment to excellence that extends across all of our services.

General Statement of Duties

The Direct Support Professional are at all times responsible for ensuring the safety and health of consumers through supervision of consumers and provision of quality personal care and home management that increases the individual's independence and participation in the community.

Responsibilities will include, but are not limited to:

Supervision and guidance during skill building activities.
Assist with daily living activities, such as preparing meals and personal hygiene.
Provide transportation to medical appointments, and other scheduled outings in the community.
Ensure the safety of consumers at all times.
Log and update resident case notes on a daily basis.

Qualifications:

Must be 21 years of age or older
Must have high school diploma or GED.
A valid driver's license
Excellent communication and organizational skills.
Compassionate about the care and well-being of others.
Must be willing to submit to background check, drug test, and pre-employment physical

Preferred:

At least one year of related experience, such as; direct care, home health, respite care, and caregiving.
CPR/First Aid certifications

Job Types: Part-time, Full-time

Benefits:

Dental insurance
Health insurance
Paid time off
Vision insurance

Schedule:

10 hour shift
8 hour shift
Day shift
Evening shift
Overnight shift
Overtime
Weekends as needed

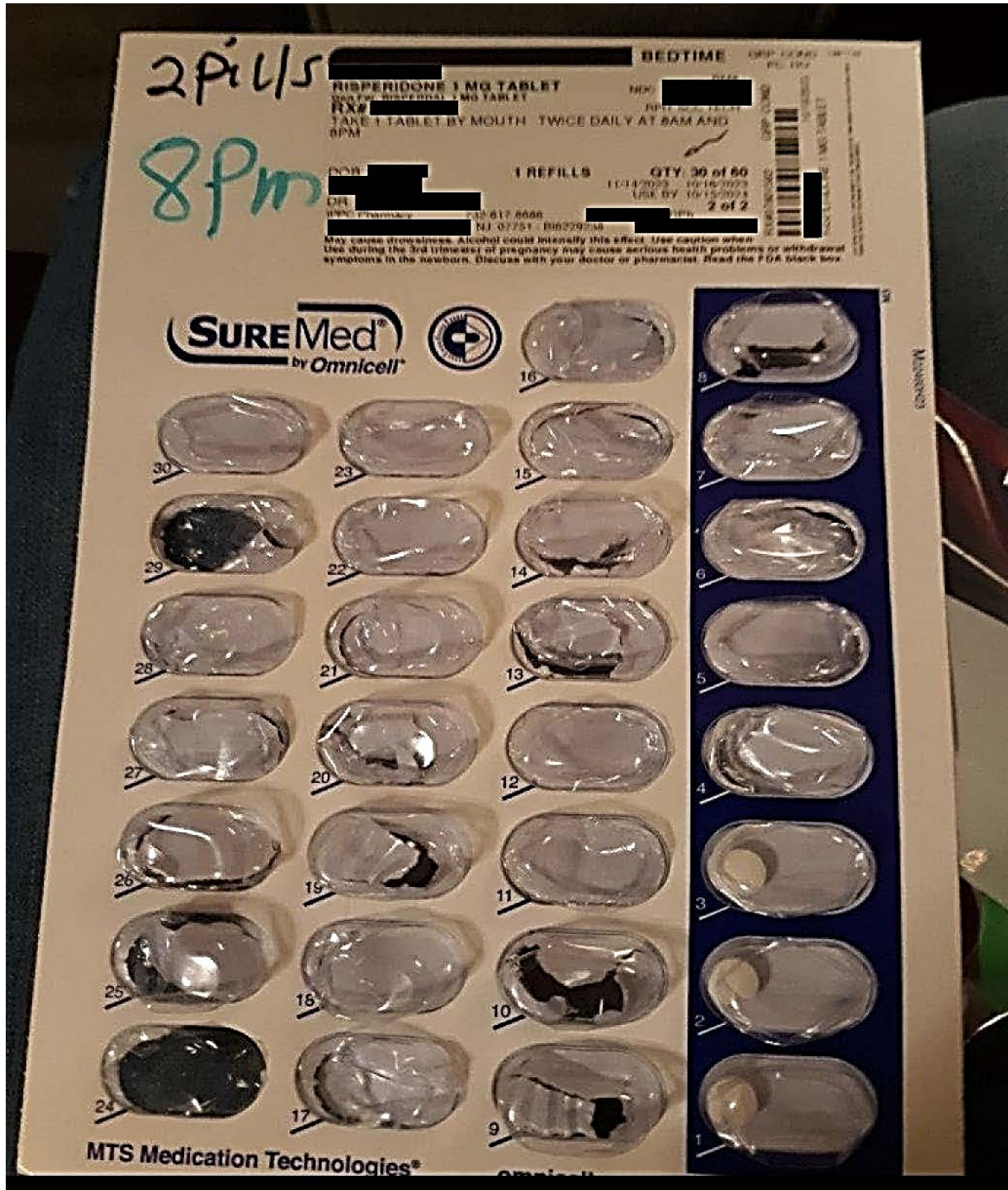
People with a criminal record are encouraged to apply

Work location: In person

Question: Is the highlighted text appropriate?

Medication Administration in Perspective

- * Note this is a medication prescribed for a young adult living in a State-licensed group home.
- * Note that group home management reportedly “changed” the dosage and time at which the medicine is to be administered, using a magic marker to effectively override the prescribing instructions.



Question: Would this have happened or been necessary if a nurse was involved?

Self-Investigation in Perspective

- * Note these 4 different letters for 4 different allegations of abuse on 4 different occasions are from the same agency.
- * Note the letters seem to be “cut and paste” form letters, although one is grammatically incorrect.
- * Note each allegation was “unsubstantiated,” yet staff have been “retrained and/or disciplined.”
- * Note the lack of detail about the incidents, including the dates that the letters were sent.
- * Note that they all arrived on the same day (June 7, 2023) in 4 separate envelopes.

[Redacted]

President/CEO
Executive Director

Re: Investigation Findings 22-325 [Redacted] 11/21/22

Dear [Redacted]

The investigation into the allegations of neglect [Redacted] unsubstantiated and has been closed by the Critical Incident Management Unit. The staff involved have been retrained and/or disciplined.

Please contact, [Redacted] if you need further information.

Sincerely,
[Redacted]
Incident Management Coordinator

[Redacted]

President/CEO
Executive Director

Re: Investigation Findings 1/6/23 23-006 [Redacted]

Dear [Redacted]

The investigation into the allegations of Neglect has been unsubstantiated and has been closed by the Critical Incident Management Unit. The staff involved have been retrained and/or disciplined.

Please contact, [Redacted] if you need further information.

Sincerely,
[Redacted]
Incident Management Coordinator

[Redacted]

President/CEO
Executive Director

Re: Investigation Findings 1/24/23 23-018 [Redacted]

Dear [Redacted]

The investigation into the allegations of Neglect has been unsubstantiated and has been closed by the Critical Incident Management Unit. The staff involved have been retrained and/or disciplined.

Please contact, [Redacted] if you need further information.

Sincerely,
[Redacted]
Incident Management Coordinator

[Redacted]

President/CEO
Executive Director

Re: Investigation Findings 2/21/23- 23-036 [Redacted]

Dear [Redacted]

The investigation into the allegations of neglect has been unsubstantiated and has been closed by the Critical Incident Management Unit. The staff involved have been retrained and/or disciplined.

Please contact, [Redacted] if you need further information.

Sincerely,
[Redacted]
Incident Management Coordinator

Question: Is there any reason to believe that this agency takes investigations seriously?

State Investigation of Abuse in Perspective

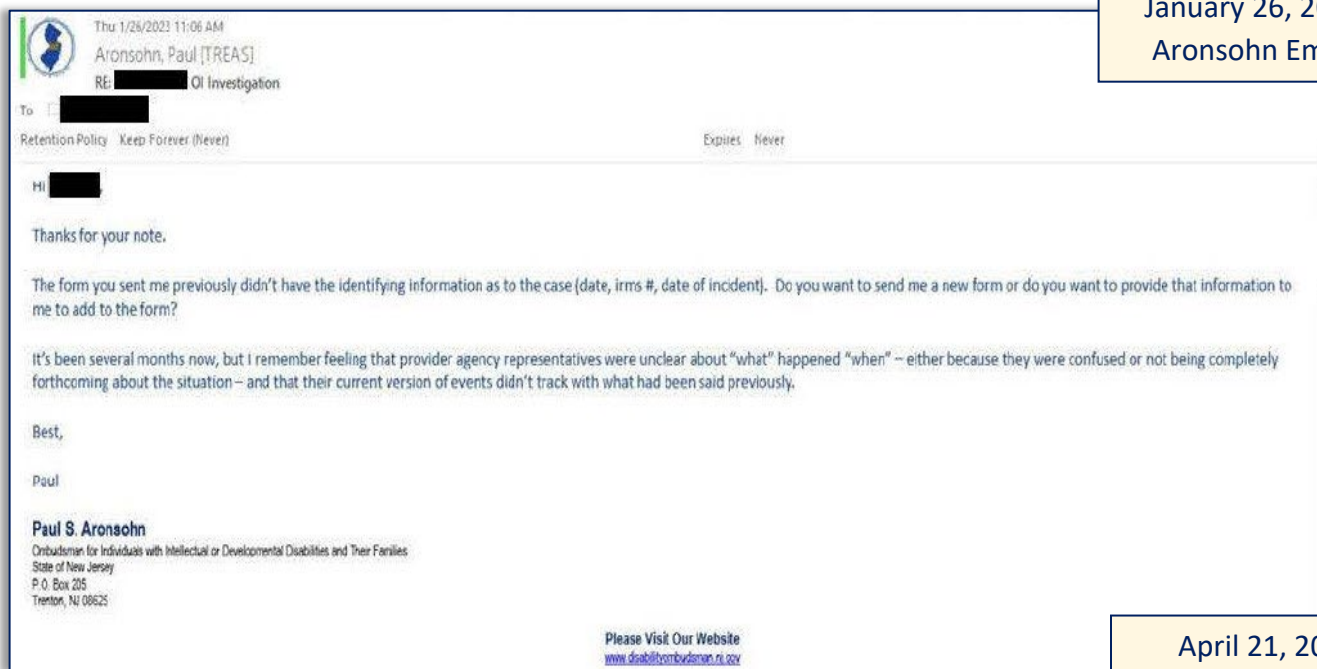
Our office was interviewed as part of an investigation into a situation involving alleged abuse and neglect of a young man living in a State-licensed group home. We were interviewed because we participated in a virtual meeting that was central to the case.

On January 26, 2023, following my comprehensive interview weeks earlier, I responded in email to a NJ Department of Human Services (DHS) investigator, “It’s been several months now, but I remember feeling that provider agency representatives were unclear about “what” happened “when” – either because they were confused or not being completely forthcoming about the situation – and that their current version of events didn’t track with what had been said previously.”

On April 21, 2023, the Department issued an investigative report that said, “Mr. Aronsohn stated that he does not recall the specifics of the information that was read out loud by a staff member....”

After I immediately raised concerns with the misrepresentation / omission of my remarks, it was acknowledged that there was a “powerful” discrepancy between what I wrote in my January email and what was included in their April report. It was also acknowledged that the Department investigators knew that the provider agency staff had been untruthful with them. I was also told that the Department would reissue the report, which had concluded that the allegations of abuse and neglect against the provider agency were “unsubstantiated.”

The Department, however, never reissued the report.



According to Mr. Aronsohn, on [REDACTED], an IDT meeting was held via Google meets to discuss the [REDACTED] in the group home. Mr. Aronsohn stated that while the meeting was in progress, [REDACTED] brought up [REDACTED]. Per Mr. Aronsohn, he recalled [REDACTED] refusing to answer questions [REDACTED] had regarding [REDACTED] injury. Mr. Aronsohn stated that he does not recall the specifics of the information that was read out loud by a staff member regarding [REDACTED] injury.

State Investigation of a Death in Perspective

*Note this matter concerned an investigation into the 2021 death of a 40-year-old resident of a State-licensed group home.

* Note the cold, informal, vague email response from the State official outlining the results of the investigation.

* Note the length of time referenced in the parent's original email.

From: [REDACTED]
Sent: Sunday, March 26, 2023 12:07 PM
To: [REDACTED] <[REDACTED]@dhs.nj.gov>
Cc: [REDACTED]
Subject: Re: [EXTERNAL] Re: [REDACTED] - New Incidents Created

Parent Email to
State Investigator

Hi [REDACTED], Can you update me on what is going this matter. It has now been over 2 years. We know it was referred to DDD. We would like to know the status of the investigation.

From: [REDACTED] <[REDACTED]@dhs.nj.gov>
Date: Wed, Mar 29, 2023, 2:49 PM
Subject: RE: [REDACTED] - New Incidents Created
To: [REDACTED]
Cc: [REDACTED]

State Investigator
Response to Parent

Good afternoon [REDACTED],
Both incidents you referenced in your email have been closed. Here is the information which I can share regarding each incident:

[REDACTED] Assigned to CIMU for review. NE211 (Neglect no injury) was found to be unsubstantiated. This means that that the agency did not have enough evidence to prove that the neglect occurred. Not that the neglect did not happen, just that there was not enough evidence to substantiate the allegation.

[REDACTED] (Theft/Loss/Damage to property) The agency determined that this event did not happen. This incident was closed on January 3, 2023.

[REDACTED] Assigned to DDD for review. MD102 (Unplanned hospitalization) It was determined that this event did occur. This incident was closed on November 4, 2022.

Thank you. [REDACTED]

[REDACTED]
New Jersey Department of Human Services
Office of Program Integrity and Accountability

From: [REDACTED]
Sent: Thursday, March 30, 2023 10:23 PM
To: [REDACTED] (DHS)
Cc: Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>; [REDACTED]
Subject: [EXTERNAL] Cased Closed?

Parent Response to
State Investigator

Hello [REDACTED]

Hearing that my son's case has been closed due to 'lack of evidence' through email is extremely disheartening. [REDACTED] was and still is an important person in my life. I am still grieving the loss of my youngest son, my baby. His life mattered! I at least would have appreciated to receive this news via a phone call.

I understand that the case is closed. However, I have tons of questions regarding how this decision was made. Questions such as what was the time frame of the investigation? What steps you took to perform this investigation? How come I was not notified throughout the investigation process? How was this decision made without me even being present for the results?

If you or someone could contact me via phone and/or email regarding this decision ASAP that would be greatly appreciated.

Thank you,
[REDACTED]

Question: Don't individuals and families deserve better?

Autism/Severe Challenging Behavior

New Jersey continues to have one of the highest prevalence rates of autism in the world.

Globally, the autism rate is **1 in 100 individuals**. Nationally, in the United States, the rate is **1 in 36**. Here in New Jersey, the rate is **1 in 35 individuals** – that includes 64,000 children and 156,000 adults, approximately 2.4% of our population.

Moreover, about 27% of those New Jerseyans with autism - 18,000 children and 44,000 adults -- are also estimated to have an intellectual disability, what is increasingly known as “**profound autism**.” This includes about 30,000 individuals, children as well as adults, with severe autism – a mix of intellectual disability and severe challenging behavior (aggression and self-injurious behavior). On average, that is approximately 53 New Jerseyans with severe autism per town/municipality.

From my first days in this position – back in 2018 – I have been working daily with families struggling to find their way through the dangerous challenges associated with severe challenging behavior. Children as well as adults physically harming themselves or others. Children as well as adults physically damaging their homes or schools. Children as well as adults being arrested or taken by the Police to hospital emergency rooms, where they stay for several hours or several weeks before being discharged on an unhealthy (and often, unhelpful) mix of psychotropic medications.

Any way you look at it, we have a crisis on our hands.

In 2023, to provide support for those with severe challenging behavior, two notable and important initiatives became operational: the NJ Department of Human Services’ behavioral health stabilization programs and the NJ Department of Children and Families’ Intensive Mobile Treatment Services (IMTS).

However, despite these and other good faith efforts, severe autism continues to be one of the most consequential challenges facing New Jersey families and communities.

“Autism is a lifelong fight. It is a diagnosis made more complicated by the lack of help and services available to parents....”

When your child is diagnosed with ASD or mental health issues, you are provided with only one resource – The Children’s System of Care (CSOC). There, you put all your faith that your child will receive services to become the best version of himself....”

Our families are left with little to no help from a system that has failed them historically.”

Parent of a 19 Year Old Son,
March 2024

For years, we have been urging a statewide, holistic approach to severe autism – one that addresses everything from early intervention to crisis response.

To that end, we stand by our recommendations from last year’s annual report:

- We should consider a policy of universal screening for autism spectrum disorder to ensure more and better early intervention, and it should include supporting/training pediatricians to gain competency in this area – 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 earlier identification and intervention for severe challenging behaviors.
- We should consider establishing a dedicated 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.

- We should ensure children in behavioral crisis get the supports they need when they need them, making appropriate, 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](#).
- We should encourage the development of more intentional residential communities – independent, yet fully supportive communities for people with the full range of behavioral needs.
- We should encourage municipal and county governments to adopt autism-friendly law enforcement practices to improve interactions and outcomes between Police Officers and individuals with autism and their family members – building on and replicating some of the important work already being led by law enforcement officials at the State, County, and Municipal levels.
- We should urge public officials – at every level of government – to become more educated about autism and severe challenging behavior, including through important short films, such as the [“A Voice for Severe Autism.”](#)

Simply stated, without urgently needed reform – without a more comprehensive, more resource-rich approach that begins with early intervention and treatment – severe autism will continue to imperil the lives of many New Jersey children, adults, families, and communities.

*“We’re here now. The bleakest of places. A special needs no-man’s land.
A place where the running timer finally stops, and life is suspended in a desolate gray expanse....*

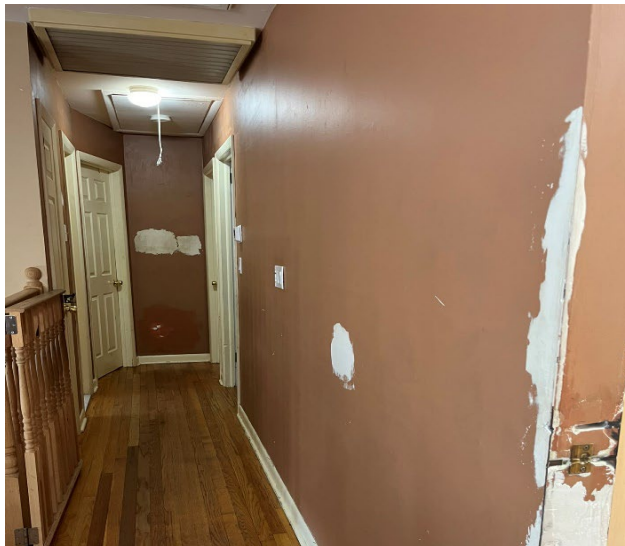
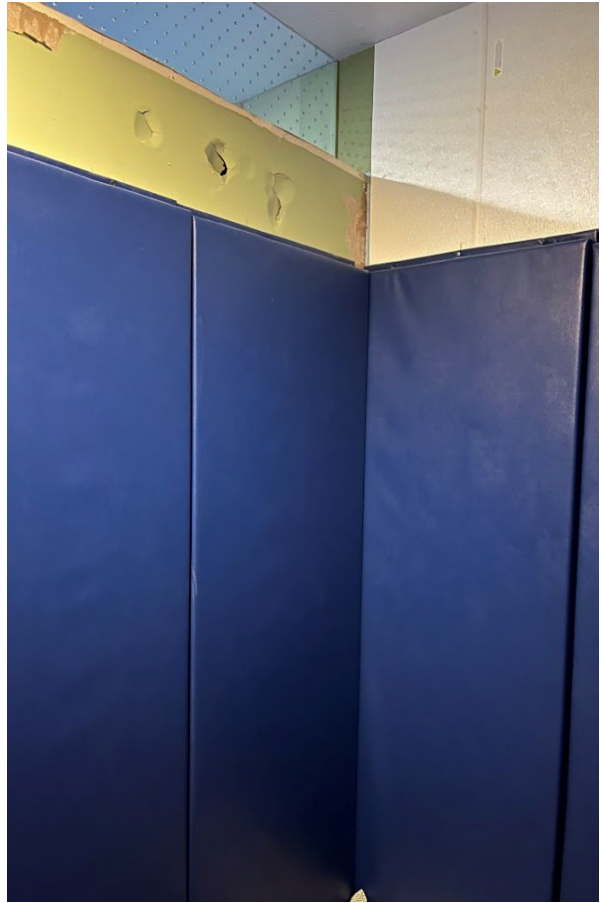
I didn’t know about this place until I realized we were living in it. This is not the special needs universe that the world had taught me about. The sweet mentally challenged boy from my neighborhood who played games with us growing up. Dustin Hoffman having a little tantrum because he can’t watch Judge Wapner at four o’clock. The genius autistic boy doctor on TV. The young man with special needs who collects carts at the local grocery store.

*This is the special needs world that’s hidden behind closed doors....
Where the rules of inclusion don’t apply because the child has little to no independence.
The child is too behavioral. Too dangerous.”*

Peg Kerswell, New Jersey Parent of a Young Woman with Severe Autism
From her 2023 Book, “Girl Storm”

Autism in Perspective

- *Note this a private family home of youths with severe autism.
- * Note the padded bedroom walls, the damage above the padding, and the damaged furniture.
- * Note the spackled holes (from head banging) on hallway and living room walls.
- * Note the lock on the stairway gate (left).



Question: Are we doing enough to support families like this?

Autism in Perspective

- * Note this is a correspondence from a Police Officer to a parent.
- * Note the Police calls were responding to a State-licensed group home for 4-5 youths.
- * Note the very high number of Police calls, averaging once per week.
- * Note that 18 of those Police calls were for one 16-year-old boy.

From: [REDACTED]
Sent: Tuesday, November 7, 2023 9:38 AM
To: [REDACTED] Aronsohn, Paul
[TREAS] <Paul.Aronsohn@treas.nj.gov>
Subject: [EXTERNAL] RE: [REDACTED] Stats

[REDACTED]

Good morning! Hope you guys are doing well! Since September 1, 2022 we have had 53 calls for service at the residence there. If I search specific to [REDACTED] it appears that 18 of those calls were for him.

If you need anything else, please let me know.

Thanks,

Lieutenant [REDACTED]

[REDACTED] Township Police

Patrol Division / Community Outreach / Deputy Emergency Manager Coordinator



Question: Are we doing enough to support children like this?

Complex Medical Needs

Many New Jerseyans with intellectual or developmental disabilities have complex medical needs. They require specialized supports. They require nursing. Often, however, the resources are not available in a community setting. Often, those with complex medical needs end up in hospitals and other institutional settings, including nursing homes.

This, however, is just wrong. Despite their smaller numbers and higher needs, individuals with complex medical conditions deserve to live safe, fulfilling lives in the community just as much as anyone else. Period. End stop.

In previous annual reports, we have spoken about this gap in our system of care. Indeed, in last year's report, we made the following recommendations:

- We should ensure Private Duty Nurses (PDN) are more readily available by paying them a more reasonable salary. The current average Medicaid rate of about \$30 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 the State paid provider agencies \$61 per hour for Registered Nurses and \$49 per hour for Licensed Practical Nurses, there is currently no requirement regarding the amount agencies must pay the actual Nurses.]

"I am very fearful of bringing my son home with inadequate nursing coverage with his new baseline of being vent dependent 24/7. This is a safety concern. As well as a real concern for my own well-being giving my age and my own recent health issues.

*The hospital is also exploring LTC (long term care) options, but the options I have been presented with are not adequate for the care my son requires. He needs a setting where there is medical staff 24/7 and low patient/staffing ratios." ****

Parent of a 21 Year Old Son,
June 2023

- 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.
- We should ensure network adequacy by our five Medicaid managed care organizations (MCO) by –
 - ensuring our Medicaid reimbursement 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 the NJ Department of Human Services' Community Care Program, like those enrolled in the Supports Program, have access to Private Duty Nurses – something not currently allowed.
- 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.

*** The young man referenced, Timothy Struble, passed from this earth on April 11, 2024.

From his obituary: “Tim was a real-life superhero, tirelessly fighting challenging medical issues throughout his life. He was a fighter and warrior to the very end. Timothy never spoke a word, but taught patience, compassion, and unconditional love just by his presence. He tendered the hearts of those around him. He was peace and love in the perfect package. His final heroic act was the gift of life.

Timothy donated his organs so that others may live on through his selflessness.”

I am adding five new recommendations to this list:

- In addition to increasing the salaries paid to Private Duty Nurses, we also should revisit State policies with respect to their availability. Currently, a youth can have 24/7 nursing support. An adult age 21 or over, however, can only have **16 hours per day** through either the [Medicaid Managed Long Term Services and Supports](#) program or the NJ Division of Developmental Disabilities' (DDD) Supports + PDN program.
Note: For New Jersey adults with intellectual or developmental disabilities, 24/7 nursing is only available in State-licensed residences, such as group homes and nursing homes.
- As discussed in the "Housing" section below, we should revisit our policies with respect to vouchers, environmental modifications, and vehicle purchases – making it easier and possible for more families to care for their loved ones at home.
- As discussed in the "Systemic Recommendations" section below, we should take a hard look at the policies and processes related to the way MCOs make decisions, to the appeals process, and to the State's oversight of these organizations.
- Relatedly, we should pursue changes in policy and practice to make medically-necessary equipment, such as hospital beds and wheelchairs, more readily available, particularly in time-sensitive situations. No one should have to spend an extra day (much less extra weeks or months) in a hospital, because an MCO denies a request for needed equipment; nor should anyone have to beg, plead, and go through an infuriating, time-consuming appeals process to overturn an MCO denial. The NJ Department of Human Services, which is home to both the State's Medicaid division and the State's Division of Developmental Disabilities, should be able to figure this out.
- We should make more adult services and programs available virtually, giving those with compromised health conditions or significant physical limitations more opportunities for community engagement.

Simply stated, without urgently needed reform – without fundamental changes in the way we support individuals with complex medical needs – the institutionalization of New Jerseyans with intellectual or developmental disabilities will continue.

"I was born with the neuromuscular disease Spinal Muscular Atrophy (SMA) and I unfortunately have the most severe type and have been 100% ventilator dependent since I was 6 months old. This means I cannot take a single breath on my own and furthermore I cannot move any muscles in my body. I require 24 hour supervision for all my needs and to make sure my airway and respiratory health stay intact.

At the age of 15, my father, the sole income of our family, died from cancer and because of this I began to receive Social Security Survivor Benefits. My 24 hour nursing dropped to 11 hours and after a year, went up to 16 hours per day.

My mother is responsible for all my care the remaining 8 hours a day 7 days a week...."

Young Woman Living in Family Home
October 2023

Denial of MCO Services in Perspective

- * Note this is a managed care organization (MCO) denial of an appeal to a prior denial.
- * Note the strong language in the letters from the primary Physician and Nurse challenging the MCO's original denial.
- * Note the MCO's May 8 letter does not reference either the Physician or Nurse recommendations.

May 8, 2023

MCO Denial Letter

PARENT OR GUARDIAN OF [REDACTED]

Member Name: [REDACTED]
Member ID Number: [REDACTED]
Date(s) of Service: PRE-SERVICE
Procedure/Service: Physical Therapy
Reference Number: [REDACTED]
Product: [REDACTED]
Requesting Provider: [REDACTED]

Dear Parent or Guardian of [REDACTED]

Action:

This is to advise you that, after reviewing your Internal Appeal, we are keeping Physical Therapy with the following action checked below:

Limiting the number of hours/days authorized for your Physical Therapy hours/days effective May 4, 2023,

Reducing the Physical Therapy service you are receiving from N/A to [REDACTED] hours/days effective May 4, 2023,

Terminating (Ending) the Physical Therapy service you are receiving 2023,

Denying your request for Physical Therapy services effective [REDACTED]

Reason for our action:

The reason for our action is: Your appeal for physical therapy for you was reviewed by a medical director. He is a medical doctor. He is board certified in Rehabilitation. We looked at your records. You are [REDACTED] years old. You have weakness. You have problems with coordination. This is due to cerebral palsy. We have decided that what you asked for cannot be approved. Based on my professional judgment, we are upholding the denial as not medically necessary. This does not meet health plan rules. You have been approved for 3 therapy visits through May 4, 2023. The notes do not show that more visits are medically needed at this time. We do not have notes that show what specific progress you are making. The notes do not show why more therapy is needed at this time. You should be trained in a home exercise program. That is why we cannot approve what you asked for. The denial is upheld. Please talk about this with your doctor. (Health plan rules used: 1. [REDACTED] Plan Medical Policy Outpatient Physical and Occupational Therapy (for New Jersey Only), Policy Number: [REDACTED] Effective 06/01/2022 2. InterQual 2023, MAR 2023 Release, LOC: Outpatient Rehabilitation & Chiropractic, Criteria Subset: Rehabilitation) Medical Director Signature: [REDACTED]

You or your provider may get copies of the documents and records relevant to this decision free of charge. Call [REDACTED] Plan at 1-800-941- [REDACTED] Friday, 8:00 a.m.

APPEAL RIGHTS

May 4, 2023

Primary Physician Letter

Patient: [REDACTED]
Date of Birth: [REDACTED]
Date of Visit: 5/4/2023

To Whom It May Concern:

I am writing to appeal the denial of ongoing physical therapy (PT) and occupational therapy (OT) services for my patient who has spastic quadriplegia. As his primary physician, I strongly believe that these services are medically necessary for my patient's ongoing care and treatment.

Spastic quadriplegia is a severe form of cerebral palsy that affects all four limbs and often results in muscle stiffness and spasms. My patient has been receiving PT and OT services to manage his symptoms and improve his quality of life. However, I have been informed that coverage for these services will be discontinued.

Without access to these essential therapies, my patient's condition will likely worsen, leading to a decline in mobility and independence. The PT and OT services help my patient maintain his range of motion, improve his coordination and balance, and prevent the development of contractures and deformities. These therapies also help manage pain and reduce the risk of secondary complications such as pressure sores.

Furthermore, my patient has shown significant progress and improvement in their physical abilities with regular therapy sessions. Discontinuing these services would undermine their progress and hinder their ability to achieve their full potential. Regression is inevitable.

I strongly urge you to reconsider your decision and provide my patient with the necessary PT and OT services to manage their condition effectively. I appreciate your attention to this matter and look forward to your prompt response.

Nursing Letter

Patient Name: [REDACTED]
DOB: [REDACTED]

To Whom It May Concern,

This letter is to request for ongoing authorization for home based physical and occupational therapy services for [REDACTED]

Patient is on service with [REDACTED] due to congenital spastic quadriplegia. Patient is homebound and qualifies for medically necessary skilled physical and occupational therapy to manage the fluctuating tone impacting safety and performance of transfers, mobility, activities of daily living, and self-care. The inherent complexity of the manual skills provided by the physical and occupational therapists are exemplified by the specialized verbal and tactile cues, specific muscle facilitation, and knowledge of the patient's anatomy to prevent injury while administering the skills. Loss of these services increases the patient's risk for loss of function and participation in family or social events, risk for skin breakdown, risk for functional deterioration increasing caregiver burden, and risk for readmission due to loss in mobility or aerobic capabilities. Physical and occupational therapy also perform medication review, pain management strategies, and medical screenings upon each visit for early detection and communication with physician. Skilled interventions provided by physical and occupational therapy have enabled caregivers to successfully manage patient in private home as compared to more costly communal group home setting away from his family.

As noted above, the patient continues to be a good candidate for home based physical and occupational therapy services to prevent decline, injury, or readmission. Patient benefits from 3 times per week from each discipline and reduction or cancellation of skilled services would be detrimental to the health and overall wellness of this patient.

Thank you for your consideration.

Question: Who should determine "medical necessity" – a person's physician or an MCO's physician?

Question: Do we need more oversight of managed care organizations?

Housing

Not surprising, the urgent need for housing continues to be a common theme in the conversations we have with individuals and families. In fact, for many people with disabilities, a housing crisis is a very real, very persistent part of their lives. Generally speaking, it is a crisis about availability, affordability, and livability - the need for housing that meets the requirements and preferences of a diverse disability community.

The concerns expressed vary.

- For children with complex medical or behavioral needs, the challenge is often availability: There are not enough safe, appropriate community-based residential options for these youth. Many are unable to obtain proper supports at home; yet, there are only a very limited number of “beds” available in State-licensed residences.
- For adults with disabilities, the challenge is often affordability: There are not enough housing options for them in the communities in which they want to live. This is due to high rents, low incomes, and vouchers that are often not aligned with economic reality.
- And for many individuals and families, the challenge is not just quantity, but also quality – finding a place that is livable and appropriate. This is particularly true with respect to State-licensed group homes (for children as well as adults) that are often in disrepair or are unsafe for a variety of reasons.

Granted, here in New Jersey, there are significant resources available that make it possible for many people with disabilities to live well in the community, but clearly, we need to do more. We need to make housing information more accessible. We need to make housing policies more flexible. And we need to be more proactive, more innovative, and more sensitive to the diversity of needs and preferences. After all, when it comes to housing, one size definitely does not fit all.

In addition to the recommendations previously discussed - with respect to intentional communities and medical group homes – here are a few suggestions to help mitigate, if not eliminate, the housing crisis that so many people experience:

Housing Web Portal: Since access to information is key, the State should develop an online, user-friendly disability-focused housing website that would make it easier for individuals and families to make informed choices about State-licensed residences as well as the opportunity to live in the community in a private, family, or other setting.

- **Youth:** This could include a youth portal about residential treatment options available through the NJ Department of Children and Families – a portal that provides background information about the agencies involved, the regions in which they operate, the types of housing available, and the services and supports (including behavior analysts, nurses, and video monitoring technology) associated with their individual residential offerings.
- **Adults:** This could include an adult portal about residential options available through the NJ Department of Human Services – a portal that provides background information about the agencies involved, the regions in which they operate, the types of housing available, and the services and supports (including behavior analysts, nurses, and video monitoring technology) associated with their individual residential offerings.
- **Accessible / Affordable Options:** This could include background and contact information about agencies and organizations that offer a range of accessible and affordable options available to people with disabilities throughout the State.
- **Advocacy Organizations:** This could include background and contact information for housing and legal advocacy groups available to people with disabilities and their families.
- **Government Programs:** This could include information about the range of programs – from housing vouchers to housing loans to utility assistance – that exist and how best to access them.
- **Information Exchange:** This could include a platform for individuals and families to share useful information based on their personal experiences.

Housing Vouchers: Fortunately, there are multiple housing voucher programs in New Jersey, including the Supportive Housing Connection, which is particularly important for individuals with intellectual or developmental disabilities. Unfortunately, however, the policies regarding their use are sometimes overly restrictive.

Rent Standards: The vouchers are based on rent standards developed by the U.S. Department of Housing and Urban Affairs, and although they vary either by county or zip code, they often do not reflect the high rents charged in New Jersey. As a result, many individuals/families are unable to live in their community. Moreover, the information available to individuals/families is not readily accessible and not reliably accurate.

“There is no way to find suitable housing until DCA (NJ Department of Community Affairs) aligns their rental chart to the current market. My daughter cannot be near other people, loud noises, illegal drugs and drunks on the porch.... my child is not in a good place and families should be able to seek appropriate housing even (if) we have to help with the rent.”

Parent of a an Adult Daughter,
Self-Directing Services in the Community
May 2023

Family Homes: These housing vouchers also cannot be used to pay rent in family-owned homes. This is unfortunate, because as discussed in previous annual reports, this makes it harder for individuals to live in their communities and makes it harder for their families to provide all-important natural supports. This, in turn, makes it more necessary for some individuals/families to live in State-licensed settings.

Our approach to both the use of rent standards and family homes should be revisited.

Housing Technology: For the past several years, there has been an active conversation within New Jersey’s disability community about the use of video monitoring technology in State-licensed residences. Led by parent advocates, this conversation has resulted in various pieces of legislation, ongoing policy discussions, and an increase in the use of such technology by residential provider agencies. Indeed, at the end of last year, there were 28 residential provider agencies with video monitoring polices approved by the NJ Department of Human Services and an additional 9 agencies waiting for approval.

“I am writing you with great pain in my heart. My son...has been abused again in another group home. His collar bone, neck and half his chest are completely black and blue.

(He) is non-verbal. (He) is supposed to have a one on one at all times. They are saying they have no idea how he has these significant injuries. I called the D.D.D. Abuse line. The group home ... has no answers. This is the third time my son has been severely injured there.

Since the answer is always “we do not know how it happened,” I have asked for cameras to be put in the home. They immediately respond “no”. It takes their rights of privacy away.

This is the third group home my son has been in. Every single one my son has been abused in. The last one my son was being hit with a hair brush and fortunately a nurse walked by. The nurse reported it. The worker was not fired. He was just moved to another house.”

Parent of an Adult Son,
Living in a State-Licensed Group Home
July 2023

Going forward, this important conversation should continue to balance the right to privacy with the right to be safe, and it should continue driving the effort to make video monitoring technology more readily available in State-licensed settings – something that can benefit both residents and staff, particularly when videos are available to help everyone understand “what” happened and “why” in a particular situation. And as discussed in last year’s annual report and in our “housing web portal” section above, we should also 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.

Moreover, we should continue to encourage additional conversation and consideration of other technologies that also can help people with disabilities live safe, fulfilling, independent lives – “smart” technologies related to lighting, door locks, bed alerts, medication distribution, temperature controls, and more.

Environmental & Vehicle Modifications: At present, the State helps with environmental modifications for both children and adults with disabilities. From fencing and wheelchair ramps on the outside to more accessible bathrooms and living spaces on the inside, the modifications make it possible for individuals to live in the community, often with family and other natural supports.

However, there are limitations, including a prohibition against increasing the overall size of a privately owned house. Although I generally agree with that limitation, I think the policy should be revisited or waived in extenuating circumstances, particularly for those with complex behavioral and medical conditions who cannot be properly supported in State-licensed settings. In such situations, for example, the State could enter into an agreement with the homeowner for reimbursement of the funding if/when the house is sold – similar to the Medicaid “[estate recovery](#)” policy that requires reimbursement to the government at the time of a person’s death.

Similarly, the policy with respect to vehicle modifications should be revised to allow for the purchase or lease of vehicles in extenuating circumstances - a critically important consideration for many people who want to live in the community, but who need specialized transportation. Here, too, the State could enter into an agreement that would ensure recovery of the funds used for this purpose.

Accessory Dwelling Units: In his recent [budget address](#), Governor Murphy expressed support for Accessory Dwelling Units (ADU) – standalone or adjacent housing structures developed on the same property as single- or double-family homes. ADUs are often discussed in the context of residential options for grandparents or other family members. Some municipalities allow them. Some do not. Governor Murphy’s proposal would make monies available to encourage their construction.

For New Jersey’s disability community, this could be a big, important step forward, because ADUs provide another important housing option – one that is affordable, accessible, community-based, and can help make it possible for individuals to benefit from the natural supports provided by family and friends. Hopefully, ADUs will become more common and therefore more readily available.

Out-of-State Residential Placement: At times, we learn of housing needs that cannot be met by residential options in New Jersey.

- An individual with severe challenging behavior, who requires a campus setting for their safety and overall well-being – an intentional community that can best provide needed supports.
- An individual with a complex medical condition, who requires 24/7 supports, but does not want to live in a nursing home, a hospital, or an intermediate care facility.

Although our State has many housing resources for people with disabilities, at present, we cannot meet everyone’s needs, and therefore, when necessary, the State should be more readily willing to consider out-of-state options.

Currently, the NJ Department of Children and Families (DCF) does occasionally consider and does occasionally place youth in out-of-state locations. The NJ Department of Human Services, however, does not. This should change.

Granted, an out-of-state placement is often not optimal. Not only can it be more challenging for the State to oversee the care provided; whenever possible, it is usually best to keep an individual close to their natural supports, namely their family.

However, sometimes an out-of-state placement is the best, safest choice available. And sometimes, the family is located physically closer to an out-of-state residence than any available in-state options. Moreover, the financial costs are not necessarily greater in out-of-state residences. In fact, [Medicaid regulations](#) may make it possible to fund such placements with a mix of State and Federal funds.

Simply stated, without urgently needed reform – without making safe, appropriate housing options more readily available – many people with disabilities, children as well as adults, will continue to face a housing crisis.

Housing in Perspective

* Note this is the main entrance to a State-licensed group home for youth.

* Note that this “crisis stabilization and assessment” residence is home to 5 young men under the age of 21.

* Note the agency annually receives about \$1,700,000 in taxpayer money to run this residence – about \$5,000 per day.



Question: Is this makeshift sign appropriate?

Question: Who is the target audience - the staff, the youths, or the guests?

Housing in Perspective

- * Note these are rent standards (maximum limits) for those with housing vouchers.
- * Note the median one-bedroom rent in New Jersey is \$1,995 per month.

N.J. Department of Human Services DDD Housing Subsidy Program Published Rent Standards January 1, 2024

Maximum rent allowed

County	0-BDR	1-BDR
Atlantic	1289	1474
*Bergen		
*Burlington		
*Camden		
Cape May	1217	1313
Cumberland	1304	1337
Essex	1516	1749
*Gloucester		
Hudson	2192	2227
Hunterdon	1768	1987
Mercer	1489	1705
Middlesex	1768	1987
*Monmouth		
Morris	1516	1749
*Ocean		
*Passaic		
*Salem		
Somerset	1768	1987
Sussex	1516	1749
Union	1516	1749
Warren	1288	1404

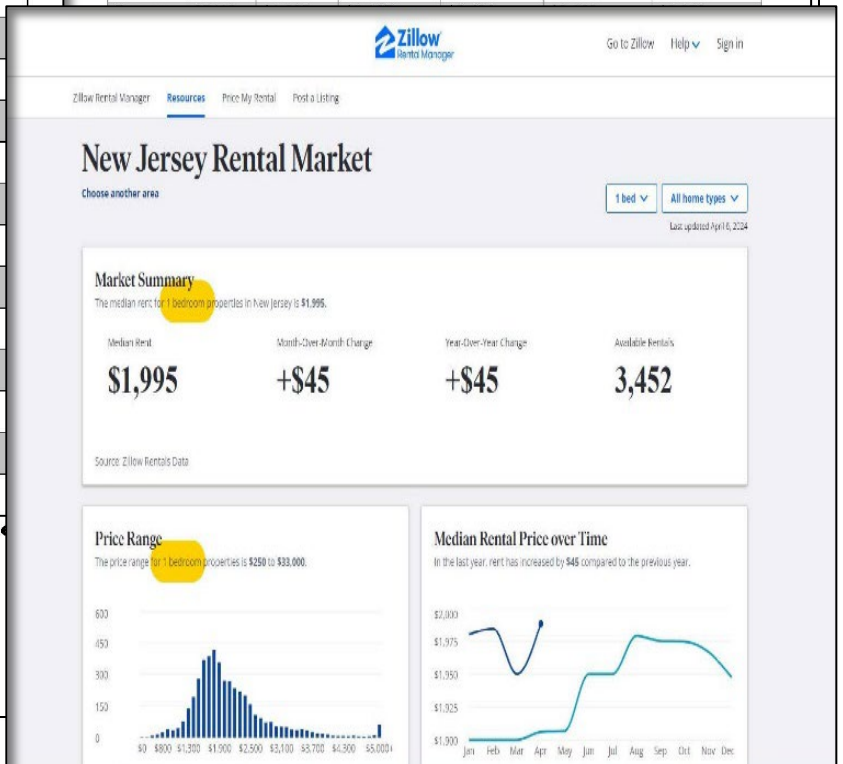
*Please refer to small area published rent standards for more details.

Burlington County Small Area PRS by Unit Bedrooms

County	Zip Code	Zero-bedroom	One-bedroom	Two-bedroom	Three-bedroom	Four-bedroom
Burlington	08010	\$1,573	\$1,749	\$2,090	\$2,530	\$2,915
Burlington	08011	\$1,672	\$1,859	\$2,222	\$2,694	\$3,102
Burlington	08015	\$1,496	\$1,661	\$1,991	\$2,409	\$2,772
Burlington	08016	\$1,353	\$1,507	\$1,804	\$2,178	\$2,519
Burlington	08019	\$2,156	\$2,398	\$2,871	\$3,476	\$4,004
Burlington	08022	\$1,617	\$1,804	\$2,156	\$2,607	\$3,014
Burlington	08036	\$1,254	\$1,397	\$1,672	\$2,024	\$2,332

Bergen County Small Area PRS by Unit Bedrooms

County	Zip Code	Zero-bedroom	One-bedroom	Two-bedroom	Three-bedroom	Four-bedroom
Bergen	07010	\$1,628	\$1,914	\$2,200	\$2,728	\$3,421
Bergen	07020	\$2,310	\$2,717	\$3,124	\$3,872	\$4,862
Bergen	07022	\$1,529	\$1,793	\$2,079	\$2,585	\$3,245
Bergen	07024	\$2,145	\$2,530	\$2,904	\$3,597	\$4,521
Bergen	07026	\$1,430	\$1,672	\$1,925	\$2,387	\$2,992
Bergen	07031	\$1,485	\$1,738	\$2,002	\$2,475	\$3,113
Bergen	07057	\$1,331	\$1,562	\$1,793	\$2,222	\$2,794
Bergen	07070	\$1,551	\$1,826	\$2,101	\$2,596	\$3,267
Bergen	07071	\$1,551	\$1,826	\$2,101	\$2,596	\$3,267
Bergen	07072	\$1,584	\$1,859	\$2,134	\$2,640	\$3,322
Bergen	07073	\$1,650	\$1,936	\$2,222	\$2,750	\$3,465
Bergen	07074	\$1,221	\$1,463	\$1,694	\$2,101	\$2,640
Bergen	07075	\$1,782	\$2,090	\$2,409	\$2,981	\$3,751
Bergen	07401	\$2,211	\$2,596	\$2,981	\$3,696	\$4,642
Bergen	07407	\$1,782	\$2,090	\$2,409	\$2,981	\$3,751



Question: Should we increase our rent standards?

Student Transportation

Few things must be more stressful than placing your special needs child on a small bus or van for a ride to a distant out-of-district school. This must be particularly true if your child is the only student on the bus or van and is nonverbal or deaf or blind or has significant physical limitations or has a significant intellectual disability. This must be particularly true if the bus or van is driven by someone who you do not know and who works for a company that was contracted by your local school district only because it was the lowest bidder.

This is a stress that thousands of New Jersey parents experience most days throughout the school year.

Periodically, throughout my time in this position, parents have brought various concerns to our attention – concerns about the lack of adequate communication with families, the lack of operational cameras in school vehicles, the lack of training on the part of drivers and aides, and the lack of accountability on the part of local school district officials. Last year, parents also brought to our attention concerns and stories born out of tragedy – stories of their children’s young lives needlessly and devastatingly lost to alleged negligence during rides home from school.

In January 2022, Governor Murphy signed into law [legislation](#) to create an Office of School Bus Safety in the NJ Department of Education “to monitor and administer all school bus safety and oversight activities.” In December 2023, that office became operational. Unfortunately, it seems to have a very limited [mandate](#).

Going forward, we need to implement some common-sense, urgently needed reforms:

- All drivers and aides should be responsible for calling 911 in potentially life threatening situations.
- All out-of-district school vehicles should be equipped with operational video camera technology.
- All out-of-district school vehicle drivers and aides should share contact information – including mobile phone numbers – with parents.
- All out-of-district school vehicle drivers and aides should be trained thoroughly and regularly about how best to support the students in their care.
- All out-of-district school vehicles should be treated as an extension of the home school district premises, requiring district officials to be held more accountable and to play a more hands-on role similar to the approach taken with respect to all other contracted services – a long-overdue cultural change for the State’s education community.

“This is a heart wrenching nightmare that no family should ever have to experience.”

Parent of a 19 Year Old Son,
Who Died Immediately Following His Ride Home From School
August 2023

Specifically, home school district officials should be responsible for the following:

- Ensuring a potential school transportation company is the right fit for their individual students with the right mix of experience, qualifications, and training. (Believe it or not, there are more than 1,700 such companies in New Jersey!)
- Orienting families with new school transportation company officials, drivers, and aides, and providing them a “guide to student transportation rights.”
- Serving as the main point-of-contact for families utilizing out-of-district transportation.
- Conducting internal investigations of all incidents.

“The district has been notified for over a year of the unsafe conditions of the transportation companies.... We have tried to get the district to provide further trainings, so the employees in the car are trained in how to install and buckle a child into a car seat.

We have tried mediation and the district said no to the idea of further trainings for driver and aide. They claim it does not fall under the jurisdiction for an IEP, which they have denied us to talk about transportation at meetings.”

Parent of a Pre-School Student,
May 2024

Simply stated, without urgently needed reform – without taking a more intentional, more student-centered approach to out-of-district transportation – the unspeakable tragedies will continue.

Student Transportation in Perspective

* Note these are sample headlines from the past year.

School bus monitor charged after 6-year-old with special needs dies in bus incident
ABC News, July 21, 2023

POSSIBLE CHILD ENDANGERMENT: Autistic Newark Teen Left Alone on School Bus for Over 8 Hours Sparks Investigation
RLS Media, March 1, 2024



STATE OF NEW JERSEY
DEPARTMENT OF EDUCATION

A Memo from the New Jersey Department of Education

Date: February 28, 2024
To: Local Educational Agency Leads
Route To: Human Resource Personnel
From: Chris Irving, Ed.D., Assistant Commissioner
Division of Field Support and Services

Criminal History and School Bus Safety Training Program

The New Jersey Department of Education is introducing a comprehensive two-part training program, offered by the Office of Student Protection and the Office of School Bus Safety. This initiative is designed to foster a deeper

A bus ride that ended in a disabled teen's death leads to charges against nurse

Star Ledger, November 3, 2023,

How did a Paterson teen with autism go missing after his bus drop-off?
Paterson Press, September 19, 2023

LOCAL NEWS

New Jersey family sues school bus company after son with special needs dies from medical emergency

CBS News, December 5, 2023

Qualified bus drivers hard to find

NJ school districts struggle with shortage

the most intense hiring markets for a small pool of drivers — especially those with commercial driver's licenses — and many New Jersey school districts are

20% to 30% by having a separate business own, operate and house the buses, while paying drivers for part-time work, said Anthony Trapasso, the third-gen-

“operated pretty thin” because of the dearth of drivers, Trapasso said.

Then the COVID-19 pandemic turned the private school bus industry on its

NJ school bus operators agree to plea deals for hiring unqualified drivers, safety violations

NorthJersey.com, March 9, 2024

Question: Are we doing enough to protect our students?

Student Transportation in Perspective

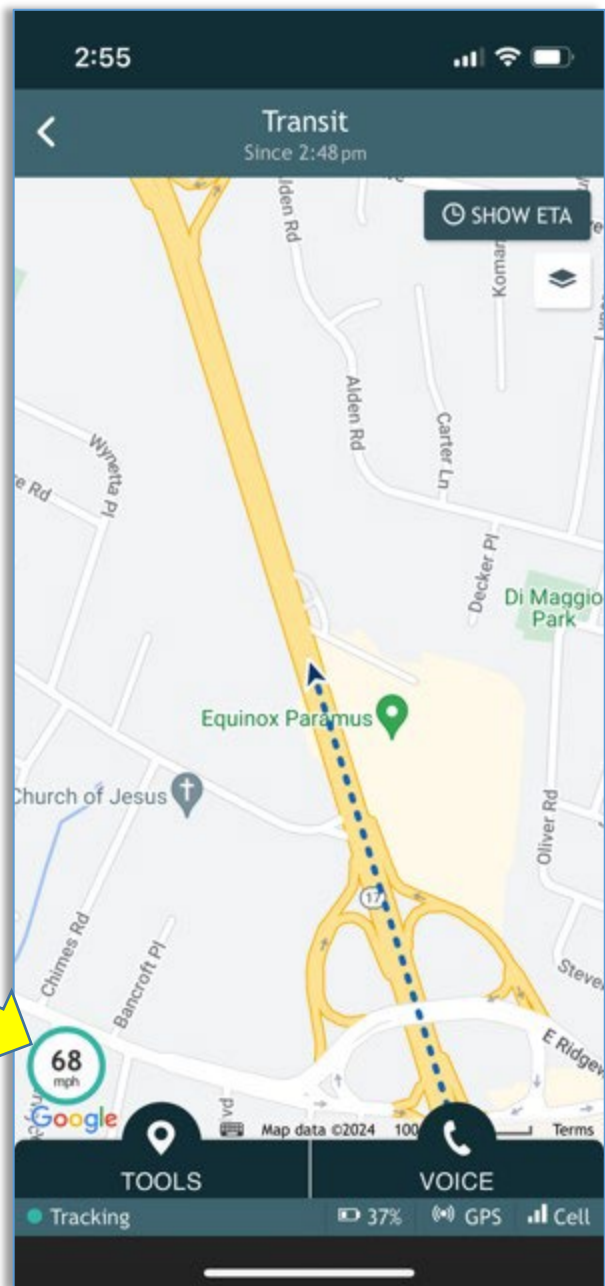
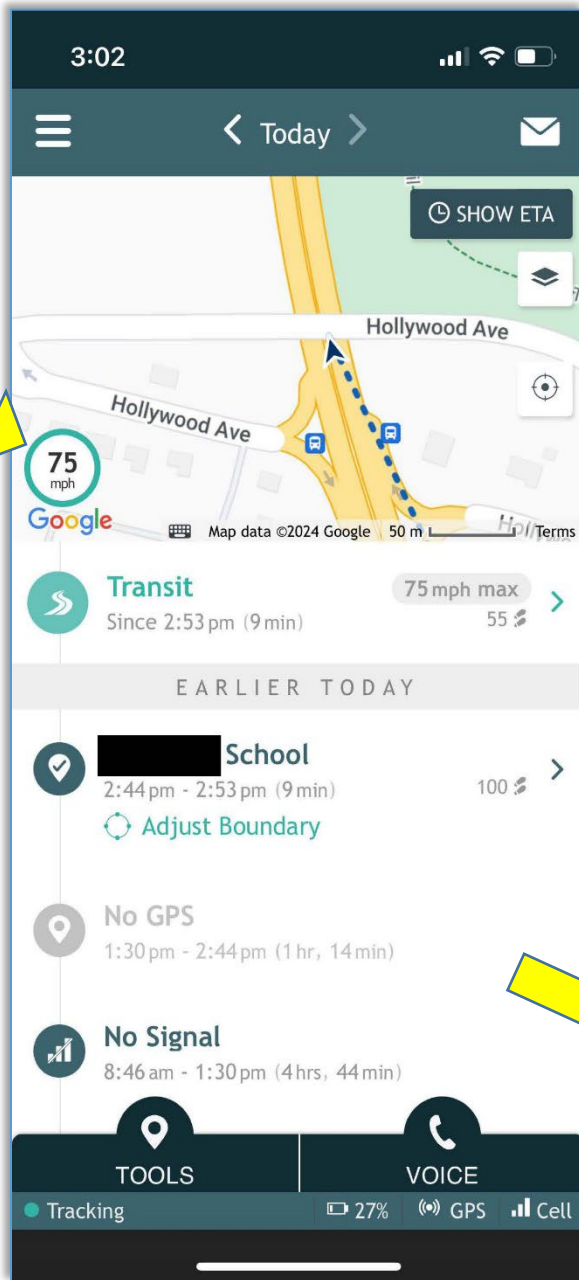
* Note these screenshots from a student's AngelSense (autism tracking) device during bus rides from an out-of-district school.

* Note the speed limit on this road, Route 17 in Paramus, varies between 55 and 50 miles per hour (mph), respectively.

* Note that the bus was traveling at 75mph and 68mph, respectively.

Screenshot from February 8, 2024

Screenshot from April 9, 2024



Question: Are we doing enough to protect our students?

Transitions (Youth to Adult)

For a young person with disabilities and their family, transitioning into adulthood involves a lot – a lot of decisions, a lot of information, a lot of planning, a lot of everything. It involves knowing what is required. It involves knowing what is available. It is a critical time in a young person’s life, because the decisions made (and not made) can have long lasting implications.

Fortunately, here in New Jersey, there are a lot of resources for adults with disabilities, and there is no need for anyone to “fall off the cliff.” Unfortunately, however, not everyone is aware of the resources available, and many young people and their families struggle their way through important milestones, missing opportunities along the way.

In our 2020 annual report, we spoke to this disturbing reality:

“For whatever reason – cultural barriers, language barriers or socio-economic barriers – I have a haunting feeling that many New Jerseyans with intellectual or developmental disabilities have been effectively shut out of our system of care. More specifically, I cannot help but think that many young adults – particularly those living in underserved communities – are “aging out” of the children’s system of entitlements and effectively falling off the figurative “cliff.” As children, they get at least some supports and services through their schools, because it is mandatory. As adults, however, many of them fall through the cracks, because it is not mandatory and no one is there to advise, guide and advocate for them.”

To put this into perspective -

According to the [NJ Department of Education](#), approximately 11,500 students with disabilities exit school each year – either graduating or “aging-out.” Of those, it is estimated that approximately 2,875 of them are likely eligible for services through the [NJ Department of Human Services’](#) Division of Developmental Disabilities (DDD).

Yet, there are only about [27,000 adults](#) registered with DDD and that number has increased only by about 1,400 and 1,100 over the past two fiscal years, respectively. Indeed, there were [24,500 adults](#) enrolled in 2021.

Accounting for those who leave DDD annually for whatever reason, including death and moves out of State, our office estimates that at least 500 to 1,000 adults with intellectual or developmental disabilities are not accessing vital supports and services each year – or between 5,000 and 10,000 New Jerseyans over a 10 year period.

And my sense is that this is a conservative estimate – that the number could be much larger. As stated, there are an estimated 156,000 New Jersey adults with autism – 44,000 of whom also have an intellectual disability – in addition to the many thousands more adults with other developmental, lifespan disabilities.

Clearly, transitioning involves so much more than the services and supports available through DDD. Decisions need to be made about a full range of important issues: Social Security. Medicaid. Legal Status. Doctors. Dentists. Employment. Higher Education. Transportation. Housing. But the numbers from the two Departments seem to be telling a disturbing story about a growing gap, if not disparity, in access to vital supports and services for adults with disabilities – a dynamic that needs to be better understood and addressed.

To be sure, there are several important initiatives underway, including a couple recent ones at the State level by the NJ Department of Education and the NJ Department of Health – initiatives that are taking an in-depth approach to the issue. Similarly, many organizations, like the Arc of New Jersey, have prioritized transitioning in their work with individuals, families and local school districts. And very recently, the Administration came together to host a comprehensive webinar about transitions, which is now available on [our website](#).

Over the years, our office has recommended that every “classified” special needs student – beginning at about age 16 – be assigned a State-funded case manager, who could be available as a resource through the transition years to answer questions and to point families in the right direction. This would help ensure all students and their families know the right questions to ask and to whom they should be asked. And this would help ensure every family – regardless of zip code – has access to the information needed to make important decisions, including those related to DDD supports and services.

We continue to stand by this recommendation.

Moreover, for those with complex behavioral or medical needs, we need to do everything possible to make the transition seamless.

- With respect to youth with complex behavioral needs, the NJ Department of Children and Families (DCF) and the NJ Department of Human Services (DHS) have taken important steps in recent years to ensure supports are in place and that the transition is smooth, if not seamless. This includes less paperwork as well as better coordination between the Departments transitioning those living in State-licensed residences. But for those with very significant needs, we should consider starting the transition earlier, allowing families to be connected with a DHS approved Support Coordinator and to begin planning months, if not years, earlier than currently permitted.
- With respect to youth with complex medical needs, however, the transition is often far from seamless. Accessing specialized medical care. Finding employment opportunities or day programs. And as noted above, trying to manage an inexplicable and inconceivable reduction in nursing support. Taken together, for some of these individuals and their families, the transition can be a horrifying experience. Fixing this needs to be a priority.

One last recommendation: It would be great to establish a “Transition Corp” of individuals and parents who have already navigated across systems and who are available to advise other families and to share their experiences – good, bad and otherwise. Similar to the statewide "[Mom2Mom](#)" program, the “Transition Corp” could be a volunteer peer-support organization for families of special needs students.

Simply stated, without urgently needed reforms – without meaningful new approaches to transitioning youth -- many young adults with intellectual or developmental disabilities will not only continue to “fall off the cliff;” they will continue to “fall off the grid” altogether and be deprived the supports and services that they need and deserve.

Transitions in Perspective

- * Note in 2022, there were 225,333 students (ages 5-21) with disabilities receiving special education services.
- * Note the NJ Department of Education estimates that 11,500 students with disabilities exit school each year.
- * Note in 2023, there were only 26,726 adults (ages 21 and above) receiving community-based services through DDD.

New Jersey Department of Education
Office of Special Education Programs
Children Receiving Free and Appropriate Education (Ages 5 to 21)
As of October 15, 2022

(Includes public and non-public students; includes 5-year olds who are in Kindergarten)

Race	Student Count(5-21 Age)	In Percentage
White	105398	46.77
Hispanic/Latino	67450	
Black or African American	35949	
Asian	10211	
Two or more races	5633	
American Indian or Alaska Native	324	
Native Hawaiian or Other Pacific Islander	368	
Total	225333	

Gender	Student Count(5-21 Age)
Female	77600
Male	147733
Total	225333

Disability Category	Student Count(5-21 Age)
Autism	25022
Deaf-Blindness	21
Developmental Delay	114
Emotional Disturbance	6406
Hearing Impairment	1354
Intellectual Disability	5333
Multiple Disabilities	12644
Orthopedic Impairment	273
Other Health Impairment	49500
Specific Learning Disability	71193
Speech or Language Impairment	52763
Traumatic Brain Injury	351
Visual Impairment	359
Total	225333

Lep Status	Student Count(5-21 Age)
English Learner	9532
Non-English Learner	215801
Total	225333



New Jersey
Division of
Developmental
Disabilities

Receiving Services in the Community - Tier by County as of 12/15/2023

Print Date: 12/15/2023

Number of individuals receiving DDD-funded services in the community per county, by NJCAT Tier.
This data does not include individuals residing in Developmental Centers as the NJCAT is not used in those settings.
Due to Federal Limited Data Set requirements, values less than 11 are suppressed.

County / Tier	A	Aa	B	Ba	C	Ca	D	Da	E	Ea	Total
Atlantic	98	<11	117	16	237	38	>198	96	94	55	960
Bergen	280	<11	346	19	624	82	539	253	>185	187	2535
Burlington	208	<11	253	27	>411	112	338	163	124	108	1756
Camden	218	<11	269	26	>395	72	346	148	92	82	1659
Cape May	32	<11	32	<11	63	<11	71	11	33	14	264
Cumberland	54	<11	67	<11	140	28	154	58	60	44	609
Essex	201	<11	>341	12	471	59	457	161	188	130	2032
Gloucester	106	<11	133	13	>265	73	252	125	93	83	1152
Hudson	116	<11	157	<11	239	20	233	61	79	44	962
Hunterdon	54	<11	45	<11	90	27	99	27	27	23	397
Mercer	154	<11	161	<11	324	55	293	147	73	73	1295
Middlesex	232	<11	279	15	>490	65	465	196	205	163	2120
Monmouth	201	<11	257	22	>444	55	458	165	175	140	1923
Morris	156	<11	194	<11	377	59	348	143	123	125	1534
Ocean	229	<11	297	11	>490	67	409	167	179	137	1998
Out-of-state	<11	<11	<11	<11	47	<11	39	24	12	<11	142
Passaic	148	<11	195	13	298	41	>312	100	121	119	1355
Salem	17	<11	15	<11	32	21	51	42	23	14	219
Somerset	118	<11	141	12	292	55	>290	159	126	103	1304
Sussex	50	<11	57	<11	161	31	148	67	57	32	610
Union	152	<11	198	<11	332	71	317	109	180	124	1494
Warren	54	<11	43	<11	109	17	84	32	37	26	406
Total	2883	84	3606	239	6357	1056	5917	2454	2297	1833	26726

Question: Although all students with disabilities will not need DDD community-based services as adults, should we be concerned about the significant difference in numbers?

Transitions in Perspective

* Note the myriad issues/resources to be considered as a youth transitions to adulthood.



Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families

Transitions Checklist

The transition from childhood to adulthood is complex. There are many issues that require a family's attention.

Here is a helpful checklist of some of the issues.
Please contact us if you have questions about any of them.

✓ **Adult Services & Supports**

- NJ Division of Developmental Disabilities
- NJ Division of Disability Services
- County Disability Offices
- Centers for Independent Living

✓ **Education**

- Pre-Employment
- Higher Education

✓ **Employment**

- NJ Division of Vocational Rehabilitation Services
- NJ Commission for the Blind and Visually Impaired

✓ **Federal/State Support Programs**

- Social Security / Supplemental Security Income
- Medicaid
- Medicare

✓ **Healthcare**

- Primary Care Physician
- Dentist
- Psychiatrist / Psychologist

✓ **Housing**

- Private
- State-Licensed

✓ **Legal Status**

- Supportive Decision-Making
- Power of Attorney
- Guardianship

✓ **Transportation**

- Driver's License / State Identification
- New Jersey Transit / Access Link
- Travel Instruction / Training

Disability.Ombudsman@treas.nj.gov
www.disabilityombudsman.nj.gov

Question: With so many issues to address, are all transitioning students and their families receiving the assistance that they need and deserve?

Systemic Recommendation

- Follow the Money -

Throughout the previous sections, we focused on some of the most serious, most persistent challenges that came to our attention on a regular basis last year – abuse and neglect, autism/severe challenging behavior, complex medical needs, housing, student transportation, and transitioning. And for each challenge, we offered several (what I believe to be) common sense issue-specific recommendations.

But to fix much of what is broken with our system also requires something more. It requires us to identify the systemic reasons for questionable policies and practices. It requires us to pull back the curtain, so to speak, and look at our system of care through clear, discerning eyes. It requires us to ask hard, uncomfortable questions.

- Are we doing enough to prevent abuse and neglect in State-licensed residences? If not, why not?
- Are we doing enough to ensure individuals with severe autism have access to vital therapies and supports? If not, why not?
- Are we doing enough to ensure individuals with complex medical needs have access to nursing care, treatments, and other vital supports? If not, why not?
- Are we doing enough to ensure individuals with disabilities live in safe, appropriate community-based housing? If not, why not?
- Are we doing enough to ensure students with disabilities are safe while traveling to and from school? If not, why not?
- Are we doing enough to ensure all young people with disabilities transition to adulthood with access to vital supports and services? If not, why not?

In our 2021 report, we spoke at length about the “disconnect” that often exists between those making decisions and those impacted by the decisions – a disconnect that is largely responsible for “the overwhelming complexity of the system, the seeming inflexibility of policies and procedures, and the maddening lack of urgency by many people working in the system.”

But answering many of the hard questions above requires us to look a little deeper and to focus on an additional consequence of this disconnect: the need for more accountability from the private sector organizations/agencies at the center of our State’s system of care.

- It requires us to look at their policies and practices.
- It requires us to look at their business models.
- And it requires us to look at the State government’s role in overseeing them, managing them, and holding them accountable.

Simply stated, to address some of our system’s most serious, most persistent challenges, we need to heed an old, cynical, but wise adage: We need to follow the money.

To be clear, since taking this position 6 years ago, I have rarely, if ever, said that we need more money in New Jersey’s system of care for people with disabilities. Indeed, if anything, I have praised the Murphy Administration and State Legislature for dedicating significant resources for the disability community, including an additional \$1 billion for the NJ Division of Developmental Disabilities’ (DDD) Community Care Program.

This is not to suggest that the system and those it serves would not benefit from more funding. Nor does it mean that specific individuals and families do not need additional monies to provide for their safety, care, and overall well-being. In fact, we often work with individuals and families to increase the resources available to them.

Our general focus, however, has been on “how” the money in the system is spent ... and not spent. And increasingly, our focus has been on some of the private sector organizations/agencies that are given millions of taxpayer dollars annually to support tens of thousands of New Jerseyans with intellectual or developmental disabilities, specifically (1) the managed care organizations, (2) the agencies providing direct care staff in State-licensed group homes/supervised apartments, and (3) the agencies providing direct care staff in private/family homes.

At a minimum, by asking hard questions and by engaging in real conversations, we can assess whether or not we are doing all that must be done and whether we are doing it the right way. We can clarify the roles of these organizations/agencies as well as the government offices that oversee them. And we can determine whether more funding is needed or whether we just need to spend it more effectively... or both.

Indeed, if we are able to identify more efficient, more effective ways to use the significant funding already available within our system of care, then we might be able to repurpose some of the monies for urgently needed investments, such as:

- Providing more residential treatment options (in-home and out-of-home) for youth with severe challenging behavior and/or complex medical needs;
- Enrolling more people in DDD’s Community Care Program, further reducing the size of the “wait list” and providing more residential and in-home supports for individuals and families; and/or
- Making available more resources – including housing, transportation, medical and behavioral supports – to individuals, families, and provider agencies.

Simply stated, by following the money, we can help guarantee that our system of care for people with disabilities is one that ensures care, rather than rations it. And we can possibly save money in the process.

Managed Care Organizations (MCO)

For us and many others, the money flow to the MCOs remains a mystery. Based on concerns shared with us by individuals and families, I have asked multiple questions over multiple years and have received only some answers. Among those questions still needing clarification:

- How much money has been paid annually to the [five MCOs](#) in our State Medicaid program?
- Are there financial incentives for MCOs to provide less supports and services to plan members?
 - Does the overall company profit more when, for example, an MCO declines a request for coverage or reduces the number of nursing or personal care assistance hours?
 - Do company executives or care managers personally benefit financially when, for example, an MCO declines a request for coverage or reduces the number of nursing or personal care assistance hours?
- Why and how was [a decision taken in 2023](#) to effectively transfer about \$40 million per year from the one company (Public Partnerships, LLC) providing fiscal intermediary services to the five MCOs – a decision taken without any public input, without any public hearing, and without any public transparency? (Only after the decision was made and announced did the NJ Department of Human Services engage in public discussions.)
- Why is the appeals process regarding decisions taken by the MCOs so fatally flawed in that the Administrative Law Judge’s decision is not actually binding, but is, in fact, only a recommendation to the State’s Medicaid division? And how often are such “decisions” against the MCOs accepted or rejected by the State’s Medicaid division?

“To follow up on our telephone conversation, attached please find a copy of the letter from (our MCO) reducing (my son’s) current nursing from 24/7 to 16/7 effective March 8, 2024. A two-week time frame from the date I got the phone call ... and one week from when I got the actual letter...”

I have also attached letter from 3 of (my son’s) doctors stating that (he) should continue the 24-hour nursing....”

Parent of a 20 Year Old Son
March 2024

- What government controls are in place to ensure appropriate decisions by the MCOs?
- Who are the government officials responsible for providing oversight of the MCOs and what is the nature and level of interaction with them?

These questions are important and deserve real answers, because the MCOs play a critical role in the lives of people with disabilities. Their decisions and actions literally affect the length and quality of life of those who depend on them.

Agencies Providing Direct Care Staff in State-Licensed Group Homes / Supervised Apartments

Generally speaking, the money flow to these agencies is cause for concern. Although costs associated with supporting people with disabilities can be very high, there seem to be relatively few controls on how money is spent by these agencies. That is true with respect to public, taxpayer money. That is true with respect to personal money.

To put this into perspective –

In 2023, there was approximately \$2.5 billion in federal and state monies allocated for approximately 12,500 adults enrolled in the NJ Division of Developmental Disabilities’ (DDD) Community Care Program (CCP).

- The average annual budget for adults enrolled in the CCP was about \$197,000 per person.
 - More than 900 of these individuals, however, had an annual budget of about \$499,000 per person.
 - An additional 1,200 of them had an annual budget of about \$390,000 per person.
 - And there was also a relatively small, but growing number of individuals receiving even larger budgets due to their extraordinarily high level of need. (See “Tier F” in the [Community Care Program manual](#).)
- Moreover, about two-thirds of those enrolled in the CCP - approximately 9,000 adults – were living in either State-licensed group homes or supervised apartments run by provider agencies.

Hence, most of the \$2.5 billion of CCP Medicaid funding was paid directly to agencies that provide direct care staff in State-licensed settings. **This is on top of the personal funding received directly from their residents, who are required to sign-over most of their monthly income from Social Security or employment to cover the cost of rent, food, utilities, etc.**

Yet, we often learned of agency-run residences that were understaffed, dirty, and/or in disrepair, and we were often told of individuals going without their preferred foods, internet service, and other “paid for” amenities.

Among the questions that we have repeatedly asked:

- Where is the money going?
- Why aren’t these agencies required to give individuals/families a detailed accounting of Medicaid revenues / expenses per resident per year?
- What controls are in place to ensure that the “fee-for-service” Medicaid dollars assigned to specific individuals annually are actually being spent on services for those specific individuals and not being used for other purposes?
- With some of these agencies being paid up to \$1,431.12 per day (\$60 per hour) per resident, why were direct care staff paid an average wage of only about \$19 per hour?
- Should these agencies, which are funded primarily with taxpayer money, keep millions of dollars in annual profits or pay their executives salaries exceeding hundreds of thousands of dollars?
- Why aren’t these agencies required to provide individuals/families with a detailed accounting of how personal monies – personal Supplemental Security Income or personal employment income - are spent?

Agencies Providing Direct Care Staff in Private / Family Homes

Generally speaking, the money flow to these agencies is also a concern.

Last year, approximately 3,500 adults – about one-third of the CCP enrollment - either lived in their own home or a family home, and many of them used their annual DDD funding to pay these agencies to provide them with direct care staff.

Depending on the individual, these agencies received either \$36.12 per hour, per person or \$57.16 per hour, per person to provide “individual supports” (direct care staff). Yet, these agencies were only required to pay direct care staff minimum wage, which last year was \$14.13 per hour. Granted, we have heard of some such agencies paying direct care staff up to about \$20 per hour. The rest of the monies, however, were reportedly kept by the agencies for “administrative” costs.

Among the questions that we have repeatedly asked:

- What “administrative” costs would justify an agency keeping an additional \$30-40 per hour, per person of Medicaid (taxpayer) money?
- Why aren’t these agencies required to return any of the taxpayer money not used for staffing purposes?

Organizations/Agencies v. Individuals/Families

Moreover, my concerns with some of these organizations/agencies have been in both absolute and relative terms. On the one hand, as discussed above, I am concerned that some are paid too much taxpayer money with too few controls. On the other hand, relative to individuals/families, they are allowed to play by a different, seemingly unfair set of rules.

Let me explain.

With respect to the MCOs, they seem to have too much authority. They can make life-changing decisions for individuals and families with seemingly few guardrails. Yes, there is an appeals process, but as noted above and as discussed at length in our [2021 annual report](#), the process is deeply flawed. Although the appeal is heard by an Administrative Law Judge, the “decision” is not binding and is merely a recommendation that the NJ Department of Human Services can accept or reject.

With respect to agencies providing direct care staff in State-licensed residences (group homes or supervised apartments), they also seem to have a disproportionate amount of authority. As discussed previously in our [2020 annual report](#), there is a power dynamic that favors these agencies at the expense of individuals/families – a power dynamic that places individuals/families at a disadvantage when it comes to disagreements over policies and procedures. In addition to the very real fear of retribution felt by many individuals/families, there is another unfortunate reality that gives these agencies the upper hand in this relationship: There are no real consequences for agency decisions, even those that violate State policies. Short of losing their license to operate in New Jersey – which rarely happens – these agencies never face financial penalties for non-compliance with State rules and regulations, including those involving confirmed incidents of abuse or neglect, inappropriate discharges, or staffing requirements. In short, they can often do as they please without any real repercussions.

And with respect to agencies that provide direct care staff in either State-licensed residential settings or private/family homes (or both), there is a double-standard that places individuals/families at a financial disadvantage, making attempts to “self-direct” their services more difficult, if not impossible. (See chart on page 47.) Simply put, State policies favor these agencies at the expense of individuals/families as well as at the expense of taxpayers more generally. Even a recent, well-intentioned Request for Proposals (RFP) to provide up to \$6 million to transition individuals from nursing homes into the community is available only to agencies. Individuals/families are precluded from applying. Even more recently, a [cost of living increase](#) for FY25 was given to agencies providing direct care staff, but not to self-directing individuals/families to use for their direct care staff.

“The case manager (at my MCO) is only a liaison. I believe patients should have direct interaction with the people in power making their health decisions.”

Upon further investigation, my mom also found out that medical doctor reviewing my claim was a geriatric specialist who is hardly qualified to decide if someone like me with a complex neurological disorder is entitled to therapeutic services to maintain my health.”

33 Year Old Man with Cerebral Palsy,
Upon Receiving a Denial for “Maintenance Therapy”
June 2023

Here is an example that highlights this double-standard -

In 2023, an individual with an intellectual or developmental disability in the NJ Department of Human Services' Community Care Program with an assigned budget tier level of "Ea" - one of the highest tier levels reserved for those requiring a very high level of care:

- If the individual lived in a private/family home and "self-directed" their direct care staffing services (hired their own staff), the State allowed them to pay staff up to \$25 per hour. There were exceptions, but an increased level of pay required the direct care staff to have advanced educational degrees / credentialing.
- If the individual lived in a private/family home and utilized a provider agency for direct care staffing services, the State paid the agency \$57.16 per hour and allowed them to pay staff any salary above minimum wage – without any requirement for advanced educational degrees / credentialing.
- If the individual lived in a State-licensed residence (group home or supervised apartment), the State paid the agency \$45 per hour and allowed them to pay direct care staff any salary above minimum wage – without any requirement for advanced educational degrees / credentialing.

Simply stated, these agencies are often given more money, but often pay low salaries and have fewer restrictions and controls on them. This is not only a questionable approach with respect to provider agencies; it also has a negative impact on self-directing individuals/families, making it more difficult for them to hire and retain direct care staff (See charts on the following pages.)

Indeed, one of the most frequent complaints we hear from self-directing individuals/families - those that are forgoing the use of a provider agency - is that they are assigned a large budget, but are unable to use it because of all of the State-imposed restrictions placed on individuals/families. Not surprisingly, we never hear that complaint from the agencies.

At a minimum, all of this undermines efforts to maintain a robust self-direction program that helps ensure individuals are able to live safely and fully in their community. It also undermines efforts to mitigate, if not eliminate, abuse and neglect in State-licensed residences. And more generally, it also seems like a big waste of taxpayer money.

Among other things, I am hoping a brand [new federal rule](#) to require a minimum of 80% of all Medicaid payments for staffing be spent on compensation for direct care workers will help address the "workforce crisis."

Regardless, there is a clear need to revisit existing policies.

Taken together, we need to 'follow the money' because we need to do everything in our power to get this right – to make sure that people with disabilities and their families have access to the supports and services that they need and deserve. Appropriate staffing. Quality behavioral and medical supports. Affordable, accessible housing. Safe student transportation. More equitable transitioning. By curbing excesses and spending money more efficiently and effectively, we can better address the 6 urgent issues discussed above and so much more.

To be clear: None of this is to suggest that any person or organization/agency is necessarily violating laws, rules or policies. **On the contrary, I actually believe most of these organizations/agencies and the people staffing them, particularly those specifically dedicated to serving people with disabilities, try to do the right thing and take their solemn responsibilities seriously.** I just believe that some of them take advantage of the system's shortcomings, and I believe we therefore need to revisit some of our laws, rules, policies, and practices to guarantee more transparency and more accountability.

Simply stated, our State government can and must do more to help guarantee that our system of care is truly person-centered and that it ensures care, rather than rations it.

Following the Money: Adult System Staffing Policies in Perspective

	Provider Agencies (State- licensed Group Homes/Supervised Apartments)	Self-Directing Individuals/Families (Private/Family Homes)
Last year, how much money could direct care staff be paid?	Up to \$59.63 Per Hour State paid these provider agencies up to \$59.63 per hour , per person to hire direct care staff.	Up to \$25 Per Hour State allowed individuals/families to pay direct care staff up to \$25 per hour , per person, with limited exceptions.
What was the average salary for direct care staff?	About \$19 Per Hour	About \$19 Per Hour
Could direct care staff be paid higher salaries?	Yes At their own discretion, agencies are permitted to pay direct care staff as much as they would like above minimum wage.	Sometimes At State’s discretion, individuals/families can pay direct care staff only up to \$25 per hour, with limited exceptions.
Have direct care staff received automatic annual salary increases?	Yes In recent years, direct care staff in State-licensed residential settings have received automatic hourly increases mandated by the government.	No Direct care staff have not received automatic salary increases, nor have many of them been allowed to receive any increase, not even cost-of-living increases.
Did direct care staff receive mandated salary increases during the pandemic?	Yes The government paid direct care staff in State-licensed settings an additional \$3 per hour.	No The government did not pay direct care staff in private/family homes any additional money.
Who decides how much to pay direct care staff?	Agencies Decide.	Government Decides.
What happens to unused monies?	Agencies Decide. Provider agencies can keep unused funds.	Government Decides. Unused funds remain with the government.
Who ensures monies are used properly?	Agencies Ensure.	Government Ensures.
How are time / attendance of direct care staff monitored?	Agencies Monitor. Residential provider agencies track their own direct care staff time/attendance.	Government Monitors. Individuals/families are required to use Electronic Visit Verification to track direct care staff time/attendance.

Question: Why are agencies given more money with fewer restrictions?

Following the Money: Contrasting Staffing Rates in Perspective

- * Note these direct care staffing (“individual supports”) rates were from the NJ Department of Human Services.
- * Note the sizable difference in rates between agencies and individual/families.
- * Note the significant amount of money provided to agencies.

Individual Supports	Rate	Frequency	Code	Notes
Base (hourly rate)	\$9.03	15 Minutes	H2016HI	E/D, I/FS, or IS (DSP service applies)
Base with Acuity (hourly rate)	\$14.29	15 Minutes	H2016HI22	E/D, I/FS, or IS (DSP service applies)
SDE (hourly rate)	R&C	15 Minutes	H2016HIU8	E/D, I/FS, or IS (DSP service applies)
Tier A Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$93.81	Daily	H2016HI52	IS (DSP service applies)
Tier Aa Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$178.89	Daily	H2016HIU1	IS (DSP service applies)
Tier B Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$187.62	Daily	H2016HIUS	IS (DSP service applies)
Tier Ba Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$357.78	Daily	H2016HIU2	IS (DSP service applies)
Tier C Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$312.70	Daily		
Tier Ca Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$596.30	Daily		
Tier D Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$437.78	Daily		
Tier Da Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$834.82	Daily		
Tier E Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$562.86	Daily		
Tier Ea Licensed or Unlicensed with shared staff for 3+ hours (daily rate – factors in 5% absentee rate)	\$1073.34	Daily		

The first two rates (“Base/Base with Acuity”) were for agencies providing direct care staff in private/family homes: \$36.12 or \$57.16 per hour

The third rate listed (“SDE”) was for individuals/families hiring direct care staff in private/family homes: up to \$25 per hour

All of the other rates were for agencies providing direct care staff in State-licensed residential settings: up to \$45 per hour

(Note: This chart does not show the Tier Fa, which paid agencies a rate for direct care staff of \$59.63 per hour.)

Question: Do these very different rate structures make sense?

Question: Are they fair to self-directing individuals & families?

Following the Money: “Administrative” Costs in Perspective

In 2023, as outlined on the previous page, if an individual/family utilized a provider agency to hire direct care staff for their private home, the State paid the agency a flat rate of either \$36.12 or \$57.16 per hour, depending on whether the individual served was assigned an acuity due to the significance of their behavioral and/or medical needs. These agencies, in turn, reportedly paid their direct care staff an average salary of about \$19 per hour. The NJ Department of Human Services allows these agencies to keep the difference – potentially \$38.16 per hour (\$57.16 - \$19.00 = \$38.16) – to cover “administrative” costs, such as payroll services and benefits.

If an individual served by the Department required direct care staff services 16 hours per day, the State could have paid the agency about **\$222,854.40** (\$38.16 x 16 hours per day x 365 days per year) of taxpayer money to cover the “administrative” costs of that one individual for one year – more than twice the amount paid to the direct care staff.

Conversely, in 2023, if a family chose to self-direct their services and hire their own direct care staff by using the Department’s designated “agency with choice,” the State would have only paid a maximum of **\$8,834.28** per individual per year to cover the “administrative” costs. See chart below (“PMPM4 column”).

That’s a big difference. That’s a lot of taxpayer money possibly being paid to provider agencies for “administrative” costs.

APPENDIX P – PER-MEMBER, PER-MONTH FEE FOR AGENCY WITH CHOICE FI MODEL

For every individual participating in one of the Division’s two self-directed service models (Agency with Choice or Vendor Fiscal/Employer Agent), a monthly fee must be paid to the fiscal intermediary for each model to cover the cost of the administrative and payroll services they provide. This monthly amount is referred to as the per-member, per-month (PMPM) fee.

The state pays an amount toward every individual’s PMPM fee. Currently, the state payment covers the monthly cost to participate in the Vendor Fiscal/Employer Agent model, but does not cover the cost to participate in the Agency with Choice model. The remaining cost to participate in the Agency with Choice model is deducted each month from the individual’s budget. Below is the PMPM cost to an individual’s budget when he/she chooses to participate in the Agency with Choice model. The PMPM is based on the number of self-directed employees an individual has and whether or not his/her employee(s) elect employer-sponsored health benefits through the fiscal intermediary.

	PMPM 1	PMPM 2	PMPM 3	PMPM 4
	One or more SDEs working 0-40 hrs. per week for the participant or the employer of record (Easterseals) and NOT electing health benefits	One SDE working less than 30 hrs. per week for the participant but 30+ hrs. per week for the employer of record (Easterseals) AND electing health benefits	One SDE working 30+ hrs. per week for the participant AND electing health benefits; --OR-- Two or more SDEs working less than 30 hrs. per week for the participant but 30+ hrs. per week for the employer of record (Easterseals) AND electing health benefits	Two or more SDEs working 30+ hrs. per week for the participant AND electing health benefits
MONTHLY Cost to Individual Budget*:	\$193.97	\$340.15	\$442.48	\$736.19
ANNUAL Cost to Individual Budget*:	\$2,327.64	\$4,081.80	\$5,309.76	\$8,834.28


*Includes state allowance toward cost

PLEASE NOTE: This table is for guidance purposes only. Support Coordinators will need to work with the Agency with Choice Fiscal Intermediary directly to determine which PMPM will be applied.

Question: Should provider agency “administrative” costs be reviewed?

Following the Money: Provider Agency Billing in Perspective

- * Note that this is from a NJ Department of Human Services Individualized Service Plan (ISP).
- * Note the agency is paid a daily rate of \$867.44 (\$36 per hour) - \$316,615 per year to provide residential support.
- * Note the same agency is paid an hourly rate of \$46.48 - \$66,931.20 per year to provide day habilitation.



New Jersey Individualized Service Plan (NJISP)

Plan ID: [REDACTED]
Print Date: 04/09/2024

Outcome 3


[REDACTED]

Service 1 : Individual Supports

Residential

[REDACTED]

Procedure : Tier D/Acuity Differentiated (14) Code : H2016HIU4 Reference : PCPT Claims : Medicaid	Provider : [REDACTED] Location : [REDACTED]	Start Date : 01/06/2024 End Date : 01/04/2025 Unit Type : Day(s) Frequency : Weekly	Rate : \$867.44 Total Units : 365 Total Cost : \$316615.60
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New Jersey Individualized Service Plan (NJISP)

Plan ID: [REDACTED]
Print Date: 04/09/2024

Outcome 4

[REDACTED]

Service 1 : Day Habilitation

Day Hab

[REDACTED]

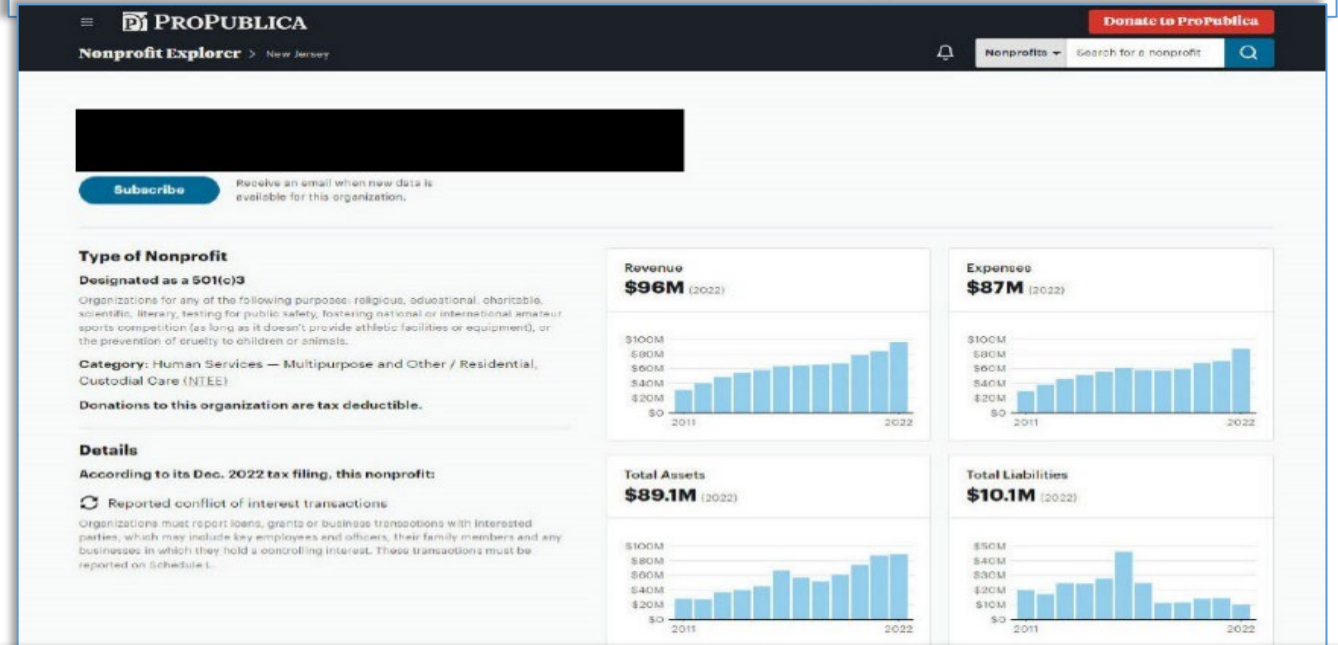
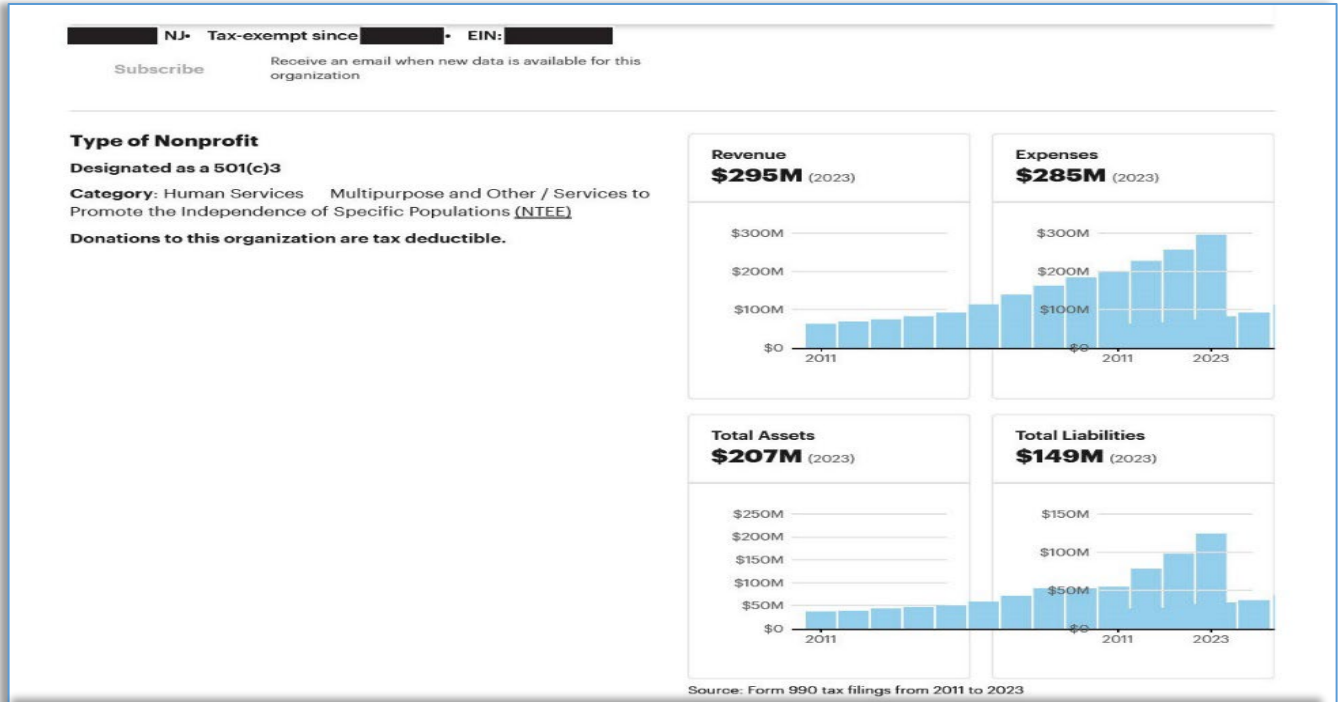
Procedure : Tier D/Acuity Differentiated Code : T2021HIU4 Reference : PCPT Claims : Medicaid	Provider : [REDACTED] Location : [REDACTED]	Start Date : 01/06/2024 End Date : 01/04/2025 Unit Type : 15 Min Frequency : Weekly	Rate : \$11.62 Total Units : 5760 Total Cost : \$66931.20
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Question: If the individual goes to a day habilitation program 6 hours per weekday (1,560 hours per year or the equivalent of 65 days), should the agency receive the full residential daily rate for all 365 days per year?

Question: Should these billing rates be revisited?

Following the Money: Provider Agency Revenues in Perspective

- * Note these are IRS 990 forms from a couple of the larger agencies providing direct care staff support.
- * Note the sizable difference in revenues and expenses for this one year.
- * Note the significant amount of assets.



Question: With most of its revenue coming from Medicaid (taxpayer money), should a provider agency have such large profits and assets?

Question: Should agencies be required to pay their Direct Care Staff a living wage?

Following the Money: Executive Compensation in Perspective

- * Note these are IRS 990 forms from a couple of the larger agencies providing direct care staff support.
- * Note the compensation paid to executives.
- * Note this is for only one year.

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)					(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee			
(1) [REDACTED] CEO/PRESIDENT	11.0 7.0	X		X			1,166,215	0	41,169
(2) [REDACTED] CHIEF FINANCIAL OFFICER	11.0 7.0			X			588,421	0	11,919
(3) [REDACTED] EXECUTIVE VP/SECRETARY	11.0 7.0	X		X			551,906	0	17,123
(4) [REDACTED] CHIEF HR OFFICER/TRUSTEE	11.0 7.0	X		X			481,018	0	26,437

Schedule J (Form 990) 2022

Page 2

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that are not listed on Form 990, Part VII.

Note. The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2, 1099-MISC compensation, and/or 1099-NEC			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
[REDACTED] EX. DIRECTOR	(i)	269,472	226,827	25,075	0	30,645	552,019	0
	(ii)	0	0	0	0	0	0	0
[REDACTED] ASSOC EX DIRECTOR- FINANCE	(i)	200,700	78,370	20,500	0	10,462	310,032	0
	(ii)	0	0	0	0	0	0	0
[REDACTED] ASSOC EX DIRECTOR - HR	(i)	202,309	63,418	20,500	0	23,310	309,537	0
	(ii)	0	0	0	0	0	0	0
[REDACTED] MANAGING ASST EX DIRECTOR	(i)	158,237	35,543	26,125	0	30,644	250,549	0
	(ii)	0	0	0	0	0	0	0

Question: With most of its revenue coming from Medicaid (taxpayer money), should provider agency executives get paid such high salaries?

Question: Although it is important to pay competitive salaries, how much is too much?

Conclusion

- “Where there’s a will, there’s a way.” -

Again, our system of care for people with disabilities remains a tale of two systems – one good, one not good enough.

Indeed, there is so much to appreciate and celebrate about our system, most notably the wonderful, hardworking people who staff it. But by necessity, the work of our office – and hence, our annual report - is focused almost exclusively on the challenges faced by the people we serve.

Last year, the list of challenges was again extensive, but for the purposes of this report, we discussed only those brought to our attention on an almost daily basis:

Abuse and Neglect
Autism/Severe Challenging Behavior

Complex Medical Needs
Housing

Student Transportation
Transitions

For each of these challenges, we have offered specific recommendations – basic, common-sense recommendations. We have also offered a larger, more systemic recommendation regarding the need for more accountability and more controls.

As part of that systemic effort, I offer one more suggestion: We should restart the work of the Independent Developmental Disability Fee-for-Service Transition Oversight Board, which was mandated by a [2017 law](#) and established the following year by Governor Murphy. The Board’s purpose was, among other things, to “determine the adequacy of fee-for-service reimbursement rates.” As noted in the legislation, “... it is both reasonable and necessary, and in the public interest, for the State ... to ensure that reimbursement rates established under the new fee-for-service system are adequate, that client access to care is maintained, and that continuity of care and quality of care are not harmed as a result of the transition.”

In 2019, the Board issued an [interim report](#), but then effectively stopped functioning at the onset of the COVID-19 public health emergency in early 2020. Now, the Board should resume its important work, and the following topics should be included on its “to do” list:

- Evaluating the current policies and rates for State-licensed residential care.
- Evaluating the current policies and rates for self-direction.
- Evaluating the current policies and rates for day habilitation.
- Evaluating the current policies and rates for transportation, including geographic/distance considerations.
- Evaluating the current policies and rates for behavioral supports and therapies.
- Evaluating the current policies and rates for Support Coordinators and Support Brokers.

Although the Board was focused exclusively on the NJ Department of Human Services – thus not including services for those 21 and under – its reconstitution could go a long way to making New Jersey’s system of care better, stronger, more accessible, and more person-centered. Specifically, it could help make sure the provider agencies at the center of our adult system have the right level of funding – not too much and not too little. It could also help make sure that we have the right policies and controls in place so funding is properly and most effectively spent.

Granted, none of this is easy. The demands placed on people who staff our system of care are often great. The work is hard. Mistakes are made. And the way forward is not always clear. That is true for those of us in government. That is true for those who serve as educators, providers, direct care staff, and advocates. But we must always remember that the demands placed on the people at the center of it all – the individuals with disabilities and their families – are even greater. Emotionally. Physically. Financially. Their lives are often challenging in ways we can only imagine.

This is why we need to share their sense of urgency. This is why we need to follow the money. And this is why we need to keep working, keep pushing, keep innovating, keep doing all we can to make sure all New Jerseyans with an intellectual or developmental disability and their families have the supports and services that they need and deserve.

Truth be told, I am an optimist and genuinely believe that we can do this. Working together, we can fix what needs to be fixed. We can improve what needs to be improved.

As my mother would (often) remind me: “Where there’s a will, there’s a way.”

Postscript

- “Nothing about us without us.” -

This year marks the 25th anniversary of the U.S. Supreme Court’s “Olmstead” decision – a case that was a watershed moment in the lives of Americans with disabilities.

To some, the 6-3 decision meant an end to the forced, “unjustified institutionalization” of people with disabilities. To some, it meant that and a whole lot more. It was about dignity. It was about civil and human rights. It was about personal choice – about acknowledging that people with disabilities – like all people everywhere – should be able to choose “where” and “how” to live their lives.

Taken together, the Olmstead decision was a long-overdue affirmation by the nation’s highest court that people with disabilities matter. What they need matters. What they want matters. What they say matters.

In that same spirit, it is incumbent on all of us working in the disability community, especially those of us in government, to ensure that the voice of people with disabilities is at the center of everything we do - every policy, every decision, every practice. To that end, it is imperative that we take long-overdue steps to ensure that happens – common-sense, practical steps suggested in our previous annual reports:

Staffing: We need to ensure that diversity in the workplace – especially positions at the most senior levels of government – includes people with lived disability experience, individuals as well as family members. Successful organizations ensure the right people are in the right positions.

- All government offices and committees - **not just those focused on disability issues** - should have meaningful representation from the disability community on their staff, because every issue affects people with disabilities.
- All government offices that make policies specifically 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.

Policy Making: We need to ensure that policy decisions are driven and guided by the needs and preferences of people with lived disability experience, individuals as well as family members. Successful organizations seek meaningful input from the people they serve prior to decisions being made.

- All government officials who make policies specifically for people with disabilities should be required to engage regularly, directly, and personally with people with lived disability experience.
- All government public meetings, including legislative hearings, should be offered in hybrid fashion, providing individuals with disabilities and family members the option to participate by video or in-person.

“I look forward to having you provide input once these materials are finalized.”

State Government Official to a Parent
April 2024

Since our office’s founding 6 years ago, we have tried to lead by example. We have lived disability experience. We have regular, personal engagement with individuals and families. And we have a profound commitment to seeing and hearing the people we serve – a commitment that includes a shared sense of urgency.

Going forward, I don’t expect that to change. Even during the transition to a new administration in 2026, I expect that the voice of individuals and families will reign supreme in the work of our office. The approach might change, but the commitment should certainly remain.

In her opinion for the majority in the Olmstead case, Justice Ruth Bader Ginsburg explained, “In sum, we conclude that Title II of the ADA requires States to provide community based treatment for persons with mental disabilities, when the State’s treatment professionals have determined that such placement is appropriate, **when the affected persons do not oppose such treatment** [emphasis added]....” Central to this decision is the individual’s preference, the individual’s voice.

Clearly, the high court got it right. Clearly, too, the rest of us should follow their lead and heed the disability community’s clarion call, which is embodied in that landmark decision: “Nothing about us without us.”

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 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. We always appreciate their passion, professionalism, and partnership.
 - We are also especially grateful to the leadership and staff of the NJ Division of Medical Assistance and Health Services (DMAHS) for their regular and timely assistance with Medicaid redetermination situations. We know it was a herculean task; yet, they were very responsive to the individuals and families who sought our assistance.
- 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 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 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.

Thank you.