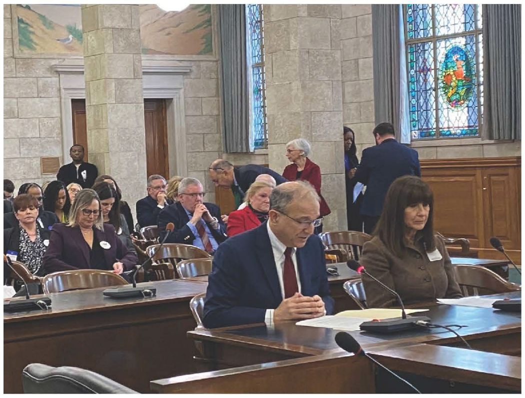
NJ Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families



2024 ANNUAL REPORT



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. We support you.

Fall and Recovery – Raising Children with Disabilities Through the Lessons Learned in Dance

(an excerpt from the preface to the book)

"I have a confession to make: ableism negatively influenced my experiences as a mother.

I didn't realize this for many years. As a parent, I didn't acknowledge the subtle and not-so-subtle messages our culture steeps us in. For me, ableism drives the awful hierarchy we live within – one where people are valued based on their cognitive intelligence and physical capabilities. I still encounter strangers who take one look at my son Benjamin in his wheelchair and say, "I'm sorry." As a parent, I have wrestled with and will continue to work on subduing the internalized belief that having a disabled child is bad.

I remember when doctors blamed mothers for their child's autism, deeming them cold "refrigerator moms." While we now know this is false, I believe these types of lies live in our culture's subconscious. Many are buried, and some have even been forgotten, but they're still there. In all my years of education, I was never taught the full history of how the disabled have been viewed and mistreated. I'm still learning.

… It's easy to say that a large part of my struggle as a parent of disabled children is because of ableism, but I think that is an oversimplification. It will always be painful for me to watch Benjamin have a seizure. It hurts me to see him in pain, and it hurts me to feel helpless in the face of that pain, to the point that I fall into the trap of blaming myself for it.

Human beings are complicated, and I believe the only way to learn and understand each other better is by sharing true stories."

— Joanne De Simone,
New Jersey Mother and Author
2024

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

2024 Annual Report

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PREFACE

A Labor of Love

This will likely be my last report as New Jersey's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families. Indeed, this will likely be my last year in this role.

In April 2018, when Governor Phil Murphy appointed me to this position, I really had no idea what to expect. In fact, none of us did. The Office was new, and there was not anything quite like it – here or anywhere else in the country. Largely the brainchild of parent advocates and State Legislators – Democrat and Republican – the idea was to create an office that would serve as a resource for individuals with lifespan disabilities and their families.

The newness of the position was both a challenge and an opportunity for us. We had to start from scratch. There was no office. There was no staff. There was no plan. All we had was an important legislative mandate and a heartfelt determination to do the right thing.

From the beginning, my priority was to help people in the most meaningful way and to do so without duplicating the work of other government offices. From my experience, I knew that meant taking an especially personal approach to our work – offering individuals and families someone at a senior level in government, who is accessible and who gives them the direct, person-centered attention they need and deserve. It also meant offering them someone with lived disability experience, who is relatable and who understands that life's challenges do not just happen weekdays between 9am and 5pm.

And so, with eyes, ears, and hearts wide open, we have made it a priority to communicate directly with people - seeing them and hearing them without any filters. No layers of staff. No buffers between us and them. Through direct emails and phone conversations and through one-on-one meetings and small gatherings, we have worked very closely with individuals and families across the State — learning firsthand about their lives, while trying our very best to help and support them. Weekdays. Weekends. Days. Nights.

Not surprisingly, due to the nature of our office, most of our work has involved some of the most serious, most difficult circumstances imaginable. Unmet medical and behavioral needs. Unchecked abuse and neglect. Untimely death. Indeed, as our office has evolved, people have increasingly sought our assistance with very challenging, very emotional situations.

Not surprisingly, too, this has been not only the most rewarding job I have ever had; it has also been the most heartbreaking and most infuriating.

On any given day, we are blessed to be in a position to help people in meaningful ways. We listen. We provide information. We offer advice. We help them navigate our State's well-resourced, albeit complex system of care. We help them advocate for a better, safer life for themselves and for their loved ones.

But on many days, we witness firsthand the disconnect that often exists between those making decisions and those impacted by them – the disconnect that sometimes results in bad policies, bad practices, and bad outcomes. And on many days, to make matters worse, we also witness a seeming disregard for the individuals and families at the center of it all – the children, adults, and families merely looking to their government or a provider organization for assistance, relief, or simple justice.

Granted, as we underscore in each and every annual report, there are many good people and good organizations providing supports and services throughout our State. People — in and out of government — who work hard and who have dedicated much of their professional lives to serving others. Organizations designed and operated to serve and protect individuals with disabilities. We know these people and organizations and are deeply grateful for them.

But make no mistake, our system also includes many other people and organizations, who do not seem to care and who do not seem to be “in it” for the right reason. They demonstrate little, if any, concern for the welfare and well-being of the individuals and families they are paid to serve. No sense of mission. No sense of urgency. No sense of responsibility. They just “check the box” or cash the check, depending on where they are in the system.

Indeed, we hear and see this indifference often, and it pains us to no end. After all, while most of us in the Office have our own personal connection to disability, all of us have a deep-seated passion for our work and all of us get emotionally invested in the many people who turn to us for assistance.

A Questionable Provider Agency Perspective

“The parents are ruining the environment for their children….
Parents poison the atmosphere and intimidate staff.
If we hire more staff, there will be more people
for the parents to complain to and intimidate.

I could suggest group therapy for all of them (parents),
but I’d end up paying for it.”

A CEO of a Provider Agency,
Responding to Parent Concerns
January 2025

Going forward, over the remaining months of this Administration, we will continue working to meet the day-to-day needs of individuals and families, while continuing to develop this relatively new office. Since the beginning, my goal has been to hand my successor a well-established organization that adds value to our State’s system of care by serving people in a particularly meaningful way.

To that end, this annual report is designed as a primer for the next Governor and next Ombudsman to help guide them through the transition to a new administration and to help prepare them to best serve our State’s dynamic, diverse, and deserving disability community.

An Administration colleague once commented that I approach my job much like a social worker would – providing my cell phone number to folks, visiting with them in their homes, and getting personally involved in their lives. Although not necessarily meant as a compliment, it was an accurate description about how I have viewed my responsibility and how I have done my work. I identified a need and have tried to meet it the best way possible based on my experience and my perspective.

The next Ombudsman may take a very different approach, which might make good sense. That person will bring to the Office a different mix of experience and perspective – one that will shape their approach to this office’s important mandate. That is to be expected. That can be both good and healthy.

I just hope and expect that the focus remains on the millions of New Jerseyans whose lives are impacted by disability – the children, the adults, the families. They need and deserve our support. They need and deserve a champion.

Without question, it has not only been a real honor to serve as New Jersey’s first Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families; as a passionate advocate and as a family member myself, it has also been a real labor of love.

Thank you.

Paul Aronsohn
Ombudsman
July 7, 2025

Our Office in Perspective

A Sample of Subject Headings from Emails Sent to Us in 2024

” Please help -Our son [redacted] CCP Residential Referral”
January 19, 2024

” Extreme Special Needs Child [redacted] [redacted] - Help Needed ?”
March 4, 2024

” Please help [redacted]!!”
March 28, 2024

“Abuse and Neglect”
January 12, 2024

Ty for the help!””
January 5, 2024

“[redacted]/abuse”
January 10, 2024

”Help-Direction for my Daughter”
January 8, 2024

“Alleged sexual abuse - [redacted]
July 22, 2024

”HELP!”
January 29, 2024

“Abuse”
April 8, 2024

“Mental Assault, Emotional abuse and Act of intimidation of a Parent/ Guardian by [redacted] Group home provider for my son with disability.”
February 6, 2024

“TBI FUND ABUSE CONTINUES”
March 22, 2024

“continued abuse”
April 2, 2024

“Help needed - DDD”
March 2,, 2024

“Can Paul A. Help?”
January 23, 2024

“Request for Public Hearing - Institutional Group Home Abuse”
February 21, 2024

“Help”
February 12, 2024

“Help needed – DDD”
February 16, 2024

“Please help me!”
April 12, 2024

“Help with Conference”
May 14, 2024

“Potential Help with Advocacy”
April 16, 2024

“Hoping you can help!”
April 3, 2024

“Seeking your help to effectuate change in our Adult Guardianship process”
February 22, 2024

“help with a [redacted] family”
May31, 2024

”Seeking urgent help for a Special Needs resident”
February 26, 2024

“Can you help please?”
April 23, 2024

“Help”
December 28, 2024

“Connecting to help a family”
April 20, 2024

“Neglect and Abuse in group homes”
May 7, 2024

“Helping with My Brother [redacted]”
May 9, 2024

Re: [redacted] - Abuse, Neglect, Injury - The [redacted] [redacted] Center”
May 6, 2024

“Report Institutional Abuse”
April 23, 2024

“Requesting update on [redacted] UIR (sexual abuse) from March 22, 2024”
May 14, 2024

“Can you help?”
November 13, 2024

“Thank you again for your help”
May 31, 2024

“Physical and verbal abuse”
September 16, 2024

“Requesting Help”
September 21, 2024

“I Desperately Need Your Help and Need To Speak To You”
June 27, 2024

“I need help”
June 26, 2024

“Urgent: Disability Help Needed”
October 1, 2024

“[redacted] - Urgent help needed please”
June 26, 2024

“I need your help…”
October 15, 2024

“Please Help”
January 4, 2024

“Help for my daughter”
July 3, 2024

“A request for your help”
June 18, 2024

“Urgent Help Needed for [redacted] Situation”
November 26, 2024

“Help”
June 14, 2024

“update still need help”
November 18, 2024

“Help needed”
December 2, 2024

“issue - hoping you can help us help families”
December 2, 2024

“Looking for some help maybe”
July 8, 2024

“Re: [redacted] Immediate Need for Placement
September 25, 2024

“Referral made to Division of Institutional abuse”
May 21,2024

INTRODUCTION

Telling The Story

This is our 7th annual report.

Since the beginning, we have tried to use these reports to tell “the story” lived by so many people across our State – extraordinary people whose lives are impacted by lifespan disabilities and whose stories often involve having to navigate difficult, seemingly intractable challenges. We share their experiences. We raise their concerns. We try to offer a way forward.

This year, as noted, the report was written with the next Administration in mind, and so we are also using it to tell our story – to share our experience as a small, but passionate staff of dedicated professionals working closely with these extraordinary individuals and families. Our lessons learned. Our key takeaways.

To that end, this report was shaped by much of what we have seen and heard over the past seven years —

- The daily accounts of abuse and neglect, primarily in State-licensed residential settings.
- The daily pleas for vital behavioral and/or medical supports.
- The daily appeals related to education, employment, housing, and transportation.
- The daily reminders that individuals and families are often mistreated by an unfair power dynamic that places them at a disadvantage when dealing with government offices, school districts, and provider organizations and agencies.
- The daily, emotional conversations with people merely seeking relief, understanding, and support from their government.

An Important Individual/Family Perspective

“I cannot begin to tell you the undue stress this has caused me and our family. Phone call after phone call, email after email. Hours and hours of my precious time for a process that is broken and ineffective. And the timing couldn’t be worse as we prepare for the sentencing in court this afternoon for the nurse who caused [our other child’s] death. It’s all just too much.”

Parent of a Young Adult with Significant Medical Needs,
Trying to Prevent an Inexplicable Reduction in Private Duty Nursing Coverage
April 2025

And the report includes our thoughts and recommendations regarding a way forward for the disability community in general and for our office in particular.

Not surprisingly, since the beginning, our reports have been met with a mix of reactions.

Individuals and families have often welcomed them for their candor and authenticity – for speaking truth to power on some difficult realities for New Jersey’s disability community. They relate to the topics covered. They agree with some, if not all, of the observations and recommendations. And they appreciate the honesty – the willingness to acknowledge that there is both good and bad in our State’s system of care for people with disabilities.

Others have had a different response. We have been told to emphasize the system’s strengths, rather than its shortcomings. We have been told to highlight improvements made, rather than opportunities missed or not pursued. We have been told to provide “context” when referring to provider agency spending, including with respect to executive compensation. And we have been told — repeatedly — not to talk so much about abuse and neglect, because doing so paints an unfairly bleak picture of the provider community. As one leader in the provider community explained, “It pains us when we see this, but the issue (abuse and neglect) is not as rampant as claimed” in the Ombudsman’s reports.

Such criticism is unfortunate and misses four key points:

1. **All of our annual reports have gone out of their way to highlight the system's "strengths," including the fact that there are a lot of good people and good organizations in our system of care.** Indeed, we have consistently recognized and praised people who staff our system – government officials, educators, direct care professionals, advocates, and providers. And with respect to provider agencies in particular, this is what was said in last year's report: "… 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."

2. **All of our annual reports have focused on the challenges faced by individuals and families, because <u>that</u> is the focus of our office's work.** People come to us with questions, concerns, and complaints. They seek our help with difficult, often crisis situations. They seek our advocacy with questionable policies and practices. Indeed, our Office was founded to assist individuals and families when challenges arise. To ignore these challenges in our reports would be to ignore our mission and our purpose and to misrepresent our work.

3. **We have long advocated for more transparency with respect to provider agency spending**. Our view is simple: Put the numbers out there. Put the "context" out there. Make this important information more readily available and let individuals, families, and the greater public decide if taxpayers' public money <u>and</u> individuals' personal money are being spent most appropriately. As we stated in last year's report, more transparency will help us to "determine whether more funding is needed or whether we just need to spend it more effectively… or both."

4. A**buse and neglect are, in fact, "rampant**." To be sure, many of the provider agencies seem to do all they can to prevent abuse and neglect. They try to develop genuinely professional, well-trained workforces. They utilize video technology in their group homes and apartments. And if/when abuse and neglect happen, they respond appropriately and thoroughly. Other provider agencies, however, are not as vigilant or serious, and frankly, our State government does not do enough to prevent or stop the abuse and neglect.

Moreover, we have a professional as well as a moral responsibility to address issues brought to our attention. That means working daily with government colleagues and providers to meet the specific challenges of individuals and families. That also means writing and speaking publicly about the system's shortcomings – identifying the problems and offering possible solutions.

Granted, ours have never been typical annual reports. They are written in a first-person, conversational style — applying the same personal touch to our reports as we apply to all of our work to make it more accessible and more relatable. They focus on outstanding issues that need to be addressed, rather than on past accomplishments. And they do not pull any punches.

That said, we do our very best to produce a report that is fair, balanced, and factual – one that tells "the story" as it is told to us without unfairly pointing fingers and laying blame. This is important. This is a priority for us. We realize it is not just "what" we say, but "how" we say it.

Regardless, the drafting of these reports has been an exhaustive annual process that involves many conversations, many reviews of notes and emails, and many rewrites. We choose our topics carefully. We choose our words judiciously. And believe it or not, we try our best to keep these reports short … or, at least, not too long.

Again, we do our best to tell the story as it is told to us.

NOTE: Throughout this report, I refer often to the "system" of care for people with disabilities. I do so because many people do not necessarily distinguish between the myriad school officials, government departments/offices, or provider agencies, <u>and</u> because many of the challenges discussed exist across the system as a whole.

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 few years, we have grown to be a full-time 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). We also had Sean Wood working with us part-time, and most recently, Leah Hughes as our Office’s first intern.

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.

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

2020	2021	2022	2023	2024
462	707	996	1,149	1,312

(estimate)

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.

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. 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 2024 SERVICES PROVIDED

The Year at a Glance

Throughout 2024, the work of our Office continued to be driven by and guided by our deep-seated sense of mission and sense of urgency. 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.

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. Indeed, our Office continues to place a premium on clear, constructive communication with and among all stakeholders.

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/Human Rights
Complex Medical Needs
Criminal Justice
Dental Health
Education/Student Transportation
Elections / Voting Accessibility
Employment
Financial Exploitation
Financial Planning
General Assistance Programs
Guardianship
Hospitals/Acute Care
Housing
Long Term Care / Nursing Homes
Managed Care
Medicaid
Medicare
Mental Health
Motor Vehicle Licenses/ID Cards
Physical Health
Private Duty Nursing
Private Insurance
Public Safety
Self-Advocacy
Self-Direction
Severe Challenging Behavior
Social Security
Transportation
Unemployment
Workability
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. Indeed, to the extent possible, we continued trying to accept any and all invitations to attend meetings, events, and other opportunities to engage with people in-person.

Accordingly, throughout 2024 –

- We worked daily with colleagues across the State's executive branch, including in the Departments of Children and Families, Community Affairs (Housing), Corrections, Education, Health, Human Services, Labor, Law & Public Safety, State, Treasury, Transportation, and 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 regular 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 Orlowski 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 42st 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 participated in regular meetings of the Attorney General's steering committee to strengthen coordination between law enforcement officers and members of the mental health and other special needs community.
- We participated in regular meetings of the NJ Group for Access and Integration Needs in Emergencies and Disasters (NJ GAINED), an advisory board to the NJ Office of Emergency Management.
- 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 a voter education event hosted by Heightened Independence and Progress in Hackensack.
- We participated in a DAWN Center for Independent Living support group session.
- We participated in multiple meetings of the NJCDD's Regional Family Support Planning Councils, and presented at a meeting of Regional Family Support Planning Council #1.
- We participated in multiple meetings of NJCDD's Developmental Disabilities Advocacy Network (DDAN) – the Children & Youth Family Support Service Committee as well as the Person-Centered Services Committee.
- We participated in multiple meetings of the New Jersey Association of County Disability Services and worked closely with several of its members to support residents in their respective counties.
- We participated in quarterly meetings of the New Jersey Legislative Disability Caucus.
- We participated in multiple meetings of The Arc of New Jersey's Statewide Self-Advocacy Network, including its 18th Annual NJ Statewide Self-Advocacy Network Spring Luncheon, its 40th Annual NJ Statewide Self-Advocacy Network Fall luncheon and meetings with each of the 5 regional councils.

- We participated in the annual Spring Carnival for Special Needs Children, which is held at Drumthwacket, the Governor’s official residence in Princeton.

- We met with the leadership of Parents with a Plan, a non-profit organization focused on person-centered supportive housing.

- We met on multiple occasions with the leadership of the New York Justice Center for the Protection of People with Special Needs.

- We participated in multiple resource fairs, including one co-organized by the Gloucester County Special Services School District and SPWA Services in Sewell, one organized by the South Bergen Jointure Commission in Lodi, the Annual Camden County Mental Health Resource Fair in Collingswood, and the NJ Special Education Administrators Association Transition Fair in Paramus.

- We participated in the annual Abilities Expo at the New Jersey Convention & Expo Center in Edison.

- We participated in an event to recognize Rare Disease Day organized by the Rare Action Network.

- We participated in the Annual Autism Support Group Retreat hosted by Nassan's Place in West Orange.

- We participated in a County Based Behavioral Threat and Management Workshop in Bergen County.

- We participated in meetings of the “Envisioning Your Best Life at All Stages” State Action Team.

- We visited Studio Route 29 in Frenchtown on two occasions – one for a meeting and one for a screening of Patrice — The Movie by Bridges Support Coordination.

- We visited the Hunterdon County Education Services Commission’s Thrive Day Habilitation Program in Califon.

- We participated in the 40th Anniversary Commemoration of the NJ Transit’s Senior Citizen and Disabled Residents Transportation Assistance Program.

- We participated in the Finally Home NJ Symposium organized by Values into Action.

- We participated in a Special Olympics New Jersey community event on the Johnson & Johnson campus.

- We participated in a Quality Assurance Forum of the Alliance for the Betterment of Citizens with Disabilities.

- We participated in programs organized by “Access-for-All” committees in Ridgewood, Hillsdale, and Mahwah.

- We participated in the "Black Impact Summit" – an event “aimed at addressing and overcoming the barriers faced by Black New Jersey residents with intellectual and developmental disabilities” and their families.

- We participated in the grand opening of the New Concepts for Living Achievement Center in Paramus.

- We participated in the second annual health and wellness conference organized by Bancroft and Cooper University Health Care.

- We participated in the Children’s Aid and Family Services’ annual 5K Run/Walk.

- We participated in the Union County “National Night Out for Everyone” event in Cranford.

- We participated in the annual Progressive Center for Independent Living softball game in Hamilton.

- We participated in meetings of the New Jersey chapter of the National Council on Severe Autism.
- We participated in a “Transitions Partnership” meeting organized by Employment Horizons in Cedar Knolls.
- We participated in a “Caregivers Conference” organized by the County of Middlesex in Edison.
- We co-organized and participated in quarterly meetings with Public Partnerships (self-direction), the NJ Division of Developmental Disabilities and individuals/families.
- We attended a Partners in Policymaking graduation ceremony.
- We attended a Mother’s Day event hosted by Mom2Mom, a family support helpline program.
- We attended the Inroads to Opportunities Spring Choir Concert and graduation in Roselle.
- We attended an outdoor musical event organized by HomeLife 21, a nonprofit organization to provide support to adults with profound autism.
- We attended the Summit House Graduation at Northern Valley Regional High School in Norwood.
- We attended a Project Search Gloucester Country graduation in Turnersville.
- We attended the STEPPS Transition Program graduation in Ridgewood.
- We attended annual BBQ hosted by the Bergen County United Way and Madeline Corporation for residents and families in Florham Park.
- We attended an Open House of the SPAN Parent Advocacy Network in Newark.
- We attended a screening of the film, “Patrice: The Movie” in Montclair.
- We attended Disability Rights New Jersey’s 30th Anniversary celebration in West Windsor.
- We attended a presentation by Jordyn Zimmerman (Educator/Disability Advocate) as part of the Montclair University Distinguished Lecture Program.
- We attended the Arc of New Jersey’s Medical Conference in New Brunswick.
- We hosted a “Transitions” webinar with colleagues from throughout the Administration – colleagues from the Departments of Children and Families, Education, Human Services, and Labor and Workforce Development.
- We attended a screening of a film about reproductive health at the Rowan-Virtua Regional Integrated Special Needs Center (RISN) in Sewell.
- We met with the leadership of the National Association of Direct Support Professionals.
- We visited with the leadership and participants of the St Joseph’s Church Basketball Clinic for adults with autism in Maplewood.
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- I delivered a presentation at the Region 7 Conference of the Self-Advocates Becoming Empowered (SABE) organization.

- I delivered a presentation at the 2024 Intellectual / Developmental Disabilities Youth Transition Conference and participated in the conference's "wrap up" conversation.

- I delivered remarks at the "Make the Disability Vote Count" event organized by the Alliance Center for Independence in Trenton.

- I delivered remarks at the Sixth Anniversary Heritage Fashion Show organized by the Passaic County Parents of Adults with Disabilities (PACOPAD) in Montclair and attended the group's holiday party.

- I delivered remarks at a housing conference organized by the Rowan University Steve Sweeney Center for Public Policy in Glassboro.

- I delivered remarks at a fashion show organized by Progressive Comprehensive Services in Whippany.

- I delivered remarks at the NJ County Jail Wardens Association meeting in Atlantic City.

- I delivered remarks at the Wally N Zavy's annual gala in Union.

- I delivered remarks at a self-direction conference organized by the Collaborative for Citizen Directed Supports at The College of New Jersey in Ewing.

- I delivered remarks at the annual meeting of ASAH in Atlantic City.

- I delivered remarks and participated in a conversation at a meeting of Community Options' Center for Advocacy Leaders in Denville.

- I testified during a hearing of the NJ Senate Committee for Health and Human Services.

- Our Office was included in media stories on various topics, including a Star Ledger series about abuse and neglect in State-licensed group homes and a NJ Spotlight story about housing.

- And again, we had more than 1,300 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 other Administration officials
    - Meetings with Legislators and Staff
    - Meetings with Providers
    - Meetings with Educators

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

- We onboarded the fifth full-time member of our team, Amanda Reece, as our Office's Constituent Relations Coordinator, who brought with her a valuable mix of energy, experience, and commitment.
- We on boarded the first part-time member of our team, Sean Wood, who brought with him a valuable mix of energy, perspective, and experience and who provided support to each of us.
- 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 second year of implementation, 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 continued to use our social media presences on Facebook and LinkedIn to share important information with the public.
- We continued to buildout our office's website into a more of a one-stop resource for individuals and families.

And lastly, we continued to prioritize training for all of us in the Office. Last year, in addition to sitting in on as many topical webinars as possible, we participated in a combined 339 hours of more formalized training on various topics, hosted by various organizations:

- Arc of New Jersey
- Autism New Jersey
- Autism Science Foundation
- Autism Speaks
- Bergen County Special Services Cape Resource Center
- Community Health Law Project (CHLP)
- Community Living Education Project (CLEP)
- Disability Rights New Jersey
- Employee Advisory Service
- NJ Children's System of Care (CSOC)
- NJ Council of Developmental Disabilities (NJCDD)
- NJ Division of Developmental Disabilities (DDD)
- NJ Division of Vocational and Rehabilitation Services (DVRS)
- NJ State Library
- Northeast ADA Center

OBSERVATIONS/RECOMMENDATIONS

A Tale of Two Systems

In each of our previous reports, I have asserted that New Jersey's system of care for people with disabilities is a tale of two systems – one good, one not good enough. After seven years in this position, I know that to be undeniably true.

Indeed, we are constantly reminded about the system's strengths and the tremendous resources available to individuals and families. The good, hardworking people — in and out of government — who have dedicated much of their professional lives to serving others. The good, mission-driven organizations that are committed to providing supports and services. And the robust, well-financed mix of state and local programs available for children, adults, and families.

However, we are also constantly reminded that those resources are not available to everyone who needs and deserves them – that systemic and issue-specific challenges often prevent people with disabilities from living safe, healthy, full lives in the community. In fact, most of our work involves individuals and families falling through the cracks in our system. Children going without vital treatments or being denied a quality education. Adults living in substandard settings or being denied much needed supports. Families having to fight nonstop to protect their loved ones against a system that is not altogether kind or friendly to families.

Systemic Observations & Recommendations

In our first annual report (2019), I offered some systemwide observations, outlining both the challenges and the opportunities associated with them. In this report, I am revisiting some of those observations, because frankly, the challenges and opportunities remain.

The Need for Empathy

For many people, living with lifespan disability can be traumatizing. Alongside any challenges and stresses presented by the disability itself, people with intellectual or developmental disabilities also often endure an ongoing, devastating mix of abuse — physical, sexual, emotional, medical, and/or financial. Indeed, they often experience this abuse at higher rates than the general population.

Moreover, individuals and their family members often endure an ongoing, insidious, psychological form of abuse from many of the people in their lives – including school officials, government officials, medical professionals, lawyers, provider agency staff, managed care organization staff, and even sometimes family, friends, and colleagues. The disregard. The disrespect. The condescension. The scorn. The exclusion. The discrimination. The humiliation. The judgement. The blame. The bullying. The curious looks. The disapproving looks. The gaslighting. The ghosting. And a host of other damaging indignities and forms of mistreatment.

For many individuals with disabilities and their family members, psychological abuse is a persistent, menacing reality in their lives – one that expresses itself in host of ongoing adverse events and experiences. It is therefore not surprising that many of them feel the effects of Post Traumatic Stress Disorder (PTSD).

An Important Individual/Family Perspective

"It chips away at you every day…. They diminish you."

A Parent Referring to the Way Provider Agency Staff Talk Down to Her
March 2025

Going forward, at a minimum, all of us working in the disability space should understand this, and we should approach our work with a heightened sensitivity. Indeed, empathy should be a job requirement. Empathy for the individual. Empathy for their family. And trauma-informed care should be required training for all frontline staff in and out of government. Rather than being part of the problem by adding to peoples' trauma, we should be part of the solution by providing much needed and much deserved relief.

The Need for Flexibility

For many people, our system of care is too rigid. Requests for accommodations are denied. Assessment tools miss the mark. One-size-fits-all policies seem more like the norm than the exception.

Granted, policies and rules are certainly important, but flexibility is sometimes necessary. This is especially true with respect to human services, because individuals have unique needs and preferences. There are always exceptions to the rule. This is not a bad thing. This is reality, and we should acknowledge it and embrace it. Importantly, doing so does not necessarily require more money; it just requires giving individuals and families more say in how money is spent. In fact, it could actually save money.

Going forward, we need to build more flexibility into our system of care for people with disabilities.

To this end, I recommend a comprehensive review of policies and practices to identify opportunities for more person-centered approaches. Such a review should include the NJ Department of Human Services' approach to self-direction as well as its decision last year to allow early enrollment into the Division of Developmental Disabilities (DDD) only for those youth planning to pursue higher education or competitive integrated employment – a policy that has raised questions about possible discrimination against those youth with the most significant disabilities.

An Important Individual/Family Perspective

"I would propose that DDD provide me with his daily rate (as if he were residing in a group home) and give me the flexibility (like a group home) to determine the right personnel and pay to best care for [my child]."

A Self-Directing Parent of a Young Adult with Significant Disabilities
February 2025

Alongside this review, frontline government staff should be reoriented and empowered to more readily consider requests, grant exceptions, and make accommodations.

Simply stated, with every individual and family situation, our goal should be to get to "yes."

The Need for Information

Information about policies as well as information about "what" resources exist and "how" best to access them is essential. It makes it possible for individuals and families to make informed choices about the supports and services available to them.

For many people, however, such information is hard to come by.

Sometimes the only information available to people is incomplete, conflicting, or just plain wrong. Sometimes the information is not really available at all, due to language, cultural, or socio-economic barriers. And sometimes people just "don't know what they don't know" and therefore never seek out the information in the first place.

Going forward, we need to make information more readily available – information that is clear, current, and correct. Granted, important steps have been taken in recent years – the Administration's launching last year of a one-stop online disability hub is a good example – but much more needs to be done.

To this end, at a minimum, the following steps should be taken —

- A requirement that State government policies are "written" and readily available to the public – putting an end to the unproductive guessing game that so many individuals, families, providers, and others are forced to play.
- A wholesale review of all State government disability-related websites to ensure that they are user-friendly and best-in-class in terms of accessibility and content.
- A concerted effort to reach underserved communities to help ensure that language, culture, and zip code are not barriers to individuals and families accessing information about the supports and services available.

The Need for a Sense of Urgency

For many people, timing is everything. Individuals and families often reach out to government offices with a sense of urgency. They need an answer. They need a decision. They need help accessing a program, a treatment, or a therapy. They need help navigating a crisis. And they need it now – not next week, next month, or next year.

We have repeatedly highlighted this sense of urgency in our annual reports, because it is so important, yet so often missing in the response from government officials, who either don't seem to "get it" or don't seem to care much about it. Either way, individuals and families are often told to wait … that is, if they even get a response at all.

Granted, some things do take time, but at a minimum, we need to understand that sense of urgency and respond accordingly with the right mix of seriousness and sensitivity. We need to understand that many people with disabilities and their families not only experience the daily pressures and stresses that we all encounter; they must also continuously navigate the challenges associated with the disability itself – the physical, emotional, and financial challenges often born out of disability. For many of them, there are no weekends. For many of them, holidays and summers are just times when government offices are closed or are even less responsive.

Going forward, at a minimum, we need to understand, embrace, and share a sense of urgency – something best achieved through personal connection.

An Important Individual/Family Perspective

"I know you said at this point we just have to "sit and wait", but there has to be something else that can be done.

Asking us to "sit and wait" for our son to do irreversible damage to his brain from punching himself and banging his head is not a viable option. We really need to put our heads together and start thinking outside the box."

A Parent of a 9-Year-Old Child with Severe Challenging Behavior,
Writing to the Family's Care Manager After Being in Crisis for About One Year
May 2025

Going forward, we offer two suggestions – both of which were included in previous reports:

- **Government policy-makers should spend more time with individuals with disabilities and their families.** In fact, it should be made a job requirement. They need to know and better understand the people at the receiving end of their policies. This does not mean making speeches to large audiences. This does not mean stopping by large events. This means spending quality, one-on-one time with individuals and families – visiting people where they live, work, school, or socialize – and listening, rather than talking.

- **More people with lived disability experience should be placed in frontline and policy-making positions.** Granted, I know that many of our colleagues in other State government offices have their own personal experience with disability, and I know, too, that a person does not need to have lived experience to be a good listener or good policy-maker. But I also know that people with lived, personal experience understand and respond to disability differently and should be a part of any policy-making conversation, if not driving it.

The Need for Simplicity

For many people, our system of care for people with disabilities is too confusing. There are so many programs with so many names and so many acronyms offered by so many offices in so many departments with so many different timelines, requirements and eligibility criteria. And to make matters even more confusing, it all seems to keep changing.

Without question, this complexity is one of the biggest barriers keeping people from accessing the supports and services they need and deserve. It is one of the reasons many individuals and families feel so overwhelmed.

Going forward, we need to simplify the system.

In my first annual report, in 2019, I suggested that we undertake "a comprehensive, zero-based budgeting type review of the State's system of services and supports for people with intellectual or developmental disabilities. Starting with a figurative blank piece of paper, we should explore ways to streamline the system – making it more efficient and more effective." Years later, I stand by that suggestion.

Such a review would not only likely result in a strengthened system of care – one more finely tuned to the current needs of individuals and families – it would also likely result in a more streamlined, more cost efficient, more user-friendly system. Outdated policies and programs could be eliminated. Needed supports and services could be better funded. And the labyrinth of State, County, and Municipal processes could be updated and simplified.

Indeed, such a review would provide an opportunity to design a system of care for people with disabilities that makes sense and saves money. I speak about this more in the Postscript to this report.

The Need for Transparency

For many people, the system lacks transparency. Decisions are made. Policies developed. Monies spent. Investigations conducted. Often without their input or knowledge. Often against their interests.

It is an unsettling feeling for many people – one that breeds mistrust towards everyone involved. And without trust, the system is weakened.

The need for more transparency is very real and systemwide:

- to help ensure decisions made are properly informed and properly executed;
- to increase accountability of those involved; and
- to help restore and maintain trust.

Indeed, transparency can be the best confidence building measure for individuals, families, and everyone else involved.

From our experience, here are the top four areas that require much more transparency (in no particular order):

Decision/Policy-Making: There needs to be much more transparency with respect to the making of decisions/policies by local school districts and State government departments – the processes as well as the outcomes. And again, there should be a requirement that all policies be more readily available to the general public. Indeed, everything should be in writing.

An Important Individual/Family Perspective

"I'd prefer to have it in writing so I can go back and reread in the future if needed, as opposed to a phone call."

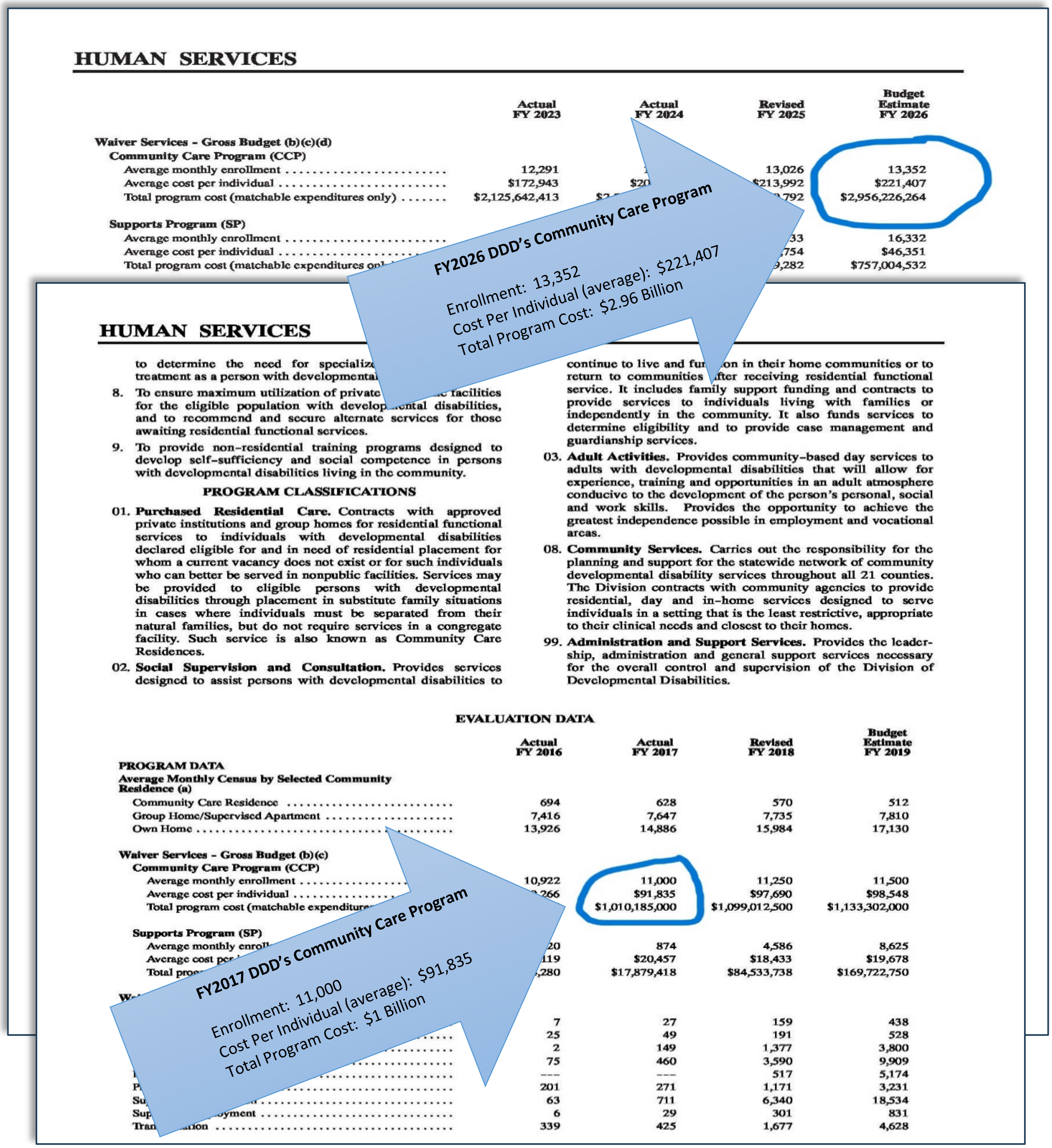
Parent of a Youth in the Children's System
March 2025

- **Investigations**: There needs to be much more transparency with respect to the investigations of abuse, neglect and unexpected deaths in State-licensed residences – the processes as well as the outcomes. Much more needs to be known about "who" is interviewed, "how" they are interviewed, the questions asked, and the information sought. And final investigative reports should be more readily available to those involved, namely the individual and/or their guardian – a practice similar to that which exists in New York.
- **Managed Care Organization**s (MCO): There needs to be much more transparency with respect to the way decisions are made and money is spent by the private companies at the center of New Jersey's multi-billion-dollar Medicaid program. And MCOs, too, should be required to put everything in writing.
- **Residential Provider Agencies**: There needs to be much more transparency with respect to the way private residential provider agencies spend public dollars as well as the way they spend the personal monies entrusted to them by their residents. In fact, I believe that transparency is even more important than caps and similar directives related to executive compensation and overall agency spending. We all need to know how money is being spent … and not being spent. There also needs to be a lot more transparency with respect to residents' medical records and agency notes. Individuals or their guardians should have access to all of their personal information available to provider agencies.

Residential Provider Agency Transparency in Perspective

Since 2017, the NJ Department of Human Services' Community Care Program budget has increased by about 200%. The program's enrollment, however, has only increased by 21%.

Approximately two-thirds of the program's budget is paid to residential provider agencies.



HUMAN SERVICES

	Actual FY 2023	Actual FY 2024	Revised FY 2025	Budget Estimate FY 2026
Waiver Services - Gross Budget (b)(c)(d)				
Community Care Program (CCP)				
Average monthly enrollment	12,291	1	13,026	13,352
Average cost per individual	$172,943	$20	$213,992	$221,407
Total program cost (matchable expenditures only)	$2,125,642,413	$2	792	$2,956,226,264
Supports Program (SP)				
Average monthly enrollment			33	16,332
Average cost per individual			754	$46,351
Total program cost (matchable expenditures onl			9,282	$757,004,532

FY2026 DDD's Community Care Program

Enrollment: 13,352
Cost Per Individual (average): $221,407
Total Program Cost: $2.96 Billion

HUMAN SERVICES

to determine the need for specialize treatment as a person with developmental

8. To ensure maximum utilization of private facilities for the eligible population with develop ental disabilities, and to recommend and secure alternate services for those awaiting residential functional services.

9. To provide non-residential training programs designed to develop self-sufficiency and social competence in persons with developmental disabilities living in the community.

PROGRAM CLASSIFICATIONS

01. **Purchased Residential Care.** Contracts with approved private institutions and group homes for residential functional services to individuals with developmental disabilities declared eligible for and in need of residential placement for whom a current vacancy does not exist or for such individuals who can better be served in nonpublic facilities. Services may be provided to eligible persons with developmental disabilities through placement in substitute family situations in cases where individuals must be separated from their natural families, but do not require services in a congregate facility. Such service is also known as Community Care Residences.

02. **Social Supervision and Consultation.** Provides services designed to assist persons with developmental disabilities to continue to live and fun on in their home communities or to return to communities fter receiving residential functional service. It includes family support funding and contracts to provide services to individuals living with families or independently in the community. It also funds services to determine eligibility and to provide case management and guardianship services.

03. **Adult Activities.** Provides community-based day services to adults with developmental disabilities that will allow for experience, training and opportunities in an adult atmosphere conducive to the development of the person's personal, social and work skills. Provides the opportunity to achieve the greatest independence possible in employment and vocational areas.

08. **Community Services.** Carries out the responsibility for the planning and support for the statewide network of community developmental disability services throughout all 21 counties. The Division contracts with community agencies to provide residential, day and in-home services designed to serve individuals in a setting that is the least restrictive, appropriate to their clinical needs and closest to their homes.

99. **Administration and Support Services.** Provides the leadership, administration and general support services necessary for the overall control and supervision of the Division of Developmental Disabilities.

EVALUATION DATA

	Actual FY 2016	Actual FY 2017	Revised FY 2018	Budget Estimate FY 2019
PROGRAM DATA				
Average Monthly Census by Selected Community Residence (a)				
Community Care Residence	694	628	570	512
Group Home/Supervised Apartment	7,416	7,647	7,735	7,810
Own Home	13,926	14,886	15,984	17,130
Waiver Services - Gross Budget (b)(c)				
Community Care Program (CCP)				
Average monthly enrollment	10,922	11,000	11,250	11,500
Average cost per individual	266	$91,835	$97,690	$98,548
Total program cost (matchable expenditure		$1,010,185,000	$1,099,012,500	$1,133,302,000
Supports Program (SP)				
Average monthly enroll	20	874	4,586	8,625
Average cost pe	119	$20,457	$18,433	$19,678
Total pro	,280	$17,879,418	$84,533,738	$169,722,750
W				
	7	27	159	438
	25	49	191	528
	2	149	1,377	3,800
	75	460	3,590	9,909
	---	---	517	5,174
P	201	271	1,171	3,231
Su	63	711	6,340	18,534
Sup oyment	6	29	301	831
Tran ation	339	425	1,677	4,628

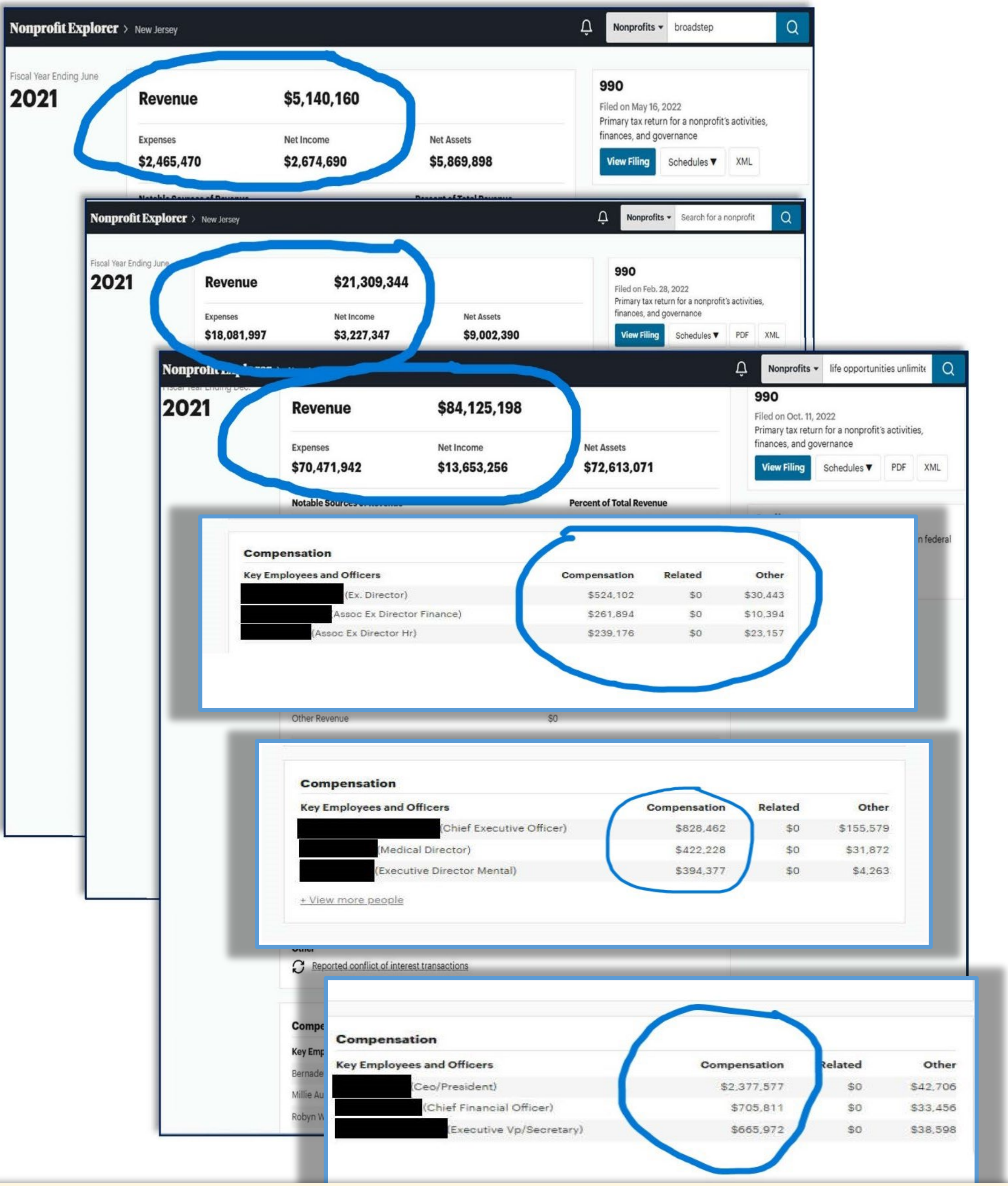
FY2017 DDD's Community Care Program

Enrollment: 11,000
Cost Per Individual (average): $91,835
Total Program Cost: $1 Billion

Question: With a near tripling of the CCP budget to almost $3 Billion and only a small increase in enrollment, where's the money going?

Residential Provider Agency Transparency in Perspective

"Fee-for-Service" Medicaid (taxpayer) funding is the source of most provider agency revenues.
Below is information from IRS 990 forms from different nonprofit residential provider agencies.



Fiscal Year Ending June
2021

Revenue	$5,140,160	
Expenses	Net Income	Net Assets
$2,465,470	$2,674,690	$5,869,898

990
Filed on May 16, 2022
Primary tax return for a nonprofit's activities, finances, and governance

Fiscal Year Ending June
2021

Revenue	$21,309,344	
Expenses	Net Income	Net Assets
$18,081,997	$3,227,347	$9,002,390

990
Filed on Feb. 28, 2022
Primary tax return for a nonprofit's activities, finances, and governance

2021

Revenue	$84,125,198	
Expenses	Net Income	Net Assets
$70,471,942	$13,653,256	$72,613,071

990
Filed on Oct. 11, 2022
Primary tax return for a nonprofit's activities, finances, and governance

Percent of Total Revenue

n federal

Compensation

Key Employees and Officers	Compensation	Related	Other
[redacted] (Ex. Director)	$524,102	$0	$30,443
[redacted] (Assoc Ex Director Finance)	$261,894	$0	$10,394
[redacted] (Assoc Ex Director Hr)	$239,176	$0	$23,157

Other Revenue $0

Compensation

Key Employees and Officers	Compensation	Related	Other
[redacted] (Chief Executive Officer)	$828,462	$0	$155,579
[redacted] (Medical Director)	$422,228	$0	$31,872
[redacted] (Executive Director Mental)	$394,377	$0	$4,263

+ View more people

Reported conflict of interest transactions

Compe
Key Emp
Bernade
Millie Au
Robyn W

Compensation

Key Employees and Officers	Compensation	Related	Other
[redacted] (Ceo/President)	$2,377,577	$0	$42,706
[redacted] (Chief Financial Officer)	$705,811	$0	$33,456
[redacted] (Executive Vp/Secretary)	$665,972	$0	$38,598

Question: In a taxpayer funded, fee-for-service system, should agencies make such large profits – revenues vs. expenses?
Question: In a taxpayer funded, fee-for-service system, how much should executives be paid?

Issue-Specific Observations & Recommendations

In our Office, we try to help individuals and families with practically any issue brought to our attention. We do not always have an answer, but we are often in a position to help in some way.

Below is a discussion of some of those issues. It is by no means an exhaustive list; nor is it a discussion of the most important issues. Indeed, every issue is important to someone. Rather, it a discussion of some of the larger issues often brought to our attention.

On each of the issues discussed below, there is much that can and should be done. However, I am offering no more than a few recommendations per issue, realizing the next Administration — like any administration — must prioritize its goals.

Abuse & Neglect

In October 2018, one of the leaders in NJ's disability provider community referred to instances of abuse and neglect as "uncommon events." Although only a few months on the job, I was confused by the statement, because my experience was already telling me otherwise – that abuse and neglect were seemingly common and pervasive. Fast forward a couple of years, the situation seemed so dire that I felt compelled to include a thorough discussion in our 2020 annual report – one that stated emphatically, "People may disagree about the prevalence of abuse or neglect, but there is absolutely no denying it exists."

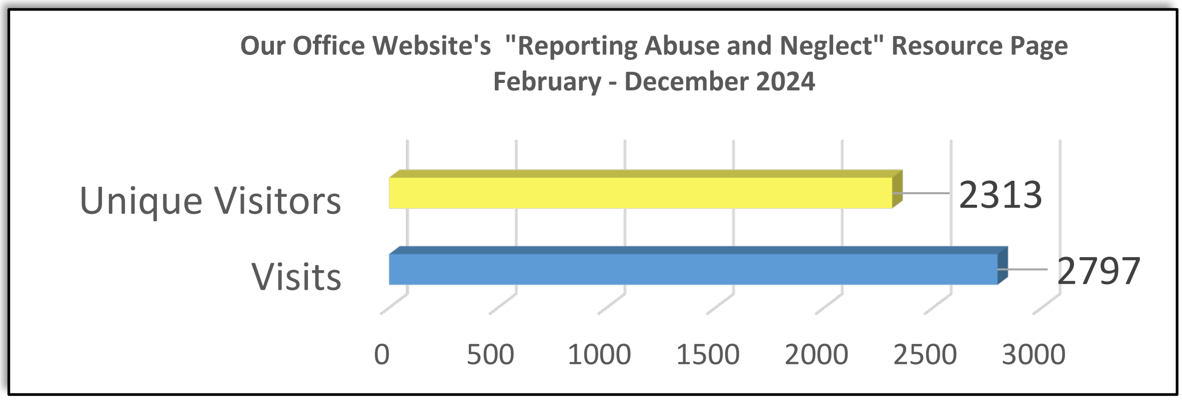
Since then, abuse and neglect has been a central topic in each of our reports. Why? Because abuse and neglect has been — and continues to be — a central focus of our day-to-day work. Physical abuse. Emotional abuse. Sexual abuse. Improper medicine administration. Improper food practices. Questionable visitation policies. Questionable house practices. Unexplained injuries. Unexplained deaths. Not a single day goes by without someone contacting us about an allegation of abuse and neglect. Sometimes it is about a new, terrible experience. Often it is about an ongoing situation.

As just one indicator of this deplorable reality, last year, our Office website's "How to Report Abuse & Neglect" section had 2,313 unique visitors – those visiting the section for the first time. In fact, during the 11 months last year that we tracked such metrics, at least one new person per day visited our site's abuse and neglect section.

Without question, abuse and neglect in State-licensed residential settings — for children as well as adults — has been one of the most concerning and most persistent challenges brought to our attention over the years. And one of the most heartbreaking and infuriating truths about this shameful reality is that relatively few people — working within the system — seem willing to acknowledge it, much less talk about it.

Granted, I fully recognize that providing supports and services for individuals with intellectual or developmental disabilities is not easy. Whether you are sitting in a government office making policy or working in a group home providing direct care, the responsibilities are challenging. The demands are great. Mistakes are sometimes made.

But let's be clear – none of this is rocket science. Preventing abuse and neglect is not hard. We know the causes. We know the solutions. We just need the collective will to take the necessary steps and make the necessary changes.



Going forward, at a minimum, we offer the following three sets of recommendations:

- **Direct Care Staffing:** We know that abuse and neglect occur in group homes that are understaffed. We know that abuse and neglect occur in group homes where staff are underpaid and undertrained. We know that there is high turnover and high vacancy rates of direct care staff in group homes, because they are underpaid, undertrained, and/or overworked. We therefore know that our approach to group home staffing is not working – that we have effectively set the system up for failure.

  And despite claims to the contrary and small annual wage increases, the undeniable fact remains: Direct Support Professionals in New Jersey are still paid only a little more than minimum wage on average and only a little more than starting salaries at supermarkets – far less than the demands of the job would suggest.

  As such, we recommend a more reality-based approach to direct care staffing – one rooted in common sense. Real simple – if we want good outcomes, we need to pay good salaries, provide good training, and require good performance. More specifically, we recommend that direct care staff be paid a living wage (indexed annually) and trained appropriately and that staff-to-resident ratios be established and enforced by the NJ Department of Human Services. (The NJ Department of Children and Families already has such ratios.)

  Importantly, this can and should be done without the State having to put more money into the system. After all, many provider agencies are already paid between $250,000 and $500,000 per year per resident.

- **Investigations:** We know abuse and neglect are under-reported. We know there are serious questions about the quality of the investigations, process as well as substance. We know most investigations are conducted by the provider agencies themselves and that, in the end, most allegations against them are "unsubstantiated." We know deaths in group homes are not automatically investigated by the State, even when they are unexpected or otherwise suspicious. We know final investigation reports are rarely shared with anyone, even the individual or guardian.

  An Important Provider Agency Admission

  "There is no transparency or accountability in the investigatory process."

  A CEO of a Provider Agency,
  In an Email to Families
  December 2024

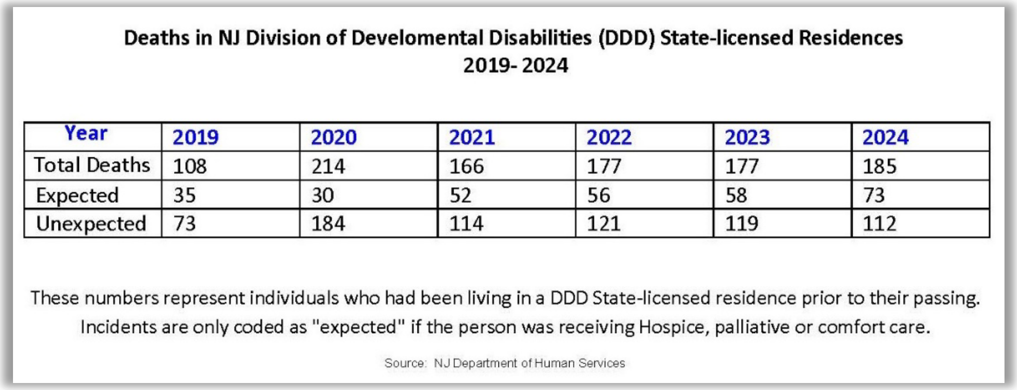
  And we also know none of this makes sense.

  Simply stated, when it comes to investigations of abuse and neglect, the status quo is clearly not working.

  Most notably, allowing provider agencies to investigate themselves is just bad policy. At the most basic level, it undermines trust in the provider agencies as well as the system of care as a whole. The process is suspect. The final report is suspect. And no finding of "unsubstantiated" will ever be believed. Moreover, not investigating all deaths in State-licensed residences is bad policy, too. This is particularly true with respect to the nearly 70% of deaths considered "unexpected."

  Therefore, for everyone's sake, we should explore the possibility of having a third party, independent organization responsible for investigations. To this end, we recommend that we look to New York's Justice Center for the Protection of People with Special Needs as a model for us to consider here in New Jersey.

  Whatever the answer, we need to get this right. Investigations have to be real if we are to stop the abuse.



Deaths in NJ Division of Develomental Disabilities (DDD) State-licensed Residences 2019- 2024

Year	2019	2020	2021	2022	2023	2024
Total Deaths	108	214	166	177	177	185
Expected	35	30	52	56	58	73
Unexpected	73	184	114	121	119	112

These numbers represent individuals who had been living in a DDD State-licensed residence prior to their passing. Incidents are only coded as "expected" if the person was receiving Hospice, palliative or comfort care.

Source: NJ Department of Human Services

- **Accountability:** We know there are good provider agencies led by good, mission-driven people and staffed by good, caring, hardworking professionals. But we also know the opposite is true – that there are some agencies that are not so good, agencies that have organizational cultures seemingly not aligned with the interests of the people they are charged to serve. We know that there are minimal incentives to keep the bad actors from acting badly. Indeed, we know that there are currently no civil financial penalties for agencies that violate State policies, understaff group homes, or allow abuse and neglect to happen.

  As such, we recommend holding provider agencies accountable by following the lead of the NJ Department of Health, which long ago established a schedule of civil monetary penalties to penalize hospitals, nursing homes, and assisted living residences for misconduct. (Indeed, the Department even publishes its enforcement letters to providers on its website.) Specifically, we recommend the NJ Department of Children and Families and the NJ Department of Human Services adopt and impose similar monetary penalties as a way to persuade even the poorest performers to do the right thing and to do it in the right way.

  With the threat of such penalties, otherwise underperforming provider agencies may be more inclined to ensure their residences are properly staffed, to ensure frontline staff have the right training and resources, and to take other preventative and corrective actions, as needed.

  A Questionable Government Policy

  "No, DHS does not have enforcement regulations that impose fines."

  A Senior NJ Department of Human Services Official,
  November 19, 2023

  We also recommend that video cameras be more readily available in State-licensed settings, because we know that many people living in group homes are among our State's most vulnerable people. We know many have an intellectual disability. We know many have a communication disability, including many who cannot speak. We know many of them and their families fear retribution from provider agencies if they express a concern or if they question a policy or practice. We know that many, if not all, families want video cameras in the common areas of group homes. We know that many, if not all, provider agencies that use video cameras swear by them as an invaluable tool for protecting residents, protecting staff, and educating all involved in particular situations.

  We also recommend that The Stephen Komninos Law be extended to the NJ Department of Children and Families. It has never made sense to me why this important law – which aims to ensure the safety and well-being of people with disabilities living in State-licensed settings – only applies to adults over the age of 21. Moreover, the NJ Department of Human Services should begin enforcing a key provision of the law, which has been largely overlooked or disregarded until now – the provision that states the following:

  > "*The provider of a community-based residential program shall request contact information from each parent or guardian of an individual with a developmental disability who is residing in the residential program, and shall advise the parent or guardian that, if the parent or guardian agrees, the provider will exchange contact information with other parents and guardians of individuals with developmental disabilities residing in the residential program, in order to provide an opportunity for parents and guardians to share experiences about the individuals.*"

  This is critically important and was put into the 2017 law for a reason: When families communicate, less abuse and neglect is likely to occur. They can share observations. They can share concerns. They can work together if abuse and neglect is suspected.

And finally, again, we recommend a lot more transparency – transparency with respect to the ways in which monies are spent and transparency with respect to the medical records and agency files involving residents.

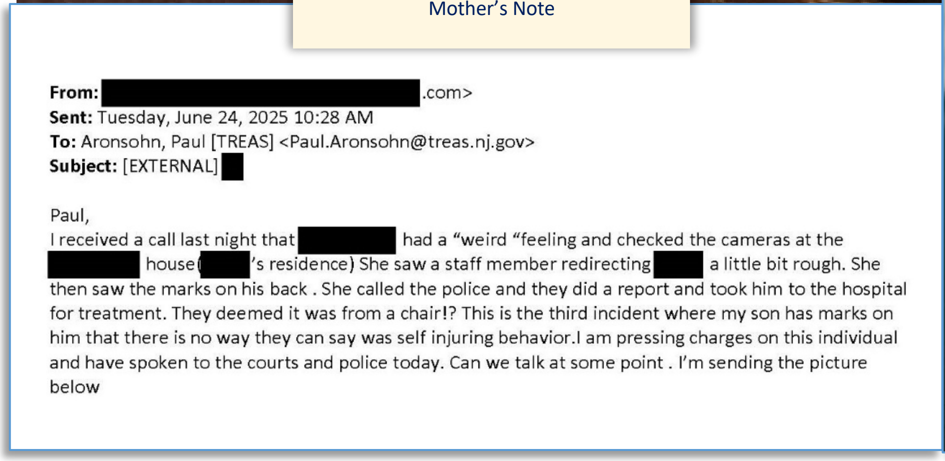
A Questionable Provider Agency Perspective

"We have problems here, because unlike in the group homes, the parents are collaborating with each other …
The ones who don't know the other parents are perfect."

A CEO of a Provider Agency,
Responding to Concerns from Parents of Residents Living in a State-Licensed Apartment Setting
January 2025

Abuse in Perspective

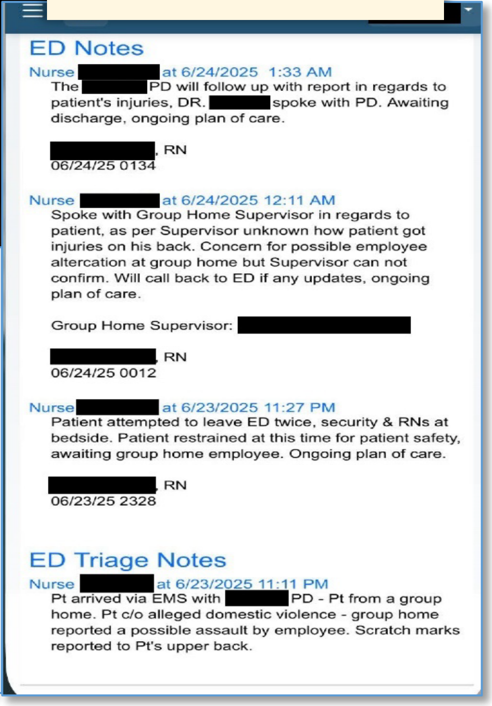
Mother's Note



From: [redacted].com>
Sent: Tuesday, June 24, 2025 10:28 AM
To: Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>
Subject: [EXTERNAL] [redacted]

Paul,
I received a call last night that [redacted] had a "weird "feeling and checked the cameras at the [redacted] house([redacted]'s residence) She saw a staff member redirecting [redacted] a little bit rough. She then saw the marks on his back . She called the police and they did a report and took him to the hospital for treatment. They deemed it was from a chair!? This is the third incident where my son has marks on him that there is no way they can say was self injuring behavior.I am pressing charges on this individual and have spoken to the courts and police today. Can we talk at some point . I'm sending the picture below

Hospital's Notes



[redacted]

ED Notes

Nurse [redacted] at 6/24/2025 1:33 AM
The [redacted] PD will follow up with report in regards to patient's injuries, DR. [redacted] spoke with PD. Awaiting discharge, ongoing plan of care.

[redacted], RN
06/24/25 0134

Nurse [redacted] at 6/24/2025 12:11 AM
Spoke with Group Home Supervisor in regards to patient, as per Supervisor unknown how patient got injuries on his back. Concern for possible employee altercation at group home but Supervisor can not confirm. Will call back to ED if any updates, ongoing plan of care.

Group Home Supervisor: [redacted]

[redacted], RN
06/24/25 0012

Nurse [redacted] at 6/23/2025 11:27 PM
Patient attempted to leave ED twice, security & RNs at bedside. Patient restrained at this time for patient safety, awaiting group home employee. Ongoing plan of care.

[redacted], RN
06/23/25 2328

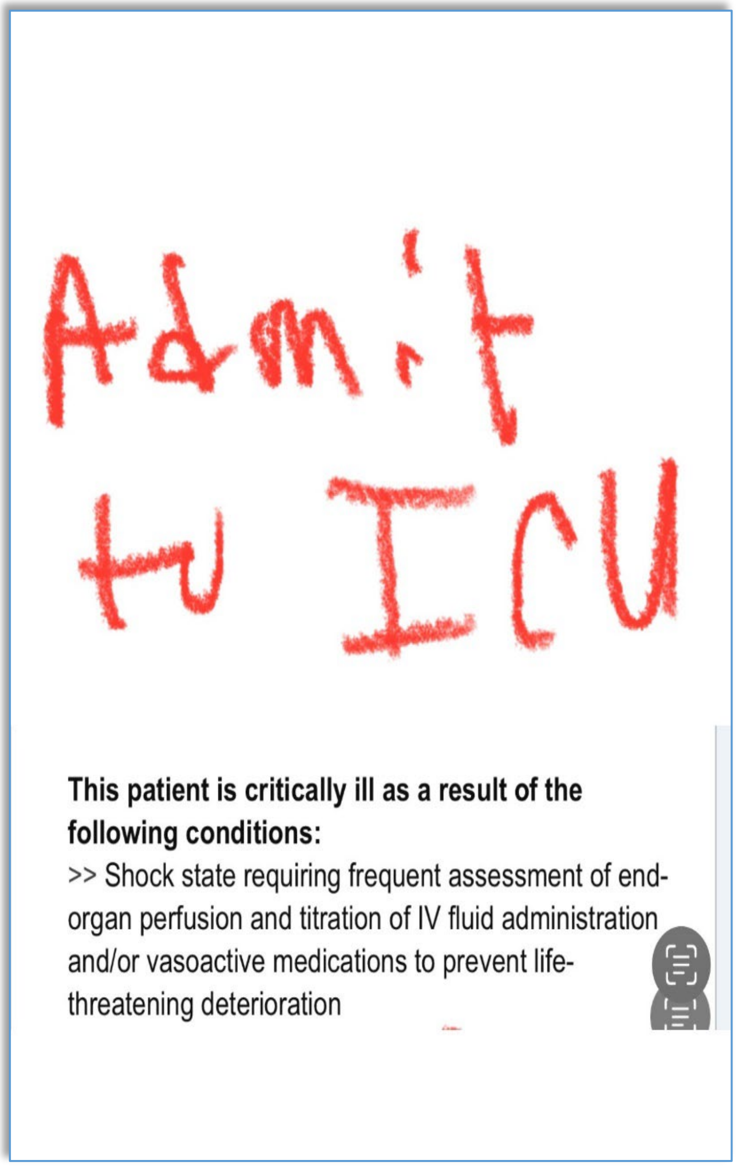
ED Triage Notes

Nurse [redacted] at 6/23/2025 11:11 PM
Pt arrived via EMS with [redacted] PD - Pt from a group home. Pt c/o alleged domestic violence - group home reported a possible assault by employee. Scratch marks reported to Pt's upper back.

Question: Why aren't we doing more to prevent abuse and neglect?

Abuse in Perspective

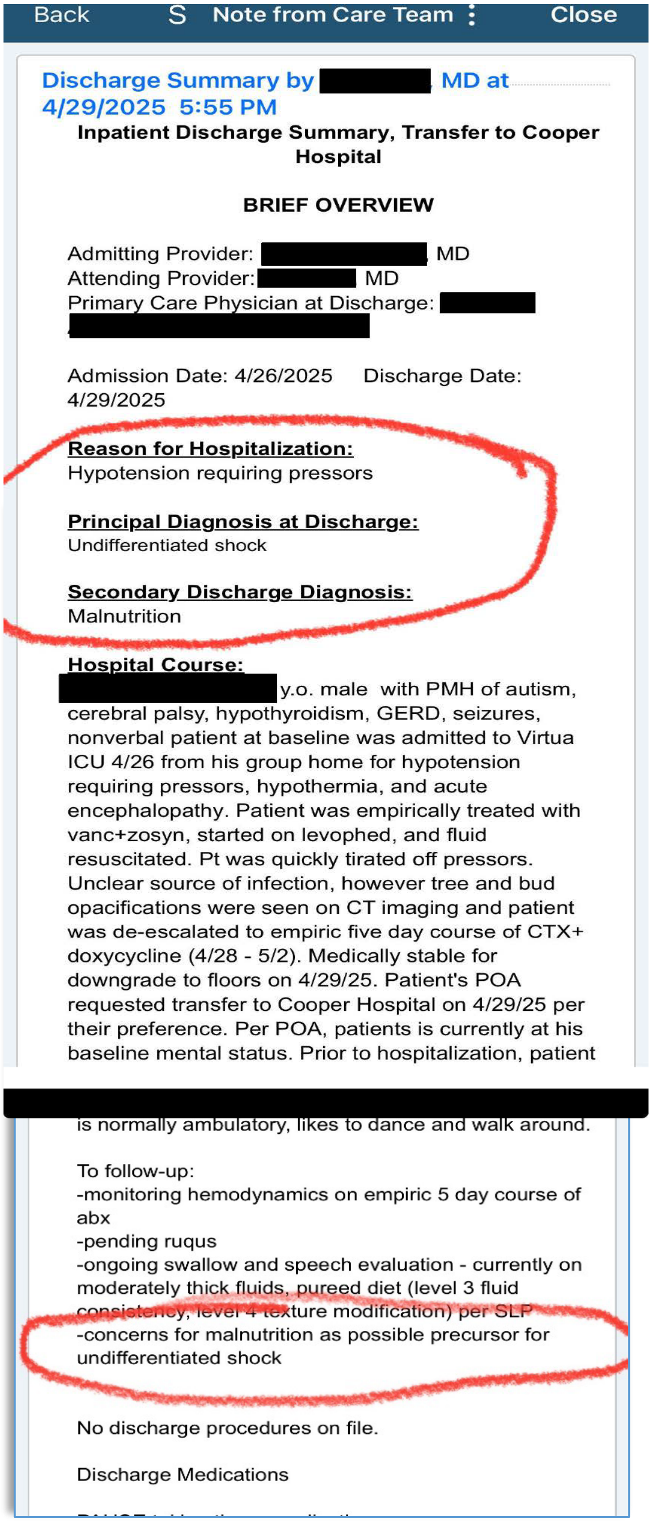
Hospital paperwork for a group home resident diagnosed with "malnutrition."



Admit to ICU

This patient is critically ill as a result of the following conditions:

>> Shock state requiring frequent assessment of end-organ perfusion and titration of IV fluid administration and/or vasoactive medications to prevent life-threatening deterioration



Discharge Summary by [redacted], MD at 4/29/2025 5:55 PM

Inpatient Discharge Summary, Transfer to Cooper Hospital

BRIEF OVERVIEW

Admitting Provider: [redacted] MD
Attending Provider: [redacted] MD
Primary Care Physician at Discharge: [redacted]
[redacted]

Admission Date: 4/26/2025 Discharge Date: 4/29/2025

Reason for Hospitalization:
Hypotension requiring pressors

Principal Diagnosis at Discharge:
Undifferentiated shock

Secondary Discharge Diagnosis:
Malnutrition

Hospital Course:
[redacted] y.o. male with PMH of autism, cerebral palsy, hypothyroidism, GERD, seizures, nonverbal patient at baseline was admitted to Virtua ICU 4/26 from his group home for hypotension requiring pressors, hypothermia, and acute encephalopathy. Patient was empirically treated with vanc+zosyn, started on levophed, and fluid resuscitated. Pt was quickly tirated off pressors. Unclear source of infection, however tree and bud opacifications were seen on CT imaging and patient was de-escalated to empiric five day course of CTX+ doxycycline (4/28 - 5/2). Medically stable for downgrade to floors on 4/29/25. Patient's POA requested transfer to Cooper Hospital on 4/29/25 per their preference. Per POA, patients is currently at his baseline mental status. Prior to hospitalization, patient

[redacted]

is normally ambulatory, likes to dance and walk around.

To follow-up:
-monitoring hemodynamics on empiric 5 day course of abx
-pending ruqus
-ongoing swallow and speech evaluation - currently on moderately thick fluids, pureed diet (level 3 fluid consistency, level 4 texture modification) per SLP
-concerns for malnutrition as possible precursor for undifferentiated shock

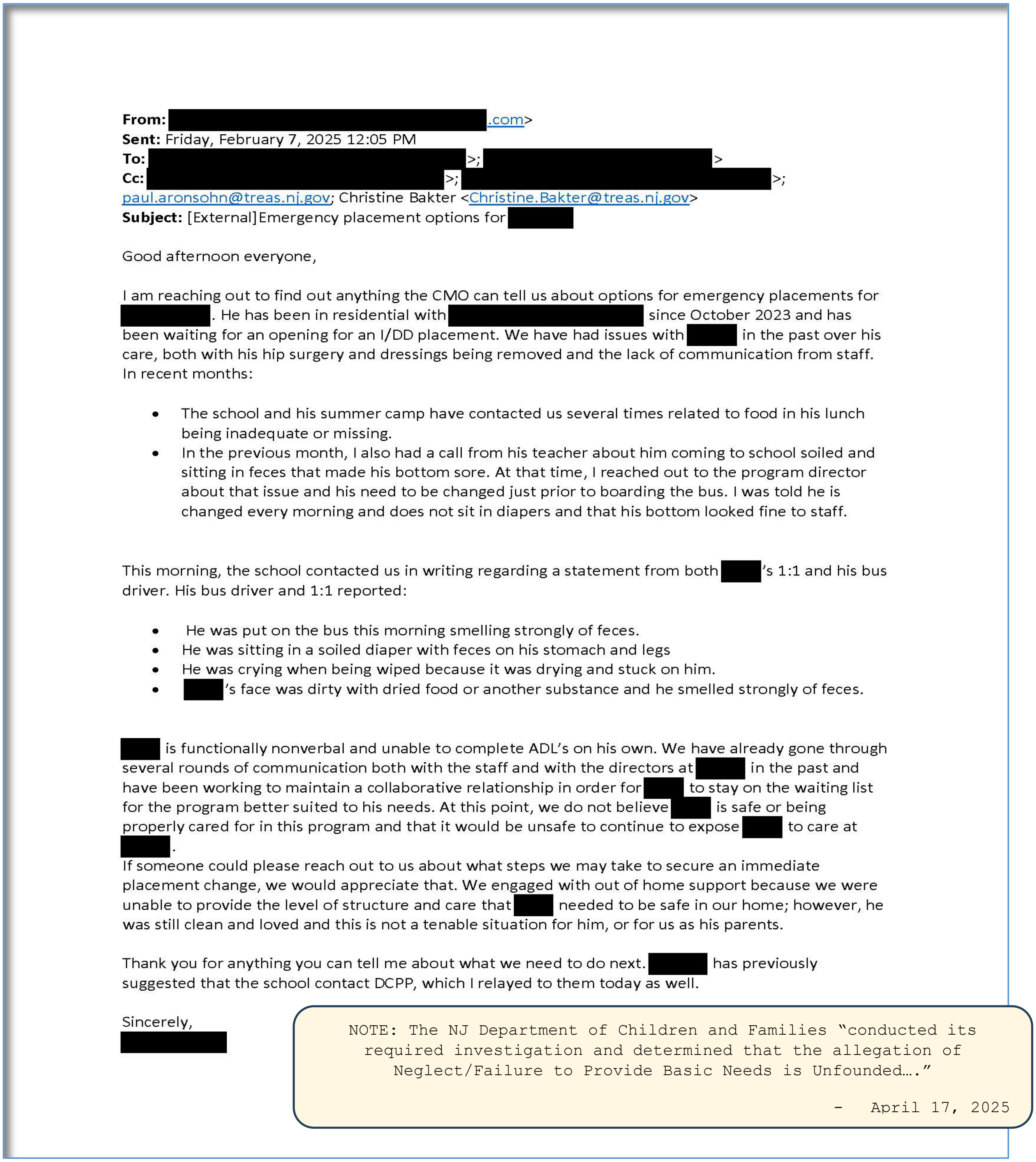
No discharge procedures on file.

Discharge Medications

Question: Should group home staff be trained better?

Question: Should the provider agency be held accountable if a resident is diagnosed with "malnutrition?"

Abuse in Perspective



From: [redacted].com>
Sent: Friday, February 7, 2025 12:05 PM
To: [redacted]>; [redacted]>
Cc: [redacted]>; [redacted]>; paul.aronsohn@treas.nj.gov; Christine Bakter <Christine.Bakter@treas.nj.gov>
Subject: [External]Emergency placement options for [redacted]

Good afternoon everyone,

I am reaching out to find out anything the CMO can tell us about options for emergency placements for [redacted]. He has been in residential with [redacted] since October 2023 and has been waiting for an opening for an I/DD placement. We have had issues with [redacted] in the past over his care, both with his hip surgery and dressings being removed and the lack of communication from staff. In recent months:

- The school and his summer camp have contacted us several times related to food in his lunch being inadequate or missing.
- In the previous month, I also had a call from his teacher about him coming to school soiled and sitting in feces that made his bottom sore. At that time, I reached out to the program director about that issue and his need to be changed just prior to boarding the bus. I was told he is changed every morning and does not sit in diapers and that his bottom looked fine to staff.

This morning, the school contacted us in writing regarding a statement from both [redacted]'s 1:1 and his bus driver. His bus driver and 1:1 reported:

- He was put on the bus this morning smelling strongly of feces.
- He was sitting in a soiled diaper with feces on his stomach and legs
- He was crying when being wiped because it was drying and stuck on him.
- [redacted]'s face was dirty with dried food or another substance and he smelled strongly of feces.

[redacted] is functionally nonverbal and unable to complete ADL's on his own. We have already gone through several rounds of communication both with the staff and with the directors at [redacted] in the past and have been working to maintain a collaborative relationship in order for [redacted] to stay on the waiting list for the program better suited to his needs. At this point, we do not believe [redacted] is safe or being properly cared for in this program and that it would be unsafe to continue to expose [redacted] to care at [redacted].

If someone could please reach out to us about what steps we may take to secure an immediate placement change, we would appreciate that. We engaged with out of home support because we were unable to provide the level of structure and care that [redacted] needed to be safe in our home; however, he was still clean and loved and this is not a tenable situation for him, or for us as his parents.

Thank you for anything you can tell me about what we need to do next. [redacted] has previously suggested that the school contact DCPP, which I relayed to them today as well.

Sincerely,
[redacted]

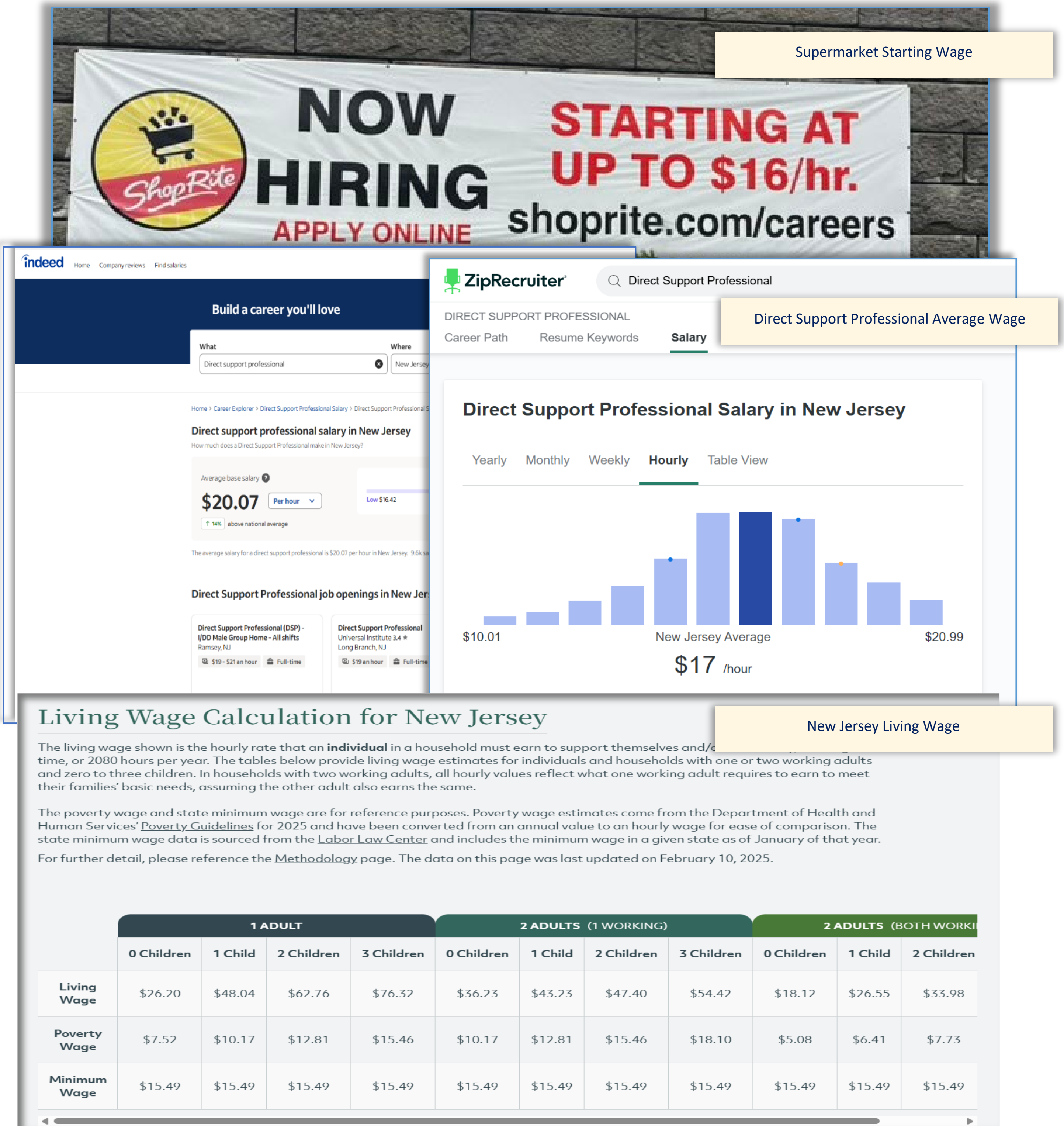
NOTE: The NJ Department of Children and Families "conducted its required investigation and determined that the allegation of Neglect/Failure to Provide Basic Needs is Unfounded…."

\- April 17, 2025

Question: Why is this allowed?

Direct Care Workforce Crisis in Perspective

Wage comparisons.



Supermarket Starting Wage

Build a career you'll love

What: Direct support professional

Where: New Jersey

Home › Career Explorer › Direct Support Professional Salary › Direct Support Professional S

Direct support professional salary in New Jersey

How much does a Direct Support Professional make in New Jersey?

Average base salary

$20.07 Per hour

↑ 14% above national average

Low $16.42

The average salary for a direct support professional is $20.07 per hour in New Jersey. 9.6k sa

Direct Support Professional job openings in New Jer

Direct Support Professional (DSP) - I/DD Male Group Home - All shifts
Ramsey, NJ
$19 - $21 an hour · Full-time

Direct Support Professional
Universal Institute 3.4 ★
Long Branch, NJ
$19 an hour · Full-time

Direct Support Professional

DIRECT SUPPORT PROFESSIONAL

Direct Support Professional Average Wage

Direct Support Professional Salary in New Jersey

New Jersey Average

$17 /hour

Living Wage Calculation for New Jersey

New Jersey Living Wage

The living wage shown is the hourly rate that an **individual** in a household must earn to support themselves and/
time, or 2080 hours per year. The tables below provide living wage estimates for individuals and households with one or two working adults and zero to three children. In households with two working adults, all hourly values reflect what one working adult requires to earn to meet their families' basic needs, assuming the other adult also earns the same.

The poverty wage and state minimum wage are for reference purposes. Poverty wage estimates come from the Department of Health and Human Services' Poverty Guidelines for 2025 and have been converted from an annual value to an hourly wage for ease of comparison. The state minimum wage data is sourced from the Labor Law Center and includes the minimum wage in a given state as of January of that year.

For further detail, please reference the Methodology page. The data on this page was last updated on February 10, 2025.

	1 ADULT				2 ADULTS (1 WORKING)				2 ADULTS (BOTH WORKI		
	0 Children	1 Child	2 Children	3 Children	0 Children	1 Child	2 Children	3 Children	0 Children	1 Child	2 Children
Living Wage	$26.20	$48.04	$62.76	$76.32	$36.23	$43.23	$47.40	$54.42	$18.12	$26.55	$33.98
Poverty Wage	$7.52	$10.17	$12.81	$15.46	$10.17	$12.81	$15.46	$18.10	$5.08	$6.41	$7.73
Minimum Wage	$15.49	$15.49	$15.49	$15.49	$15.49	$15.49	$15.49	$15.49	$15.49	$15.49	$15.49

Question: Is it any wonder we have a direct care workforce crisis?

Investigations in Perspective

Provider agencies investigating themselves.

A Family's Concerns with a Provider Agency's Investigation

---------- Forwarded message ---------
From: [redacted]@gmail.com>
Date: Wed, Apr 24, 2024 at 10:55 AM
Subject: Attn: [redacted] (re: request for objective investigation)
To: <DHS.OPIA.Admin@dhs.nj.gov>
Cc: [redacted].org>, <paul.aronsohn@treas.nj.gov>, [redacted]>, [redacted]

Dear [redacted]-

We respectfully request additional action on an incident involving our [redacted], [redacted]. The incident [redacted] occurred while she was residing at her [redacted] group home at [redacted]. This incident involved allegations of verbal and psychological abuse in retaliation for reporting another allegation of physical abuse [redacted] reported on October 27, 2023, at the same location. We are not at all satisfied with the process and outcome of these reports.

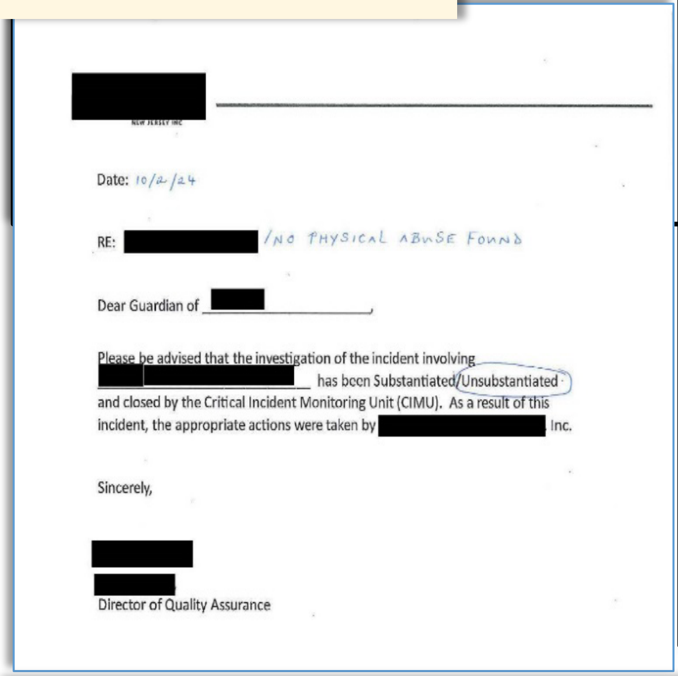
Both of those reports were investigated by the provider agency only. Not only have we still not received ANY verbal or written communication from the provider on the outcome of these investigations, but we also do not believe that they were investigated objectively or thoroughly. Although [redacted] is no longer receiving services from this provider, we have serious concerns about their accountability regarding these allegations. We felt it necessary to remove [redacted] from the [redacted] group home due to the worsening of [redacted] mental health symptoms as a result of ongoing verbal abuse and retaliation.

We are asking for another review of these incidents, preferably an objective investigation from the Office of Investigations on these allegations, along with a written communication on the outcome.

Thank you very much for your help in this serious matter.

Best regards,
[redacted]
cell: [redacted]

Form Letter Response from a Provider Agency Telling a Family the Results of its Investigation



[redacted]
NEW JERSEY INC

Date: 10/2/24

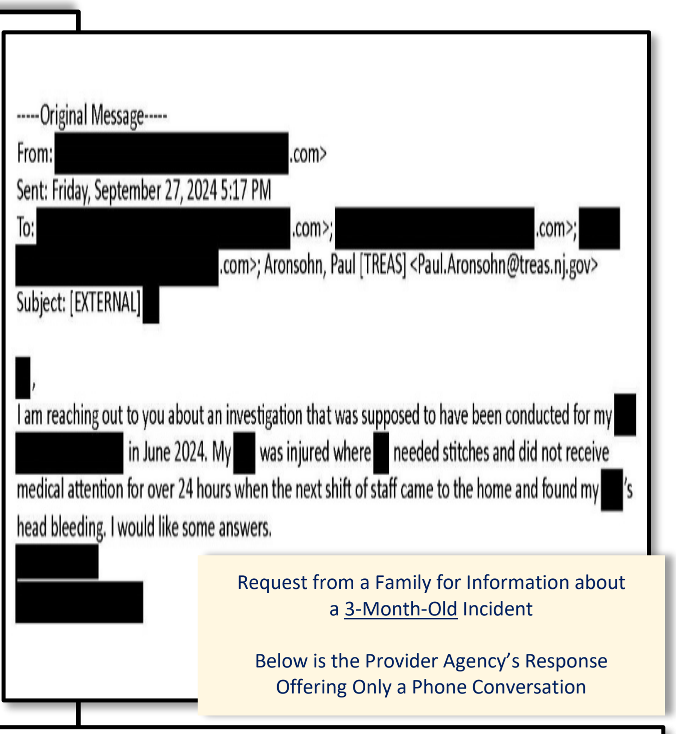
RE: [redacted] /NO PHYSICAL ABUSE FOUND

Dear Guardian of [redacted],

Please be advised that the investigation of the incident involving [redacted] has been Substantiated/[✓ Unsubstantiated] and closed by the Critical Incident Monitoring Unit (CIMU). As a result of this incident, the appropriate actions were taken by [redacted] Inc.

Sincerely,

[redacted]
[redacted]
Director of Quality Assurance



-----Original Message-----
From: [redacted].com>
Sent: Friday, September 27, 2024 5:17 PM
To: [redacted].com>; [redacted].com>; [redacted].com>; Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>
Subject: [EXTERNAL] [redacted]

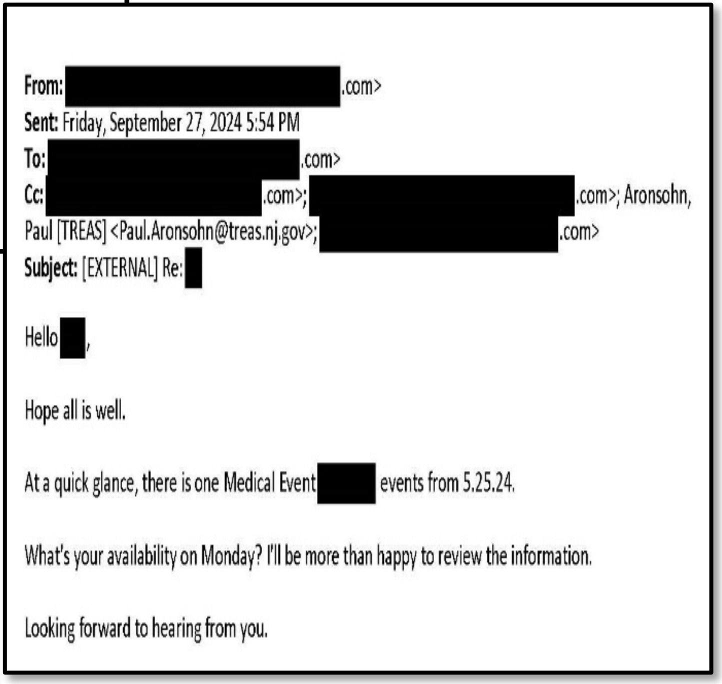
[redacted],

I am reaching out to you about an investigation that was supposed to have been conducted for my [redacted] in June 2024. My [redacted] was injured where [redacted] needed stitches and did not receive medical attention for over 24 hours when the next shift of staff came to the home and found my [redacted]'s head bleeding. I would like some answers.

[redacted]

Request from a Family for Information about a <u>3-Month-Old</u> Incident

Below is the Provider Agency's Response Offering Only a Phone Conversation



From: [redacted].com>
Sent: Friday, September 27, 2024 5:54 PM
To: [redacted].com>
Cc: [redacted].com>; [redacted].com>; Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>; [redacted].com>
Subject: [EXTERNAL] Re: [redacted]

Hello [redacted],

Hope all is well.

At a quick glance, there is one Medical Event [redacted] events from 5.25.24.

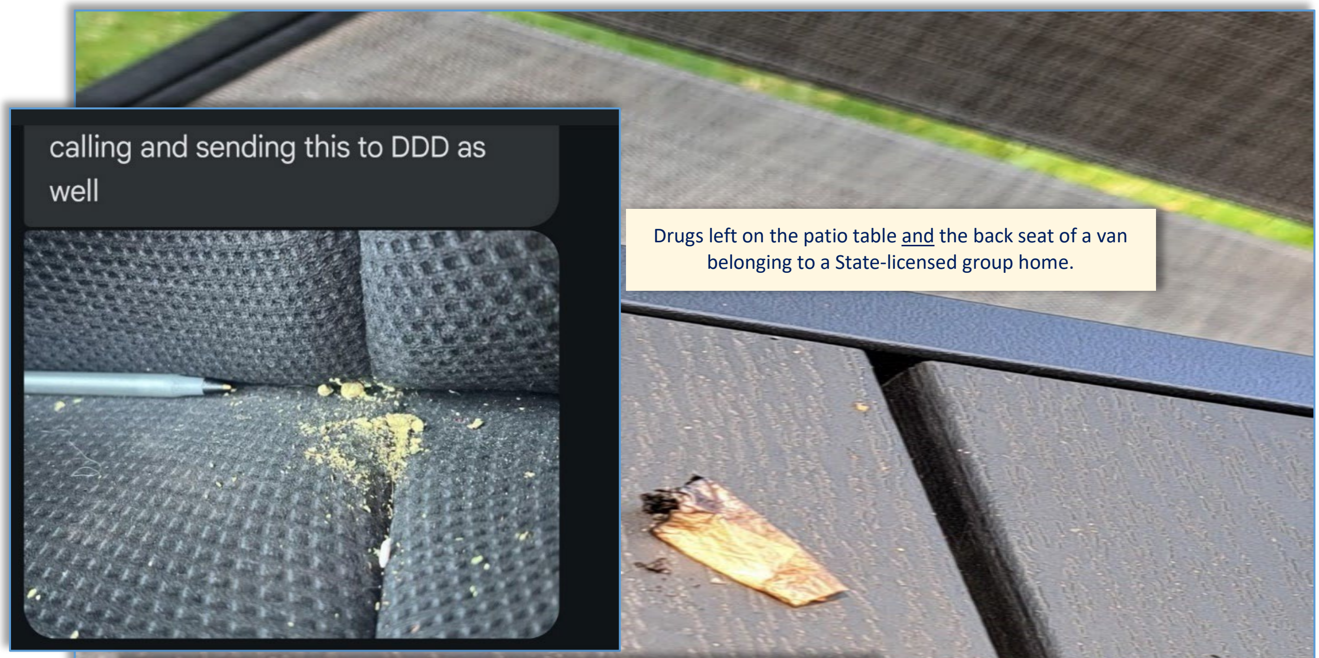
What's your availability on Monday? I'll be more than happy to review the information.

Looking forward to hearing from you.

Question: Should provider agencies investigate themselves?

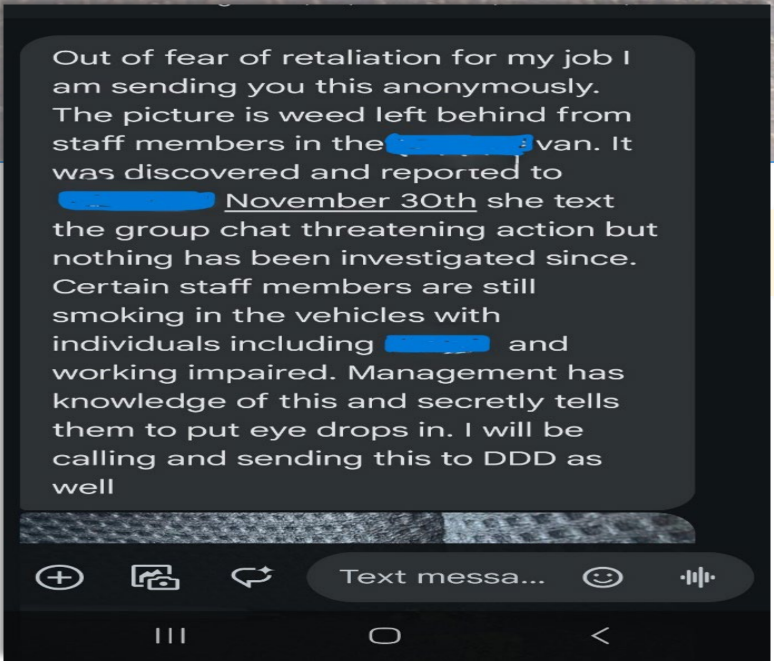
An Adult Group Home in Perspective

Drug use at a State-licensed residence for adults.
This incident was investigated. "Neglect was substantiated and contraband was confirmed."



calling and sending this to DDD as well

Drugs left on the patio table and the back seat of a van belonging to a State-licensed group home.



Out of fear of retaliation for my job I am sending you this anonymously. The picture is weed left behind from staff members in the [redacted] van. It was discovered and reported to [redacted] November 30th she text the group chat threatening action but nothing has been investigated since. Certain staff members are still smoking in the vehicles with individuals including [redacted] and working impaired. Management has knowledge of this and secretly tells them to put eye drops in. I will be calling and sending this to DDD as well

Text from a group home staff member about alleged drug use by other staff members.

Question: Would video cameras in the group home's vehicles and common areas help in a situation like this?
Question: Should there be "whistleblower" protections for group home staff?

A Youth Group Home in Perspective

Pictures from the campus of a State-licensed residence for youth with significant disabilities (under age 21).
This provider agency gets paid more than $1,200 per day per resident.
The provider agency's CEO was paid just under $1 million last year.

Question: Why is this allowed?

Autism/Severe Challenging Behavior

On April 18, 2018 — the day before my official appointment to this position — I met with a parent, whose child had both autism and severe challenging behavior (physical aggression, self-injury, and/or property destruction). I did not realize then that speaking with a parent whose child has autism and severe challenging behavior would be a daily feature of my work for the next seven years.

According to the nonprofit organization Autism New Jersey, there are an estimated 242,123 individuals with autism throughout our State (70,801 children and 171,322 adults). Indeed, with one of the highest prevalence rates in the world (1 in 29) people with autism represent about 2.5% of our population.

Moreover, about 27% of those New Jerseyans with autism (28,037 children, 67,844 adults) are also estimated to have an intellectual disability, including some with what is increasingly known as "profound autism." This includes some of the approximately 28,000 individuals with autism, intellectual disability, and severe challenging behavior living in our State — an average of about 50 New Jerseyans per municipality. (Note: Some believe this is a very conservative number.)

One last statistic: One in three children with autism engage in self-injurious behavior – meaning that thousands of New Jersey children likely bang their own head against a wall, punch themselves in the face, bite themselves or engage in some other self-injurious aggression, often as a pattern of ongoing behavior.

Simply stated, we have a full-blown crisis on our hands — one that is taking an increasing toll on all involved in terms of human and financial costs. And one of the most frustrating and terrible truths about this statewide reality is that we have important resources available throughout our State, but not nearly enough for the many individuals and families who need and deserve them.

Indeed, New Jersey is home to some outstanding autism programs and clinicians and probably some of the most important, noteworthy autism research. But daily, we have been working with individuals and their families who do not seem to be benefiting from much of this – individuals and families falling through devastating cracks in the system. Again, this is particularly true with respect to those with severe challenging behavior, and this is particularly true with respect to youth under 21 years old, because the NJ Department of Children and Families provides insufficient in-home and out-of-home treatment options.

An Important Individual/Family Perspective

> "We are writing to urgently request your assistance regarding our daughter … who is 18 years old and has Autism. [She] has been in a crisis since December, and despite our efforts to seek the appropriate support, we have faced numerous obstacles in securing the care she desperately needs…
>
> We are reaching out to you for assistance as we are desperate and feel we have exhausted all options. Our daughter's well-being is at stake, and we are deeply concerned about her safety and stability without the intensive support she needs."
>
> Parent of an 18-Year Old Youth in the Children's System
> November 2024

Yes, there have been important steps forward in recent years – including the increased availability of therapies and technologies, the licensure of Behavior Analysts, and the important work being done with New Jersey's law enforcement community – but so much more needs to be done for children, adults, and their families.

In a recent "open letter" to New Jersey's gubernatorial candidates, I expressed my hope that the next Governor will make autism a priority. I urged them to understand autism, to talk about it, and to connect with individuals and families who can educate them through their real-life experiences – educate them about the nuances, the complexities, the challenges, and the possibilities. I also urged them to take a holistic approach to autism by bringing together our State's academic, advocacy, medical, and family communities to determine the best way forward — providing hope, relief, and support to thousands of New Jerseyans, while providing an example for the rest of the country to follow.

Simply stated, we have an obligation and an opportunity to do more and to do it better.

Going forward, we offer the following few recommendations, which were included in our previous annual reports:

- **Universal Screening/Early Intervention**: We know that clinical screening for autism is unlike screening for other childhood disorders and diseases – that there is no blood test that will detect autism and that making a diagnosis is more complicated and nuanced. However, we also know that early identification and intervention of autism is critical to an individual's development – that, among other things, it can help forestall severe challenging behavior by promoting early access to treatments and technologies. We know, too, that there are racial, ethnic, and socio-economic disparities that have delayed such identification and intervention in underserved populations.

  We should therefore explore the possibility of universal autism screening of all New Jersey children.

- **Crisis Response**: In our first annual report, in 2019, I spoke of individuals who experience behavioral crisis and of the system's questionable response: "Too often we hear stories of them [individuals with autism] having a behavioral crisis and ending up in situations — or rather, real life vicious cycles — that only aggravate their condition: the police are called; an ambulance takes the person to an emergency room; the doctors are unable to treat the person, who remains in the emergency department for anywhere between 3 hours and 3 weeks before being discharged on a mix of psychotropic medicines."

  Unfortunately, the system's response has not changed. In fact, we have often heard Care Managers contracted by the NJ Department of Children and Families advise families to "call 911" in moments of crisis. Although we certainly understand the need sometimes for Police involvement to guarantee the safety of everyone involved, it is disturbing that this is often the first and often only advice given to families – advice reluctantly disregarded by some parents, who fear the possible repercussions (physical and emotional) of involving law enforcement and emergency room visits.

  Clearly, we need to do better. Calling 911 should not be our State's default position. Having the Police bring an individual to a hospital often does more harm than good and is a questionable use of community resources. At a minimum, we should explore the possibility of expanding the successful ARRIVE Together program now being utilized across the State to support law enforcement officials in situations involving someone with mental health challenges – expanding it to include people with intellectual or developmental disabilities in crisis.

- **Interagency Committee**: We know that the mix of autism with severe challenging behavior often expresses itself in a variety of harmful ways. Physical aggression. Self-injurious behavior. Property destruction. We know that many individuals – children as well as adults – and their families are not getting the supports and services that they need and deserve. We know that this is true in practically every community in every part of our State. And we know that responsibility for addressing all of this reaches across multiple State departments and offices:

  - NJ Department of Banking and Insurance
  - NJ Department of Children and Families
  - NJ Department of Community Affairs (Housing)
  - NJ Department of Education
  - NJ Department of Health
  - NJ Department of Human Services
  - NJ Department of Labor & Workforce Development
  - NJ Department of Law and Public Safety
  - New Jersey Transit

  It therefore stands to reason that our approach should be broad, inclusive, and coordinated.

  To that end, we should establish a standing interagency group to take a more holistic approach to autism – one that collaborates across silos and works closely with the academic, advocacy, provider, and family communities.

An Important Individual/Family Perspective

"You may not think I am worth listening to
but I am and I may surprise you.

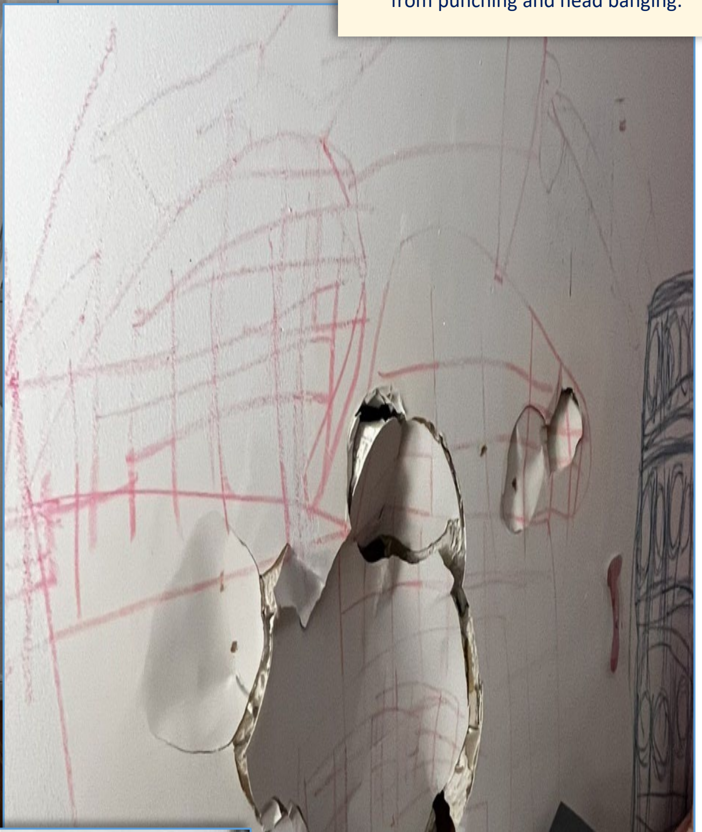
I am only one of many many forgotten souls
that are waiting to be heard."

A 19-Year-Old Non-speaking Man with Autism and Severe Challenging Behavior,
Using an Augmentative and Alternative Communication Device for the First Time,
April 2025

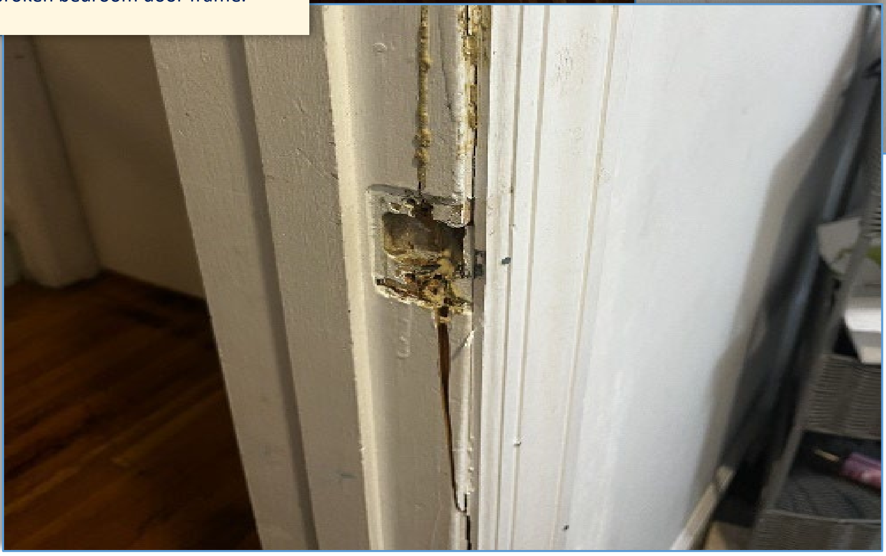
Autism / Severe Challenging Behavior in Perspective

Scenes from a family home.

Holes in a hallway door
from punching and head banging.



Holes in a bedroom wall
from punching and head banging.



A broken bedroom door frame.

Question: Are we doing enough to support youth with autism and their families?

Case/Care Management *

For youth (up to age 21) and their families, the NJ Department of Children and Families utilizes 15 regionally-based care management organizations (CMO) to provide case/care management. For adults (21 and above) and their families, the NJ Department of Human Services now uses about 140 support coordination agencies (SCA) to provide this critical service.

Not surprisingly, our office has worked closely with both CMOs and SCAs, which serve as vital links between individuals/families and the resources they need and deserve. Sometimes we play a supportive role, recognizing that the CMO or SCA is a lead member of the individual's/family's team. Sometimes we play a more active role, because the individual/family has concerns about the level of support being provided by the CMO or SCA. Indeed, in some instances, individuals and families have even felt that their CMO or SCA was conflicted and actually working against them, due to their relationship with a State government office or a provider agency.

With respect to CMOs, our experience has been mixed at best. Although we have worked with some really outstanding Care Managers, who know the system and who advocate for their families, this is often not the case. This might be due to the fact that most youth situations brought to the attention of our office involve a family in crisis, thus presenting extraordinary challenges for the CMO.

Regardless, we have often found that Care Managers – although well-intentioned – are new to the system, do not understand intellectual or developmental disabilities, do not have a sense of urgency, and/or know less than the families they serve. Moreover, due to the limited number of CMOs and the requirement that a family must utilize the one designated for their county (with some exceptions), families often feel underserved and without options.

A Questionable Care Management Response

"At this time due to other obligations, I am unable to commit to weekly meetings. However, the CM [care manager] will follow up with you weekly regarding any changes."

A Care Manager Organization Supervisor from **Central** New Jersey,
Declining a Request for Weekly Meetings from a Family in Crisis
April 2025

A Questionable Care Management Response

"Yes, if there is a need, we do meet in person or virtually, however our policy says up to twice a month and weekly contact through text, phone call, email, etc, which is what I am following."

A Care Manager Organization Supervisor from **South** New Jersey,
Declining a Request for a Meeting from a Family in Crisis
April 2025

With respect to SCAs, our experience has been largely positive. Granted, we have certainly worked with Support Coordinators whose effectiveness has been undermined by an excessive client list, inexperience, or seeming indifference. We have also occasionally sensed potential conflicts of interest whereby the SCA's relationship with a provider agency seemed more important than their relationship with the individual or family. More often than not, however, we have worked alongside Support Coordinators who are professional, knowledgeable, and dedicated to providing person-centered assistance – Support Coordinators who have a sense of urgency and make it a priority to be available to their clients whenever, wherever necessary. Moreover, unlike in the children's system, individuals and families have far more choice and can far more easily replace their SCA with another if they find it necessary to do so.

One concern that was recently brought to our attention involves "non-solicitation" agreements. Specifically, we learned that at least one SCA has required its Support Coordinators to agree not to solicit former clients for one year if/when they leave the agency to work elsewhere. The agency also requires its Support Coordinators to agree not to accept solicitations from those clients – a type of indirect non-solicitation agreement that could have a chilling effect on individuals/families' ability to work with the Support Coordinator of their choice. It could also drive Support Coordinators out of this important role, due to fear of aggressive and expensive legal litigation.

When asked if any of this should be permitted, the NJ Department of Human Services said only that it "reserves judgement" on the issue.

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* I do not like the terms "case" management and "caseloads," because they seem so dehumanizing. People are individuals, not "cases." However, I use them in this context, because they are terms familiar to many people and are used by the NJ Department of Human Services in its Community Care Program manual.

Going forward, we offer the following recommendations:

- **Care Management Organizations (CMO)**: In addition to better overall training, CMOs should ensure that only their most experienced Care Managers are working with families in crisis. They should also more often utilize other resources, such as The Boggs Center on Disability and Human Development and Autism New Jersey, when complex situations require additional expertise. All of this would result in better outcomes for the youth and less trauma for the parents and other family members.

  Additionally, the NJ Department of Children and Families should explore the possibility of allowing more choice of CMOs for families, adopting a model similar to the NJ Department of Human Services. Competition may help improve service.

- **Support Coordination Agencies (SCA):** Consideration should be given to limitations on caseload, particularly when a Support Coordinator is working with an individual or family whose needs are especially complex or significant, such as those in a crisis situation or those transitioning into the self-direction program. Relatedly, the rates for support coordination should be tiered, giving consideration to such situations that often require more time and attention from the Support Coordinator.

  With respect to non-solicitation agreements, they should not be allowed, because they limit the choices available to individuals and families.

One additional thought with respect to case/care management: The State's decision years ago to outsource this critical function to private organizations might make sense from a logistical perspective, but I fear that it has created too much space between those making decisions and those impacted by the decisions. As I discussed in our 2019 annual report –

> "Although there may be a business case for using this approach to case management, I am concerned that it has created more distance – physical as well as emotional – between individuals/families and the government professionals charged with serving them. Reliance on intermediaries — Care Managers and Support Coordinators — has created somewhat of a moat around State government, effectively walling off people from having direct contact with the public officials making decisions about their lives."

This is not good, and this should change. At least occasionally, people should have unfiltered, one-on-one access to public officials, particularly those making decisions that directly impact their lives. Such direct interaction would not only be the right thing to do; it would also be the smart thing to do in that it would likely result in better, more person-centered decisions.

As such, government officials – particularly at the Assistant Commissioner level – should make themselves more readily available for meetings and phone calls with individuals and families. This would make them better policy-makers.

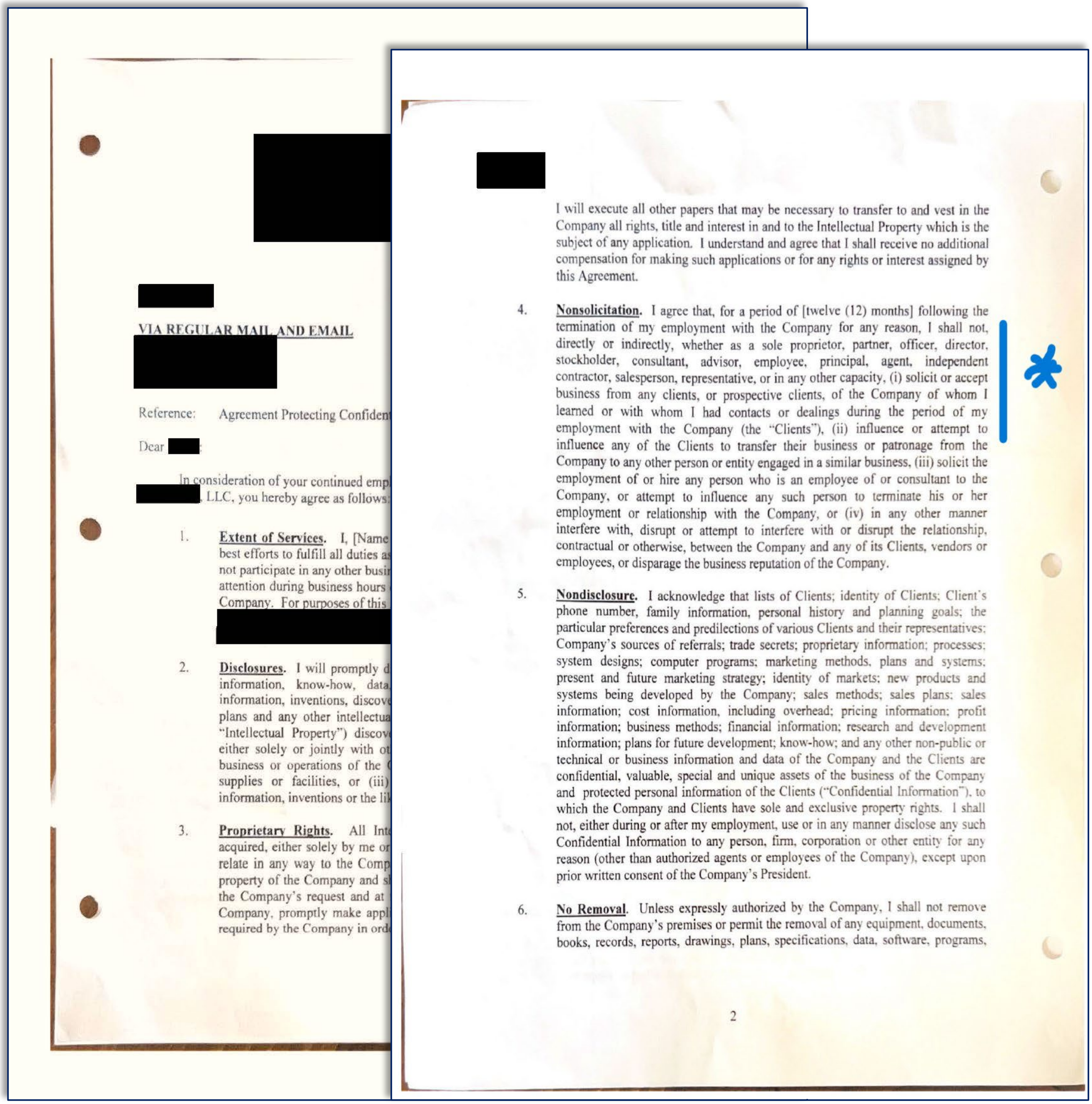
Public Funding for Case/Care Management

Monthly Rates

Care Management Organizations For Youth Under Age 21 Source: NJ Department of Children & Families	$1,032.09 per individual/family
Support Coordination Agencies For Adults Aged 21 and Older Source: NJ Department of Human Services	$376.48 per individual/family

Support Coordination in Perspective

A signed form required of new hires to a particular support coordination agency.



[redacted]

[redacted]

VIA REGULAR MAIL AND EMAIL

[redacted]

Reference: Agreement Protecting Confiden

Dear [redacted]:

In consideration of your continued emp
[redacted], LLC, you hereby agree as follows:

1. **Extent of Services.** I, [Name
best efforts to fulfill all duties a
not participate in any other busi
attention during business hours
Company. For purposes of this
[redacted]

2. **Disclosures.** I will promptly d
information, know-how, data
information, inventions, discove
plans and any other intellectua
"Intellectual Property") discov
either solely or jointly with ot
business or operations of the
supplies or facilities, or (iii)
information, inventions or the li

3. **Proprietary Rights.** All Int
acquired, either solely by me or
relate in any way to the Comp
property of the Company and s
the Company's request and at
Company, promptly make appl
required by the Company in ord

[redacted]

I will execute all other papers that may be necessary to transfer to and vest in the Company all rights, title and interest in and to the Intellectual Property which is the subject of any application. I understand and agree that I shall receive no additional compensation for making such applications or for any rights or interest assigned by this Agreement.

4. **Nonsolicitation.** I agree that, for a period of [twelve (12) months] following the termination of my employment with the Company for any reason, I shall not, directly or indirectly, whether as a sole proprietor, partner, officer, director, stockholder, consultant, advisor, employee, principal, agent, independent contractor, salesperson, representative, or in any other capacity, (i) solicit or accept business from any clients, or prospective clients, of the Company of whom I learned or with whom I had contacts or dealings during the period of my employment with the Company (the "Clients"), (ii) influence or attempt to influence any of the Clients to transfer their business or patronage from the Company to any other person or entity engaged in a similar business, (iii) solicit the employment of or hire any person who is an employee of or consultant to the Company, or attempt to influence any such person to terminate his or her employment or relationship with the Company, or (iv) in any other manner interfere with, disrupt or attempt to interfere with or disrupt the relationship, contractual or otherwise, between the Company and any of its Clients, vendors or employees, or disparage the business reputation of the Company.

5. **Nondisclosure.** I acknowledge that lists of Clients; identity of Clients; Client's phone number, family information, personal history and planning goals; the particular preferences and predilections of various Clients and their representatives; Company's sources of referrals; trade secrets; proprietary information; processes; system designs; computer programs; marketing methods, plans and systems; present and future marketing strategy; identity of markets; new products and systems being developed by the Company; sales methods; sales plans; sales information; cost information, including overhead; pricing information; profit information; business methods; financial information; research and development information; plans for future development; know-how; and any other non-public or technical or business information and data of the Company and the Clients are confidential, valuable, special and unique assets of the business of the Company and protected personal information of the Clients ("Confidential Information"), to which the Company and Clients have sole and exclusive property rights. I shall not, either during or after my employment, use or in any manner disclose any such Confidential Information to any person, firm, corporation or other entity for any reason (other than authorized agents or employees of the Company), except upon prior written consent of the Company's President.

6. **No Removal.** Unless expressly authorized by the Company, I shall not remove from the Company's premises or permit the removal of any equipment, documents, books, records, reports, drawings, plans, specifications, data, software, programs,

2

Question: Does this "non-solicitation" clause threaten an individual's ability to choose a Support Coordinator?
Question: Should such a clause be allowed?

Civil/Human Rights

The civil and human rights of people with disabilities is a theme (and concern) that has run through most of our work over the years. Indeed, we take great care not only to talk about what people with disabilities "need," but also what they "deserve."

Most notably –

- All of our work with respect to mitigating, if not eliminating, abuse and neglect is rooted in our commitment to the civil and human rights of people with disabilities.

- All of our work to promote access to vital supports, services, treatments, and therapies is rooted in our commitment to the civil and human rights of people with disabilities.

- All of our work to promote access to education, employment, health care, housing, and transportation is rooted in our commitment to the civil and human rights of people with disabilities.

- All of our work to expose and push back against questionable practices by school districts, government officials, provider agencies, managed care organizations, and landlords is rooted in our commitment to the civil and human rights of people with disabilities.

Indeed, most of our work is driven by moral as well as practical imperatives.

In this context, there are two additional issues that need to be addressed:

Human Rights Committees (HRC): The NJ Department of Human Services long ago established a Human Rights Committee within the Division of Developmental Disabilities to "protect the civil and human rights of individuals with developmental disabilities." Provider agencies have a choice to develop their own committees or rely on the one run by the Department. All of the committees are required to meet regularly or as needed, and all are required to follow similar rules with respect to membership, decision-making, procedures, etc.

The committees provide forums to address a full-range of human rights issues – from requests for safety features (such as cameras and window locks) to concerns about food restrictions or visitation policies. Practically anyone can raise a concern with the committees.

In theory, this is an important function. In practice, however, we have concerns, particularly with respect to HRCs established and run by provider agencies. Simply stated, the process seems deeply flawed.

- HRC membership is decided by a provider agency's CEO or Executive Director.

- After considering the HRC's advice, final decisions are made by the provider agency's CEO or Executive Director.

- And if an individual or family appeals an HRC decision, that appeal goes to the provider agency's CEO or Executive for a final, final decision.

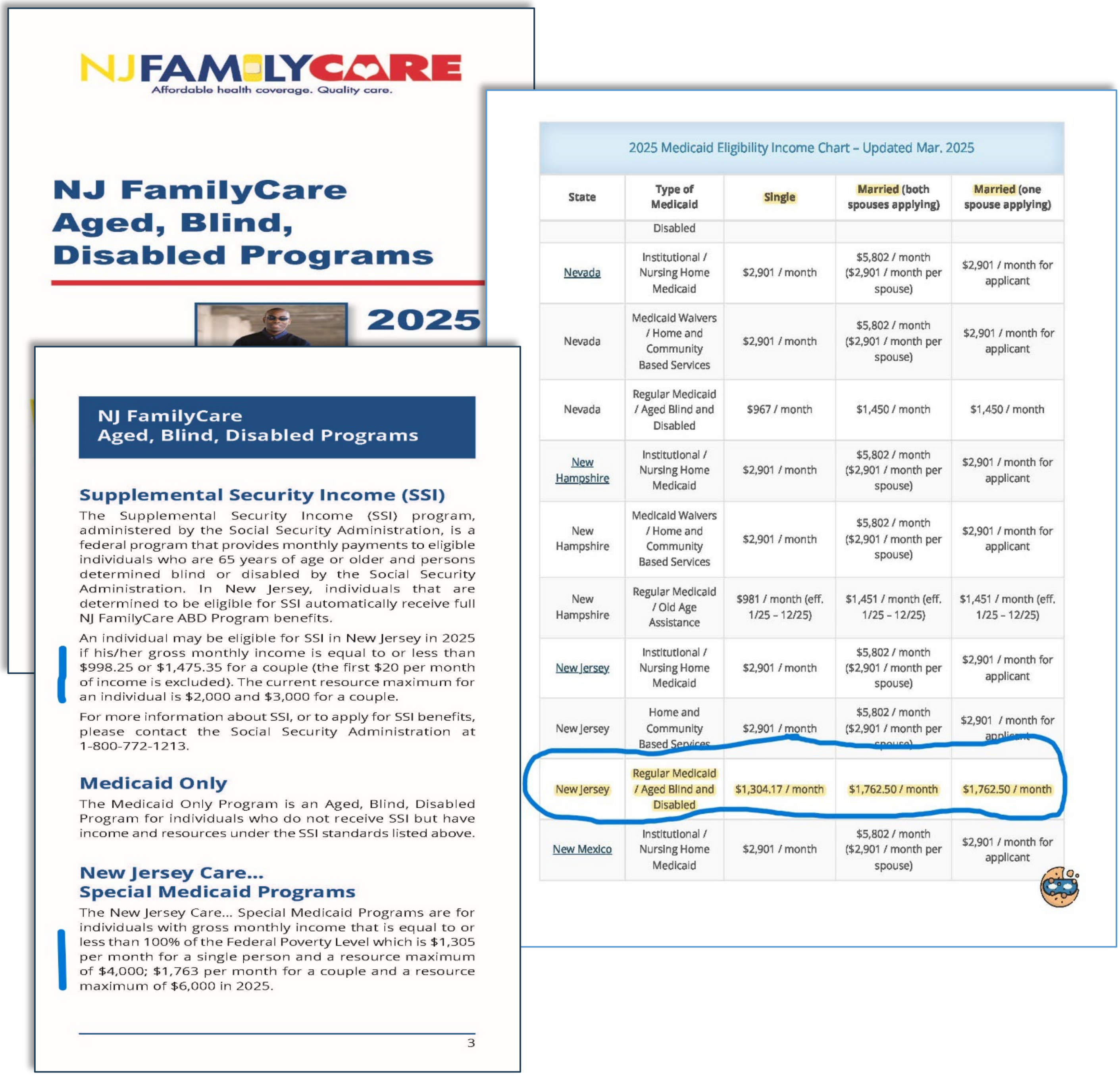
This makes little sense. With all due respect, provider agency leadership are not necessarily positioned to rule on matters of civil and human rights. And even if they were, this type of predetermined process seems questionable at best.

Going forward, we recommend that this entire process be revisited – either taking this function away from the provider agencies or putting in place safeguards to help ensure more expertise and more objectivity.

Marriage Equality: Many people with disabilities are effectively precluded from getting married due to rules governing multiple Federal and State programs that penalize couples. Specifically, the rules related to asset and income limits often favor individuals over couples. And while there has been increasing focus on this important civil and human rights issue, most of the attention has been on the federal level and related to Social Security.

However, on the State level, we can and should revisit our own policies that may have such marriage penalties embedded in them. For example, our State Medicaid program allows individuals to earn up to $1,255 per month and have assets up to $4,000. Couples, however, are only allowed combined monthly incomes of $1,704 and combined asset limits of $6,000. Rather than doubling the respective limits for couples, the rules make it financially difficult, if not impossible, for them to maintain their eligibility in this vital program, which is nothing short of a lifeline for millions of New Jerseyans.

This should change. We should follow the lead of other States that do not have this marriage penalty embedded in their Medicaid programs and adopt a more family-friendly approach.



NJ FAMILYCARE
Affordable health coverage. Quality care.

NJ FamilyCare Aged, Blind, Disabled Programs

2025

NJ FamilyCare Aged, Blind, Disabled Programs

Supplemental Security Income (SSI)

The Supplemental Security Income (SSI) program, administered by the Social Security Administration, is a federal program that provides monthly payments to eligible individuals who are 65 years of age or older and persons determined blind or disabled by the Social Security Administration. In New Jersey, individuals that are determined to be eligible for SSI automatically receive full NJ FamilyCare ABD Program benefits.

An individual may be eligible for SSI in New Jersey in 2025 if his/her gross monthly income is equal to or less than $998.25 or $1,475.35 for a couple (the first $20 per month of income is excluded). The current resource maximum for an individual is $2,000 and $3,000 for a couple.

For more information about SSI, or to apply for SSI benefits, please contact the Social Security Administration at 1-800-772-1213.

Medicaid Only

The Medicaid Only Program is an Aged, Blind, Disabled Program for individuals who do not receive SSI but have income and resources under the SSI standards listed above.

New Jersey Care... Special Medicaid Programs

The New Jersey Care... Special Medicaid Programs are for individuals with gross monthly income that is equal to or less than 100% of the Federal Poverty Level which is $1,305 per month for a single person and a resource maximum of $4,000; $1,763 per month for a couple and a resource maximum of $6,000 in 2025.

3

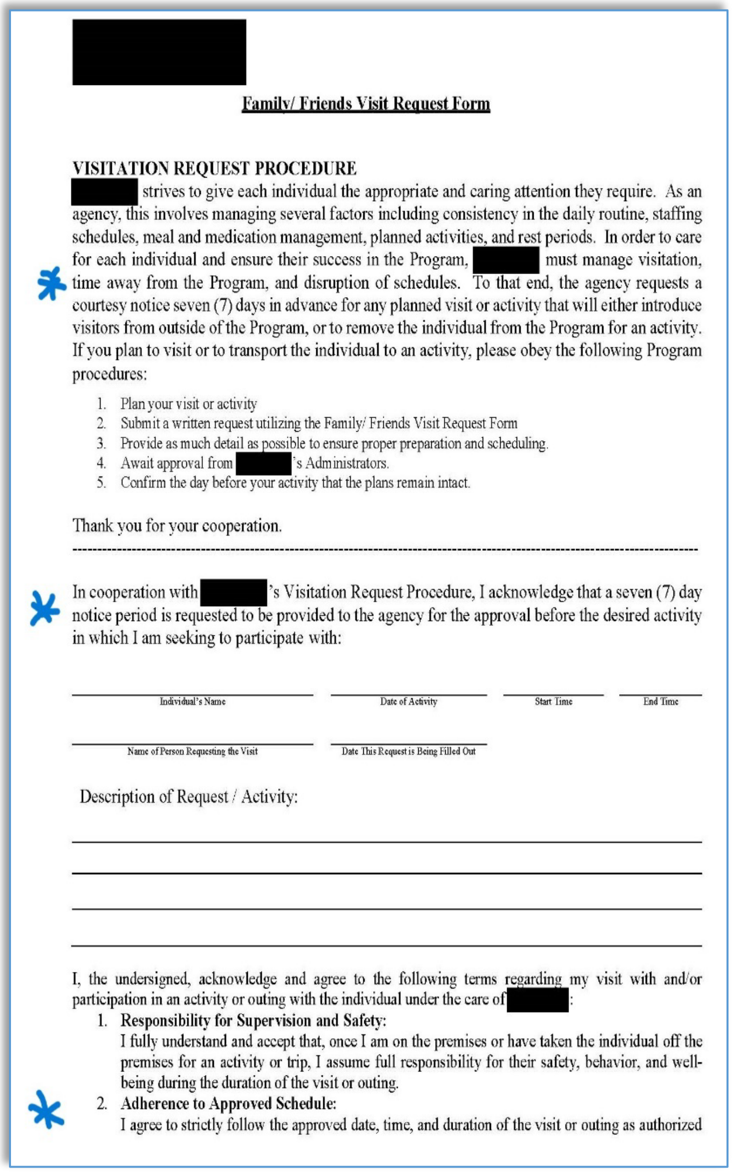
2025 Medicaid Eligibility Income Chart – Updated Mar. 2025

State	Type of Medicaid	Single	Married (both spouses applying)	Married (one spouse applying)
	Disabled			
Nevada	Institutional / Nursing Home Medicaid	$2,901 / month	$5,802 / month ($2,901 / month per spouse)	$2,901 / month for applicant
Nevada	Medicaid Waivers / Home and Community Based Services	$2,901 / month	$5,802 / month ($2,901 / month per spouse)	$2,901 / month for applicant
Nevada	Regular Medicaid / Aged Blind and Disabled	$967 / month	$1,450 / month	$1,450 / month
New Hampshire	Institutional / Nursing Home Medicaid	$2,901 / month	$5,802 / month ($2,901 / month per spouse)	$2,901 / month for applicant
New Hampshire	Medicaid Waivers / Home and Community Based Services	$2,901 / month	$5,802 / month ($2,901 / month per spouse)	$2,901 / month for applicant
New Hampshire	Regular Medicaid / Old Age Assistance	$981 / month (eff. 1/25 – 12/25)	$1,451 / month (eff. 1/25 – 12/25)	$1,451 / month (eff. 1/25 – 12/25)
New Jersey	Institutional / Nursing Home Medicaid	$2,901 / month	$5,802 / month ($2,901 / month per spouse)	$2,901 / month for applicant
New Jersey	Home and Community Based Services	$2,901 / month	$5,802 / month ($2,901 / month per spouse)	$2,901 / month for applicant
New Jersey	Regular Medicaid / Aged Blind and Disabled	$1,304.17 / month	$1,762.50 / month	$1,762.50 / month
New Mexico	Institutional / Nursing Home Medicaid	$2,901 / month	$5,802 / month ($2,901 / month per spouse)	$2,901 / month for applicant

Human Rights in Perspective

A common concern involves restrictions placed on family visits with loved ones, who live in group homes.

Here is an example of a residential provider agency visitation policy that does not seem to align with the federal government's home & community-based settings rule concerning a person's "right to receive visitors at any time."



[redacted]

Family/ Friends Visit Request Form

VISITATION REQUEST PROCEDURE

[redacted] strives to give each individual the appropriate and caring attention they require. As an agency, this involves managing several factors including consistency in the daily routine, staffing schedules, meal and medication management, planned activities, and rest periods. In order to care for each individual and ensure their success in the Program, [redacted] must manage visitation, time away from the Program, and disruption of schedules. To that end, the agency requests a courtesy notice seven (7) days in advance for any planned visit or activity that will either introduce visitors from outside of the Program, or to remove the individual from the Program for an activity. If you plan to visit or to transport the individual to an activity, please obey the following Program procedures:

1. Plan your visit or activity
2. Submit a written request utilizing the Family/ Friends Visit Request Form
3. Provide as much detail as possible to ensure proper preparation and scheduling.
4. Await approval from [redacted]'s Administrators.
5. Confirm the day before your activity that the plans remain intact.

Thank you for your cooperation.

In cooperation with [redacted]'s Visitation Request Procedure, I acknowledge that a seven (7) day notice period is requested to be provided to the agency for the approval before the desired activity in which I am seeking to participate with:

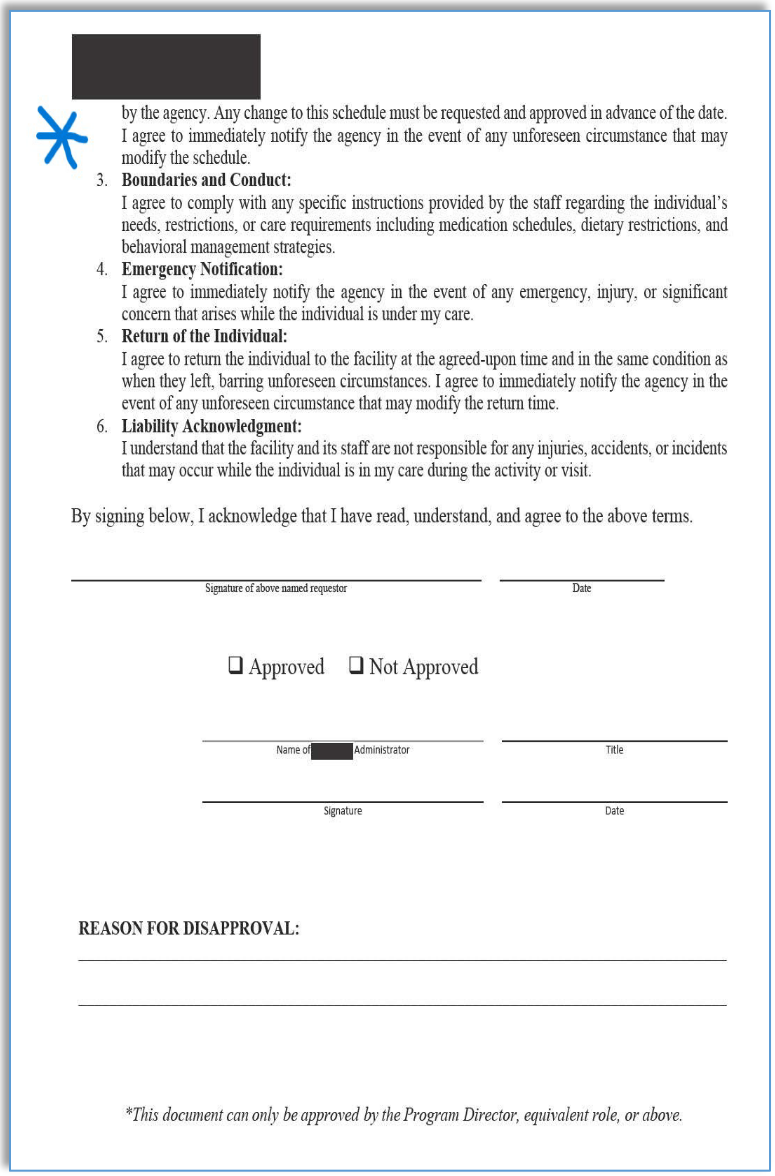
Individual's Name ______ Date of Activity ______ Start Time ______ End Time ______

Name of Person Requesting the Visit ______ Date This Request is Being Filled Out ______

Description of Request / Activity:

I, the undersigned, acknowledge and agree to the following terms regarding my visit with and/or participation in an activity or outing with the individual under the care of [redacted]:

1. **Responsibility for Supervision and Safety:**
   I fully understand and accept that, once I am on the premises or have taken the individual off the premises for an activity or trip, I assume full responsibility for their safety, behavior, and well-being during the duration of the visit or outing.
2. **Adherence to Approved Schedule:**
   I agree to strictly follow the approved date, time, and duration of the visit or outing as authorized



[redacted]

by the agency. Any change to this schedule must be requested and approved in advance of the date. I agree to immediately notify the agency in the event of any unforeseen circumstance that may modify the schedule.

3. **Boundaries and Conduct:**
   I agree to comply with any specific instructions provided by the staff regarding the individual's needs, restrictions, or care requirements including medication schedules, dietary restrictions, and behavioral management strategies.
4. **Emergency Notification:**
   I agree to immediately notify the agency in the event of any emergency, injury, or significant concern that arises while the individual is under my care.
5. **Return of the Individual:**
   I agree to return the individual to the facility at the agreed-upon time and in the same condition as when they left, barring unforeseen circumstances. I agree to immediately notify the agency in the event of any unforeseen circumstance that may modify the return time.
6. **Liability Acknowledgment:**
   I understand that the facility and its staff are not responsible for any injuries, accidents, or incidents that may occur while the individual is in my care during the activity or visit.

By signing below, I acknowledge that I have read, understand, and agree to the above terms.

Signature of above named requestor ______ Date ______

☐ Approved ☐ Not Approved

Name of [redacted] Administrator ______ Title ______

Signature ______ Date ______

REASON FOR DISAPPROVAL:

**This document can only be approved by the Program Director, equivalent role, or above.*

Following intervention from the NJ Department of Human Services,
the provider agency made only the following changes to its policy:

1. Instead of "requesting" notification, the agency now "**strongly recommends** that we are provided a courtesy notice seven (7) days in advance of any planned visit…."
2. The "approve" and "not approved" section was removed.

Question: Even with these changes, does this provider agency's visitation policy violate HCBS rules?
Question: Does this visitation policy seem "institutional?"

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, such as a group home or family home. Often, those with complex medical needs end up in hospitals and other institutional settings, including long-term care nursing facilities. This is true for children as well as adults.

Theoretically, New Jersey children living at home with complex medical needs are allowed up to 24 hours of private duty nursing per day, seven days per week, through Medicaid. Adults, however, are limited to no more than 16 hours per day. There is no good rationale for this seemingly arbitrary limitation, which does not exist in states like New York. To me, it just seems cruel and painfully disconnected from the reality faced by many individuals and their families — a short-sighted policy that jeopardizes the health and well-being of many New Jerseyans. Decisions regarding nursing coverage should be based exclusively on the clinical need of the individual.

I said "theoretically" above, because accessing private duty nursing is an elusive goal for many, regardless of the number of hours technically permitted. This is due to the State's relatively low Medicaid reimbursement rates coupled with the largely unchecked power by the State's five managed care organizations (MCO) to determine the number of hours of nursing an individual can receive. The result is that many children and adults do not receive the community-based care and support effectively promised to them in NJ regulations and MCO policy manuals. Again, this inevitably leads to otherwise unnecessary hospitalizations and otherwise unnecessary institutional admissions for people of all ages.

An Important MCO Admission

"It doesn't make sense that a person turns 21 and can only
get 16 hours. Their needs haven't changed.
The state has made the decision.
I don't agree with it."

MCO Division Supervisor,
Referring to the NJ Department of Human Services' Cap on Private Duty Nursing Hours
June 2025

Moreover, for those adults who want to live in a State-licensed community-based residence, the options are very limited in that a "medical" group home means only that a nurse is on-call 24 hours per day, not necessarily more readily present and available to residents. And for those adults who want to participate in a State-licensed day habilitation program, the options are very limited in that the provider agencies involved are <u>not</u> required to have a nurse on staff, nor are they required to allow someone to bring their own nurse. This inevitably leads to many people with complex medical needs effectively being shut-out from most day habilitation programs and stuck at home without many options for community integration and engagement – a terrible reality that is compounded by the scarcity of transportation options, particularly for those who are non-ambulatory and require the use of a wheelchair.

And to make matters worse for adults with complex medical needs and their families, the NJ Department of Human Services only allows Private Duty Nursing in its more limited Supports Program, rather than its more resourced Community Care Program. This effectively forces some individuals and families to make a dreadful choice between maintaining vital nurse coverage and receiving other vital supports and services.

Taken together, as discussed in our 2022 annual report, all of this makes institutionalization a real possibility for those with complex medical needs – a disturbing and avoidable reality that is just wrong – morally as well as financially. Individuals with complex medical conditions deserve to live safe, fulfilling lives in the community … just as much as anyone else.

Going forward, we offer these few commonsense recommendations, which have been included in previous reports:

- **Nursing**: We should remove the arbitrary 16-hour cap on the number of Private Duty Nursing (PDN) hours per day <u>and</u> give adults more flexibility in how best to utilize the hours given to them. We should also increase the Medicaid rates for PDN, thus making more nurses available to those living in the community. And we should make adult day programs more accessible for people with complex medical needs by ensuring that nurses are either available in such programs or allowed to accompany individuals enrolled in them.

- **Housing:** 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. This means relaxing New Jersey's effective cap on the size (6 beds) of State-licensed group homes, allowing provider agencies greater financial efficiencies so that they can hire appropriate medical staff.

- **Community Care Program** (CCP): 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.

A Questionable Government Response

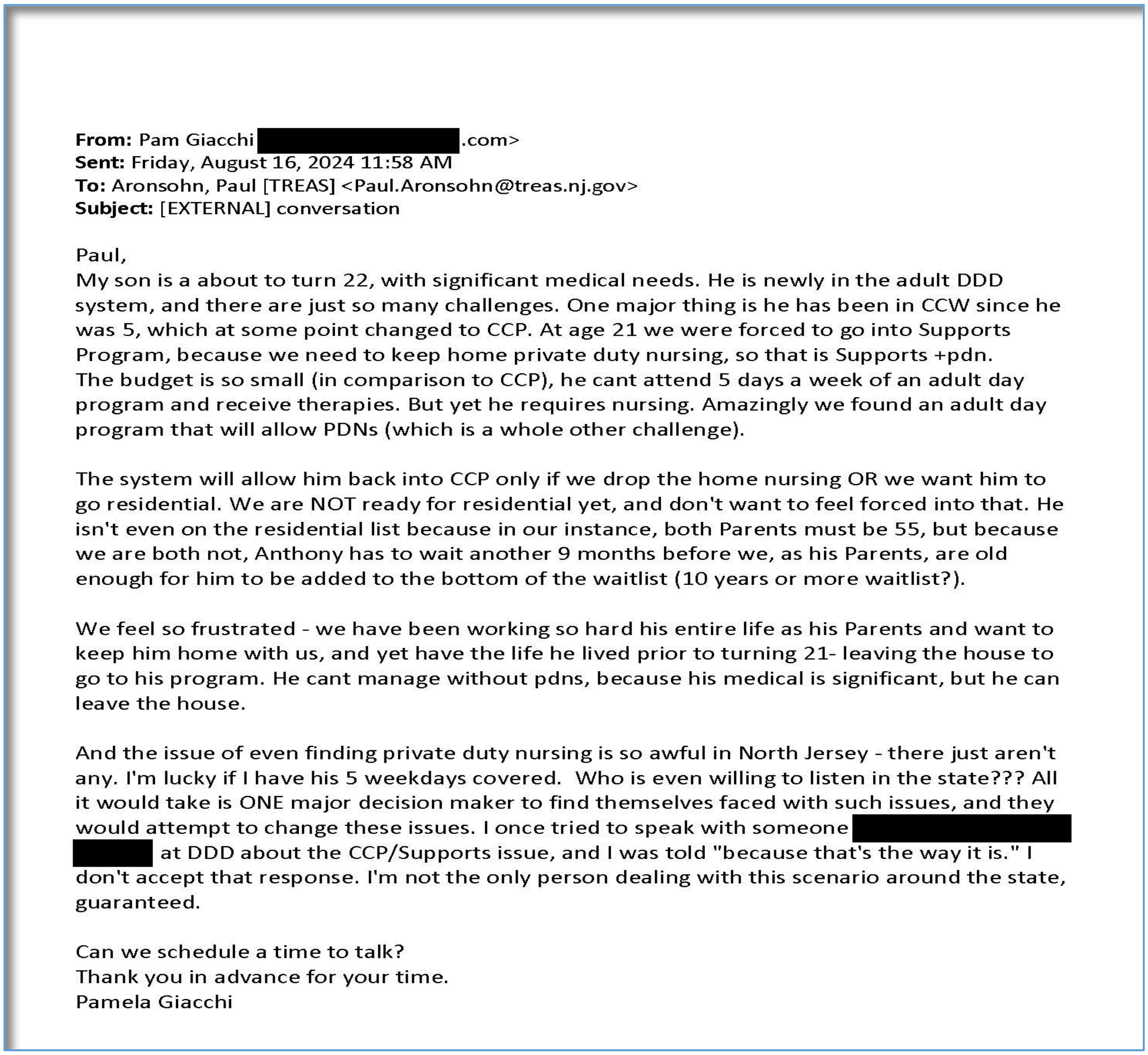
"This is a complicated issue, and it is rooted in a lot of historic reasons that, in part, I think challenges the question for government payers about if someone requires 24-hour care, should they actually be supported in an institution or a facility or can we afford to fund 24-hour around the clock care for every individual in their home?

I think historically this conversation has been rooted in the idea that if you are living at home with your family that there are family members at home for part of that time to help supplement the nursing costs."

A Senior Government Official,
Explaining the Reason for New Jersey's 16-Hour Daily Cap on Private Duty Nursing
May 2025

Complex Medical Needs in Perspective

A mother's advocacy.



From: Pam Giacchi [redacted].com>
Sent: Friday, August 16, 2024 11:58 AM
To: Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>
Subject: [EXTERNAL] conversation

Paul,
My son is a about to turn 22, with significant medical needs. He is newly in the adult DDD system, and there are just so many challenges. One major thing is he has been in CCW since he was 5, which at some point changed to CCP. At age 21 we were forced to go into Supports Program, because we need to keep home private duty nursing, so that is Supports +pdn.
The budget is so small (in comparison to CCP), he cant attend 5 days a week of an adult day program and receive therapies. But yet he requires nursing. Amazingly we found an adult day program that will allow PDNs (which is a whole other challenge).

The system will allow him back into CCP only if we drop the home nursing OR we want him to go residential. We are NOT ready for residential yet, and don't want to feel forced into that. He isn't even on the residential list because in our instance, both Parents must be 55, but because we are both not, Anthony has to wait another 9 months before we, as his Parents, are old enough for him to be added to the bottom of the waitlist (10 years or more waitlist?).

We feel so frustrated - we have been working so hard his entire life as his Parents and want to keep him home with us, and yet have the life he lived prior to turning 21- leaving the house to go to his program. He cant manage without pdns, because his medical is significant, but he can leave the house.

And the issue of even finding private duty nursing is so awful in North Jersey - there just aren't any. I'm lucky if I have his 5 weekdays covered. Who is even willing to listen in the state??? All it would take is ONE major decision maker to find themselves faced with such issues, and they would attempt to change these issues. I once tried to speak with someone [redacted] at DDD about the CCP/Supports issue, and I was told "because that's the way it is." I don't accept that response. I'm not the only person dealing with this scenario around the state, guaranteed.

Can we schedule a time to talk?
Thank you in advance for your time.
Pamela Giacchi

Pamela Giacchi wrote this message on August 16, 2024.
Her son, Anthony, subsequently passed from this earth on March 7, 2025.

"Anthony had a way of charming those he encountered with his sweet smile and strong spirit. He had a mischievous side to him which he would begin to reveal with a smirky smile. He enjoyed laughing with his family and his peers at school. Anthony also had a strong side and worked very hard at everyday tasks, which were often no small feat. He struggled to live an everyday life despite his mounting health issues. During his short life he touched countless people and developed special bonds with those he crossed paths with, including Teachers, Therapists, Doctors, and private duty Nurses….

Anthony was truly an Angel on this earth, entrusted to his Parent's care. May he rest in peace. Anthony is now relieved of all his earthly burdens and is free to run, play, dance and sing freely amongst the stars."

(from Anthony's obituary)

Criminal Justice

Over the years, we have worked with individuals and families who have had difficult, damaging experiences with the criminal justice system. Some have involved a behavioral crisis requiring police intervention. Some have involved prosecution and incarceration for crimes allegedly committed.

To be sure, our experience with these types of situations has been limited, but we have seen and heard enough to know that changes are necessary. This includes a concerning 2020 conversation with senior NJ Corrections officials, who claimed that of the nearly 14,000 people incarcerated in our prison system at the time, only 89 of them had an intellectual or developmental disability, including only 4 individuals with autism – numbers that defy logic and national statistics. At a minimum, these numbers suggest that we need to be more thorough when screening individuals entering our criminal justice system and that we are probably not providing appropriate accommodations to all those who need and deserve them.

On the positive side, we know of several important developments in recent years. The NJ Attorney General's establishment of a Statewide Steering Committee as well as County Working Groups to address challenges related to special needs populations. Autism New Jersey's launching of an initiative that brings together the law enforcement and autism communities "to identify best practices" and "increase the adoption of autism-friendly practices." The 2022 appointment of a NJ Corrections Ombudsperson, who has worked with us and families to understand and better support incarcerated individuals with disabilities and their families. And various examples of State, County, and Local law enforcement officials leading autism-friendly efforts across the State.

On the negative side, however, people have shared with us their traumatizing experiences with the criminal justice system. Experiences when law enforcement seemingly used excessive force or improper language. Experiences with county-based officials involved in the prosecution or incarceration of individuals with intellectual or developmental disabilities – individuals who probably should have been given more accommodations and more considerations. This includes one child with a neurodevelopmental disability and no criminal record, who was prosecuted as an adult, despite being considered a "victim" by federal law enforcement officials – a child who was physically assaulted while incarcerated and, along with his family continues to suffer psychologically from the devastating experience.

Going forward, we offer these recommendations:

- The Arc of New Jersey's Criminal Justice Advocacy Program, which is currently available to adults enrolled in the NJ Division of Developmental Disabilities, should be expanded to support youth and other adults – making this important service available to more people who need and deserve it.

- A comprehensive assessment of the entire criminal justice system should be undertaken to ensure that meaningful checks are in place to screen for people with disabilities at key points along the continuum to ensure proper accommodations and considerations are in place.

    - Such an assessment should include a review of the Moderate Security Unit at the New Lisbon Developmental Center, which is run by the NJ Department of Human Services – a review of its role, its size, its policies and procedures, and the awareness of Judges to its existence.

    - Such an assessment could be led by the Attorney General's Statewide Steering Committee.

An Important Judicial Perspective

"If this was my child, I would have the same outrage as you have expressed to the court today…
I don't know what happened with the Prosecutor's office. I know they normally do good work,
but it sounds as though in this particular case there may have been inadequate follow up…."

A Judge's Closing Comments in a Questionable Case Involving the Prosecution of a Teenager with Multiple Disabilities
August 2024

Education

Over the years, we have worked with many families trying to navigate challenges involving their child's education. A contentious Individualized Education Program (IEP) process. A local school district refusing an out-of-district placement. A system of transportation that places special needs students at great risk or worse.

On the positive side, there are certainly many school districts that are staffed by educators who are mission-driven, student-centered, and effective. They care about their students and families. They understand the opportunities as well as the limitations of the system. And they advocate with a wonderful mix of passion and expertise.

On the negative side, however, families usually seek our assistance when there is a problem – when they do not feel that their local school officials understand their child or much less care. They often contact our office when they feel that their child is unsafe, unsupported, or not being provided a "free appropriate public education" — a critically important legal and moral obligation of local school districts. Indeed, many families tell us they fear that decisions are made based on the short-sighted budget considerations of the district, rather than the long-term interests of their children.

To help these families, in addition to our one-on-one conversations, we have often collaborated with NJ's Office of Special Education Ombudsman as well as advocates, such as the SPAN Advocacy Network. We have also joined families for IEP meetings, although our presence is sometimes contested by local school officials.

An Important Individual/Family Perspective

> "…I'm asking for desperate help for the educational needs for my son …. Our advocacy for our son is now going on over 3 years. Attached please find the expert reports for [our son]. Attached please also find a picture of [him] to represent that there is a child in the middle of all of this who desperately needs help and his district has failed him for years….
>
> I feel at this moment that we may be fighting against a possible broken system. [Our son's] due process is now being dragged since it was filed on April 24, 2023. [He] has been in a due process for now 429 days and still doesn't have a hearing date and he is a child with a severe disability needing help asap."
>
> A Parent of a 10-Year-Old Student
> June 2024

Going forward, we offer these recommendations:

- **The Individualized Education Program (IEP) Process**: We have heard numerous stories about IEP processes that are seemingly unfair and unproductive. Parents feeling that they are not being heard or respected. Parents feeling that they are alone in meetings against an array of school officials. Parents feeling they have to "lawyer up" because the conversation about what is in their child's best interest is being driven by legal counsel hired by the local district, yet paid for with their taxpayer money.

  To help address or even avoid these types of situations, the NJ Department of Education recently developed and launched a "Facilitated Individualized Education Program" that seeks to promote a productive, student-centered conversation. Currently, this important resource is only utilized when all involved – the family as well as the school district – agree to do so. Our recommendation is to make this service mandatory if a family requests it.

  Out of District Placement: Sometimes a local school district is unable to meet the needs of a student with disabilities and therefore unable to provide a "free appropriate public education" in district. Sometimes the "least restrictive environment" is not in the local school district. At all times, these determinations are to be made in the context of the IEP process and should be student-centered – driven only by what is in the best interest of the student.

  However, parents often feel that local school districts make such decisions based on cost considerations, which seems to explain why discussions about an out-of-district placement often become so contentious.

  The State has long offered local school districts Extraordinary Special Education Aid (EXAID) to help defray the costs. The goal of such assistance is to mitigate the very real budget concerns of local boards of education and to help keep everyone's focus on the student at the center of it all. Clearly, however, this is not always the case.

Our recommendation is to undertake a thorough review of EXAID in the context of out-of-district considerations. Is the aid enough, particularly in low-income school districts? Are there better ways to help ensure that local districts' decisions are, in fact, student-centered?

Student Transportation: In last year's annual report, we identified student transportation to out-of-district schools as one of the most pressing issues demanding immediate attention. That sense of urgency remains, and it is imperative that some vital, commonsense steps be taken as soon as possible. More safety measures, including video technology and 911 protocols. More student-centered training of drivers and aides. And more accountability on the part of local school districts.

There are nearly 1,800 student transportation vendors operating in New Jersey, responsible for the safety and well-being of many of the approximately 8,500 students with disabilities, who attend out-of-district schools. Yet, contracts are awarded to the lowest bidders, who receive minimal training.

A Questionable School District Response

"Regarding IEP protections, the IEP can't guarantee bus safety or a specific transportation service. "

A Senior Local School District Official,
June 2025

This makes no sense.

There is a reason that that these students must attend school out-of-district: They have significant disabilities. But rather than ensure the right protections are in place, responsibility for transporting them to and from school every morning is often placed in small companies with questionable credentials and little, if any, oversight.

Our recommendations are again:

- 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.

An Important Individual/Family Perspective

"We continue to have our daughter put in unsafe conditions on her S2 vehicle. The company will not respond to texts, calls, or requests to call us back. We have been trying and they won't answer…. I've contacted the county superintendent's office. The transportation person said he has been waiting for [a NJ Department of Education official] to respond. [The Official] has known about our issues since May of 2024 and does not respond to calls or emails.

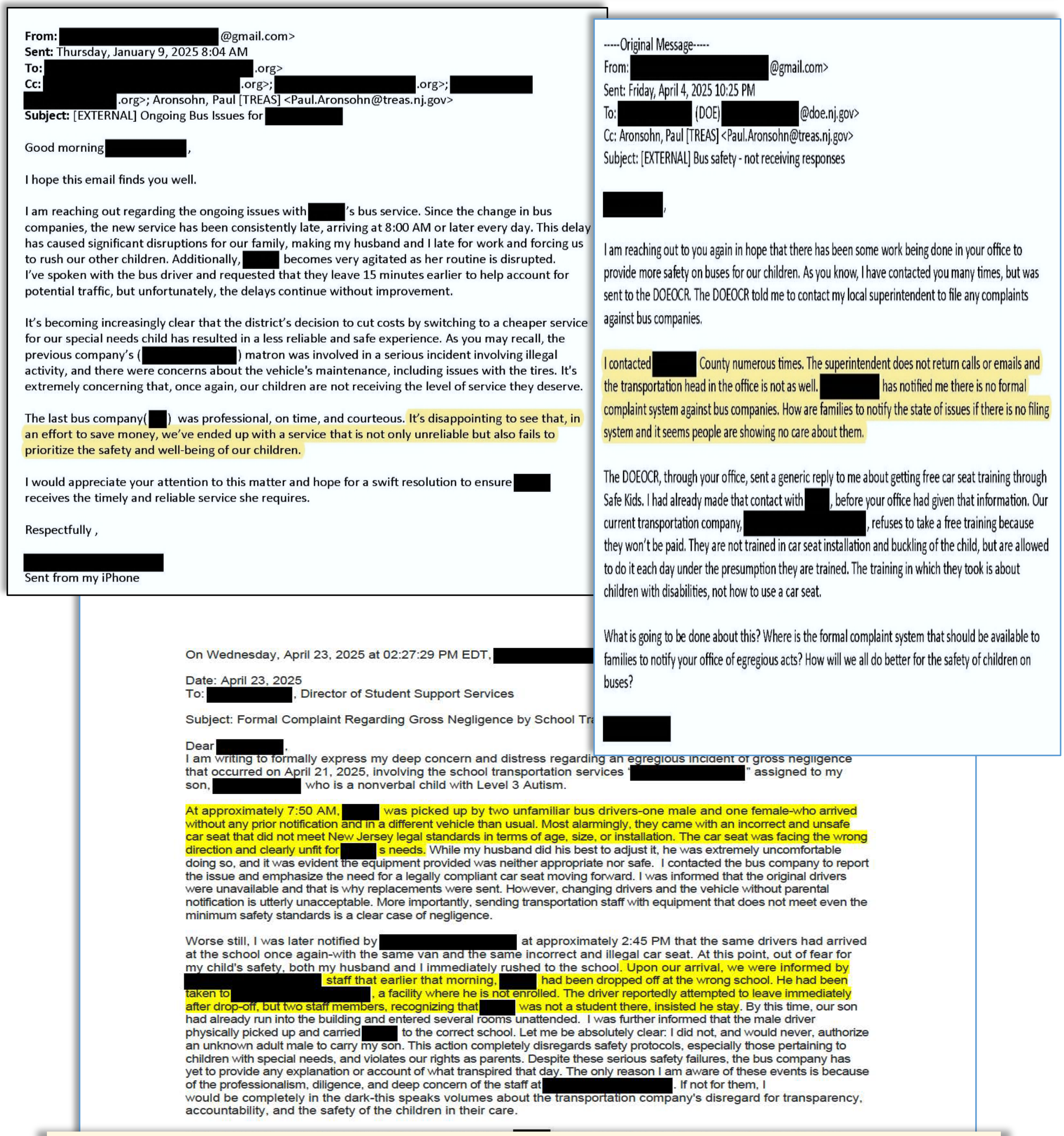
The county superintendent said everyone is trained, but it's the vendors responsibility. The company claims they were trained from the district. Our district won't even entertain the idea of training or add it to an IEP.

We have even tried filing a police report to find the police say it's all a "gray area." We are so disheartened and scared for our child. The state is gambling with children's lives.

A Parent of a Student Who Attends an Out-of-District School,
Trying for More Than a Year to Have Their "Bus" Drivers Trained to Install a School-Purchased Car Seat
April 2025

Student Transportation in Perspective

Recent messages from multiple parents.



From: [redacted]@gmail.com>
Sent: Thursday, January 9, 2025 8:04 AM
To: [redacted].org>
Cc: [redacted].org>; [redacted].org>; [redacted].org>; Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>
Subject: [EXTERNAL] Ongoing Bus Issues for [redacted]

Good morning [redacted],

I hope this email finds you well.

I am reaching out regarding the ongoing issues with [redacted]'s bus service. Since the change in bus companies, the new service has been consistently late, arriving at 8:00 AM or later every day. This delay has caused significant disruptions for our family, making my husband and I late for work and forcing us to rush our other children. Additionally, [redacted] becomes very agitated as her routine is disrupted.
I've spoken with the bus driver and requested that they leave 15 minutes earlier to help account for potential traffic, but unfortunately, the delays continue without improvement.

It's becoming increasingly clear that the district's decision to cut costs by switching to a cheaper service for our special needs child has resulted in a less reliable and safe experience. As you may recall, the previous company's ([redacted]) matron was involved in a serious incident involving illegal activity, and there were concerns about the vehicle's maintenance, including issues with the tires. It's extremely concerning that, once again, our children are not receiving the level of service they deserve.

The last bus company([redacted]) was professional, on time, and courteous. It's disappointing to see that, in an effort to save money, we've ended up with a service that is not only unreliable but also fails to prioritize the safety and well-being of our children.

I would appreciate your attention to this matter and hope for a swift resolution to ensure [redacted] receives the timely and reliable service she requires.

Respectfully ,

[redacted]
Sent from my iPhone

-----Original Message-----
From: [redacted]@gmail.com>
Sent: Friday, April 4, 2025 10:25 PM
To: [redacted] (DOE) [redacted]@doe.nj.gov>
Cc: Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>
Subject: [EXTERNAL] Bus safety - not receiving responses

[redacted],

I am reaching out to you again in hope that there has been some work being done in your office to provide more safety on buses for our children. As you know, I have contacted you many times, but was sent to the DOEOCR. The DOEOCR told me to contact my local superintendent to file any complaints against bus companies.

I contacted [redacted] County numerous times. The superintendent does not return calls or emails and the transportation head in the office is not as well. [redacted] has notified me there is no formal complaint system against bus companies. How are families to notify the state of issues if there is no filing system and it seems people are showing no care about them.

The DOEOCR, through your office, sent a generic reply to me about getting free car seat training through Safe Kids. I had already made that contact with [redacted], before your office had given that information. Our current transportation company, [redacted], refuses to take a free training because they won't be paid. They are not trained in car seat installation and buckling of the child, but are allowed to do it each day under the presumption they are trained. The training in which they took is about children with disabilities, not how to use a car seat.

What is going to be done about this? Where is the formal complaint system that should be available to families to notify your office of egregious acts? How will we all do better for the safety of children on buses?

[redacted]

On Wednesday, April 23, 2025 at 02:27:29 PM EDT, [redacted]

Date: April 23, 2025
To: [redacted], Director of Student Support Services

Subject: Formal Complaint Regarding Gross Negligence by School Tra

Dear [redacted],
I am writing to formally express my deep concern and distress regarding an egregious incident of gross negligence that occurred on April 21, 2025, involving the school transportation services "[redacted]" assigned to my son, [redacted] who is a nonverbal child with Level 3 Autism.

At approximately 7:50 AM, [redacted] was picked up by two unfamiliar bus drivers-one male and one female-who arrived without any prior notification and in a different vehicle than usual. Most alarmingly, they came with an incorrect and unsafe car seat that did not meet New Jersey legal standards in terms of age, size, or installation. The car seat was facing the wrong direction and clearly unfit for [redacted] s needs. While my husband did his best to adjust it, he was extremely uncomfortable doing so, and it was evident the equipment provided was neither appropriate nor safe. I contacted the bus company to report the issue and emphasize the need for a legally compliant car seat moving forward. I was informed that the original drivers were unavailable and that is why replacements were sent. However, changing drivers and the vehicle without parental notification is utterly unacceptable. More importantly, sending transportation staff with equipment that does not meet even the minimum safety standards is a clear case of negligence.

Worse still, I was later notified by [redacted] at approximately 2:45 PM that the same drivers had arrived at the school once again-with the same van and the same incorrect and illegal car seat. At this point, out of fear for my child's safety, both my husband and I immediately rushed to the school. Upon our arrival, we were informed by [redacted] staff that earlier that morning, [redacted] had been dropped off at the wrong school. He had been taken to [redacted], a facility where he is not enrolled. The driver reportedly attempted to leave immediately after drop-off, but two staff members, recognizing that [redacted] was not a student there, insisted he stay. By this time, our son had already run into the building and entered several rooms unattended. I was further informed that the male driver physically picked up and carried [redacted] to the correct school. Let me be absolutely clear: I did not, and would never, authorize an unknown adult male to carry my son. This action completely disregards safety protocols, especially those pertaining to children with special needs, and violates our rights as parents. Despite these serious safety failures, the bus company has yet to provide any explanation or account of what transpired that day. The only reason I am aware of these events is because of the professionalism, diligence, and deep concern of the staff at [redacted]. If not for them, I would be completely in the dark-this speaks volumes about the transportation company's disregard for transparency, accountability, and the safety of the children in their care.

[redacted]

Question: Why is more not done to protect students with disabilities?
Question: Who is responsible for student transportation – The State? The County? The local school district?

Student Transportation in Perspective

Page 1 of 3

[redacted] Police Dept

Incident #: [redacted]

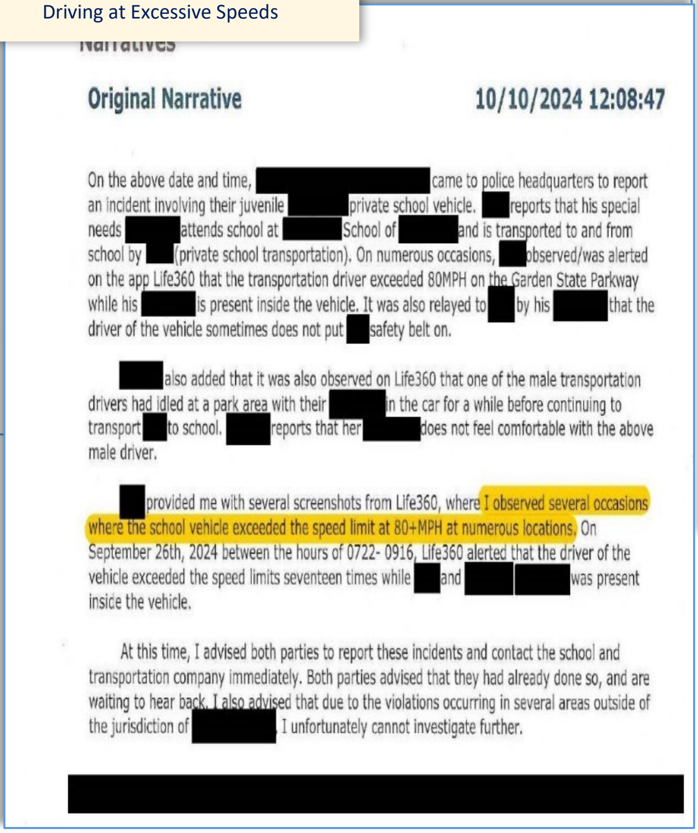
Reporting Officer: [redacted]

Report Time: 10/10/2024 11:40:11

Incident

Incident Nature REPORT TO HEADQUARTERS	Address [redacted]	Occurred From 10/10/2024 11:40:11
Occurred To 10/10/2024 11:40:11	Received By [redacted]	How Received [redacted] Initiated
Contact	Disposition Closed Case	Miscellaneous Entry
Disposition Date 10/10/2024	Cleared	Judicial Status
Cleared Date	Clearance Report Required	Cargo Theft Related

Police Report Confirming School Vehicle Driving at Excessive Speeds



Narratives

Original Narrative 10/10/2024 12:08:47

On the above date and time, [redacted] came to police headquarters to report an incident involving their juvenile [redacted] private school vehicle. [redacted] reports that his special needs [redacted] attends school at [redacted] School of [redacted] and is transported to and from school by [redacted] (private school transportation). On numerous occasions, [redacted] observed/was alerted on the app Life360 that the transportation driver exceeded 80MPH on the Garden State Parkway while his [redacted] is present inside the vehicle. It was also relayed to [redacted] by his [redacted] that the driver of the vehicle sometimes does not put [redacted] safety belt on.

[redacted] also added that it was also observed on Life360 that one of the male transportation drivers had idled at a park area with their [redacted] in the car for a while before continuing to transport [redacted] to school. [redacted] reports that her [redacted] does not feel comfortable with the above male driver.

[redacted] provided me with several screenshots from Life360, where I observed several occasions where the school vehicle exceeded the speed limit at 80+MPH at numerous locations. On September 26th, 2024 between the hours of 0722- 0916, Life360 alerted that the driver of the vehicle exceeded the speed limits seventeen times while [redacted] and [redacted] [redacted] was present inside the vehicle.

At this time, I advised both parties to report these incidents and contact the school and transportation company immediately. Both parties advised that they had already done so, and are waiting to hear back. I also advised that due to the violations occurring in several areas outside of the jurisdiction of [redacted]. I unfortunately cannot investigate further.

[redacted]

Question: Why hasn't this company been penalized?
Question: Why was this company's contract renewed?

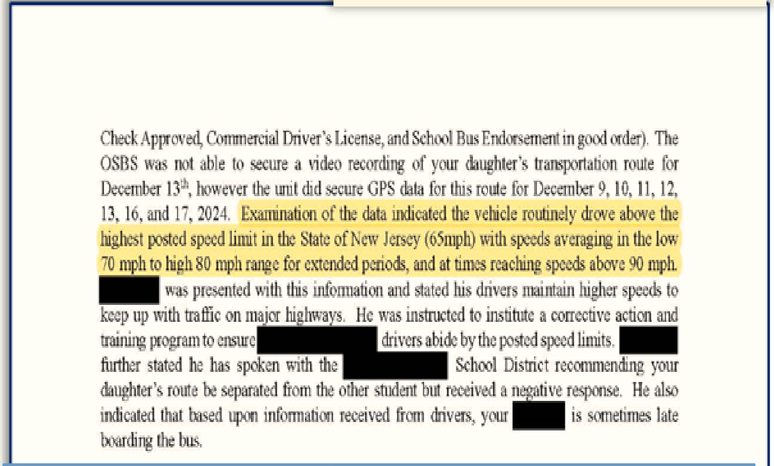
State of New Jersey
Department of Education
PO Box 500
Trenton, NJ 08625-0500

Philip D. Murphy
Governor

Tahesha L. Way
Lt. Governor

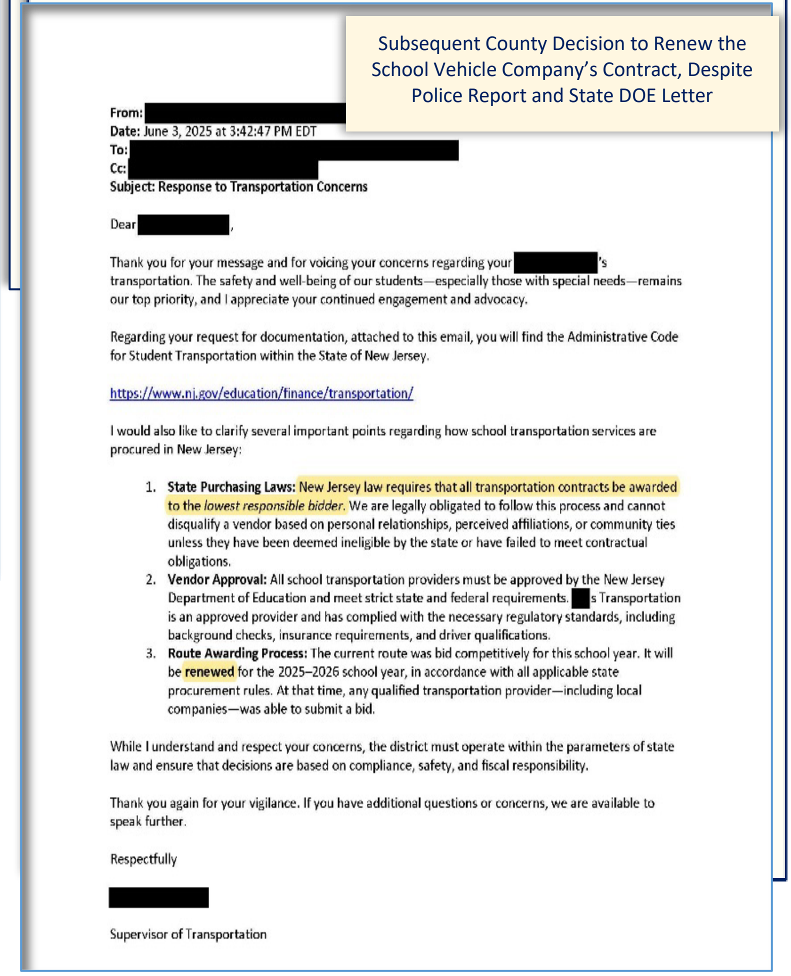
January 22, 2025

NJ Department of Education Confirming School Vehicle Driving at Excessive Speeds



Check Approved, Commercial Driver's License, and School Bus Endorsement in good order). The OSBS was not able to secure a video recording of your daughter's transportation route for December 13th, however the unit did secure GPS data for this route for December 9, 10, 11, 12, 13, 16, and 17, 2024. Examination of the data indicated the vehicle routinely drove above the highest posted speed limit in the State of New Jersey (65mph) with speeds averaging in the low 70 mph to high 80 mph range for extended periods, and at times reaching speeds above 90 mph. [redacted] was presented with this information and stated his drivers maintain higher speeds to keep up with traffic on major highways. He was instructed to institute a corrective action and training program to ensure [redacted] drivers abide by the posted speed limits. [redacted] further stated he has spoken with the [redacted] School District recommending your daughter's route be separated from the other student but received a negative response. He also indicated that based upon information received from drivers, your [redacted] is sometimes late boarding the bus.

Subsequent County Decision to Renew the School Vehicle Company's Contract, Despite Police Report and State DOE Letter



From: [redacted]
Date: June 3, 2025 at 3:42:47 PM EDT
To: [redacted]
Cc: [redacted]
Subject: Response to Transportation Concerns

Dear [redacted],

Thank you for your message and for voicing your concerns regarding your [redacted]'s transportation. The safety and well-being of our students—especially those with special needs—remains our top priority, and I appreciate your continued engagement and advocacy.

Regarding your request for documentation, attached to this email, you will find the Administrative Code for Student Transportation within the State of New Jersey.

https://www.nj.gov/education/finance/transportation/

I would also like to clarify several important points regarding how school transportation services are procured in New Jersey:

1. **State Purchasing Laws:** New Jersey law requires that all transportation contracts be awarded to the *lowest responsible bidder*. We are legally obligated to follow this process and cannot disqualify a vendor based on personal relationships, perceived affiliations, or community ties unless they have been deemed ineligible by the state or have failed to meet contractual obligations.
2. **Vendor Approval:** All school transportation providers must be approved by the New Jersey Department of Education and meet strict state and federal requirements. [redacted]s Transportation is an approved provider and has complied with the necessary regulatory standards, including background checks, insurance requirements, and driver qualifications.
3. **Route Awarding Process:** The current route was bid competitively for this school year. It will be **renewed** for the 2025–2026 school year, in accordance with all applicable state procurement rules. At that time, any qualified transportation provider—including local companies—was able to submit a bid.

While I understand and respect your concerns, the district must operate within the parameters of state law and ensure that decisions are based on compliance, safety, and fiscal responsibility.

Thank you again for your vigilance. If you have additional questions or concerns, we are available to speak further.

Respectfully

[redacted]

Supervisor of Transportation

Employment

As a State, we recognize that access to employment opportunities can be central to a full, meaningful life. It is not only about personal finances; it is also about dignity, self-esteem, and personal accomplishment.

For this reason, New Jersey is an "Employment First" State – a designation that underscores the priority placed on competitive, integrated employment for people with disabilities. And in recent years, important steps have been taken to promote such employment. Most notably, the State Legislature passed and the Governor signed legislation to expand the "NJ WorkAbility"program, which makes it possible for people with disabilities to earn good salaries without jeopardizing their vital Medicaid-related supports.

Yet, we have talked with many individuals and families who effectively feel shutout of employment. Lack of transportation. Lack of awareness of resources and opportunities. Lack of interest on the part of some employers. Lack of helpful support from government and community-based agencies, including the recent decision to impose premiums/fees on some people enrolled in the NJ WorkAbility program. Taken together, for a host of reasons, meaningful employment remains an elusive goal for many people with disabilities.

To be sure, such challenges are not unique to New Jersey. Indeed, the relatively high national unemployment rate for people with disabilities has remained more than double that of those without disabilities.

Going forward, we offer the following few recommendations.

- **Transportation**: As we discuss later in the report, without transportation, many people cannot get to and from a job. It is that simple. It is that serious. Although much work can now be done virtually at home, more and more employers are requiring staff to be back in-person at an actual worksite. Therefore, we need to make transportation more readily available. There is no getting around it.

- **Workability:** The decision to impose "premiums" (fees) on many of those participating in the NJ WorkAbility program was unfortunate, particularly since the federal Centers for Medicare and Medicaid Services (CMS) made it clear that it was the State's decision. Many of us believe the premiums are unnecessary and unfair and serve as a disincentive for people contemplating employment – placing yet another financial hardship on people with disabilities. At a minimum, we should study the NJ WorkAbility program to determine whether there are actually legitimate costs that need to be covered by the premiums/fees OR whether the premiums/fees should be eliminated, because the program could actually result in additional revenue for the State since higher earners pay higher taxes and have less need for other government programs, including food or rental assistance.

- **Pre-Employment Transition Services**: For more than a decade, pre-employment transition services for students with disabilities has been required by Federal and State law. Yet, many parents have told us that they were either not aware of such services or did not know how to access them. Indeed, many parents have told us that "Pre-ETS" (as the services are widely known) was not a topic discussed in the context of their child's Individualized Education Program (IEP) – a concerning revelation that aligns with a recent national report that singled out New Jersey for having the lowest participation rate by students. Clearly, we need to find a way to ensure these important services are available to every student with a disability, regardless of school district or zip code. We have both a legal and moral responsibility to do so.

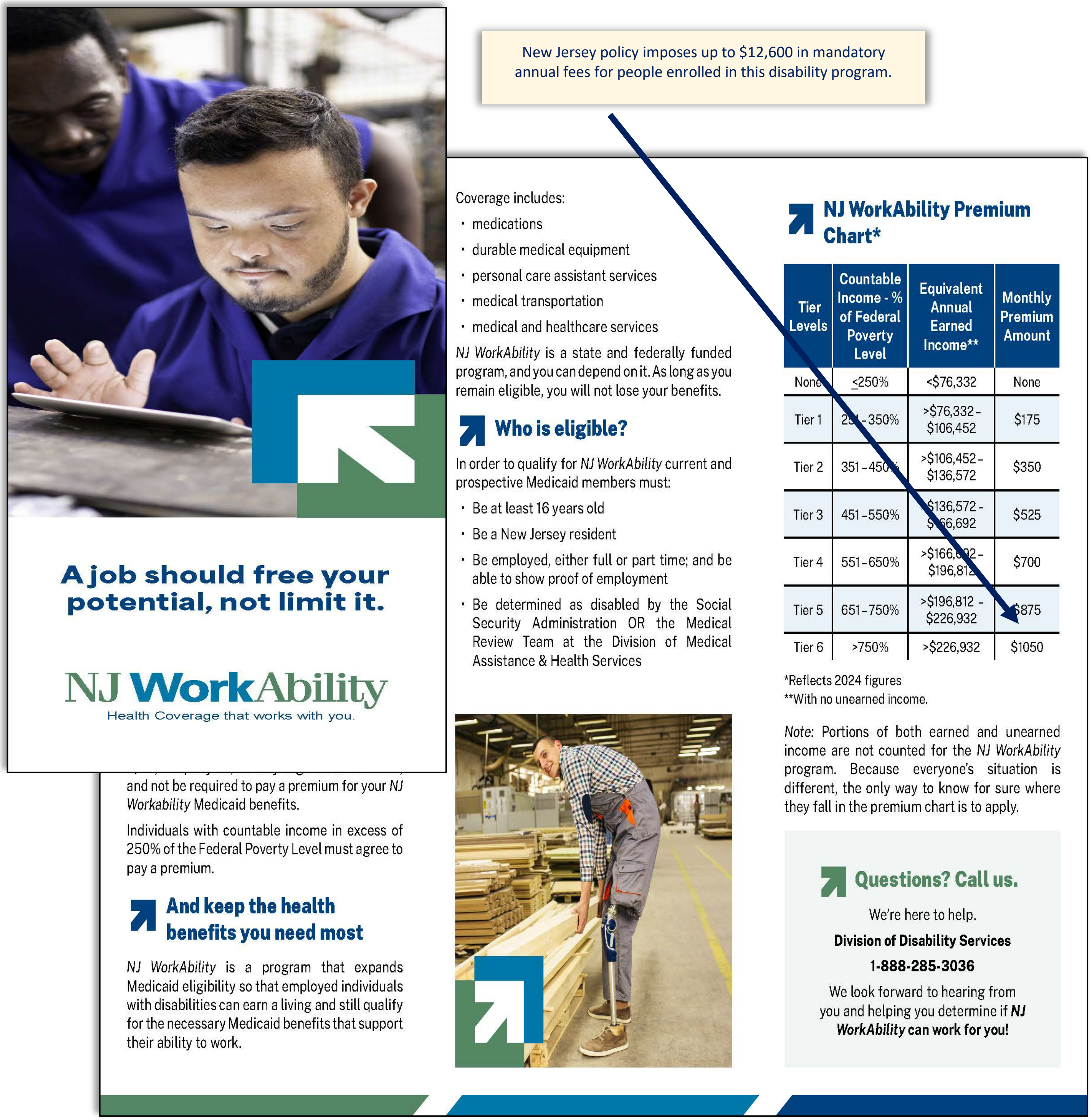
An Important Individual/Family Perspective

"It is unfair because a "premium" – which is just another word for a "tax" – would single out people with disabilities who want to work and effectively punish them for having disabilities and needing accommodations. After all, practically everyone – with or without a disability – benefits from government-funded programs, directly or indirectly. From students to seniors to homeowners to small business leaders – practically everyone benefits from some sort of public assistance or tax code provision. Yet, none of them have to pay a "premium."

Norman Smith, Former Chairperson, NJ Statewide Independent Living Council,
Expressing His Views about the Administration's Proposal for WorkAbility Premiums
July 2022

NJ WorkAbility in Perspective

New Jersey policy imposes up to $12,600 in mandatory annual fees for people enrolled in this disability program.



A job should free your potential, not limit it.

NJ WorkAbility

Health Coverage that works with you.

and not be required to pay a premium for your *NJ Workability* Medicaid benefits.

Individuals with countable income in excess of 250% of the Federal Poverty Level must agree to pay a premium.

And keep the health benefits you need most

NJ WorkAbility is a program that expands Medicaid eligibility so that employed individuals with disabilities can earn a living and still qualify for the necessary Medicaid benefits that support their ability to work.

Coverage includes:

- medications
- durable medical equipment
- personal care assistant services
- medical transportation
- medical and healthcare services

NJ WorkAbility is a state and federally funded program, and you can depend on it. As long as you remain eligible, you will not lose your benefits.

Who is eligible?

In order to qualify for *NJ WorkAbility* current and prospective Medicaid members must:

- Be at least 16 years old
- Be a New Jersey resident
- Be employed, either full or part time; and be able to show proof of employment
- Be determined as disabled by the Social Security Administration OR the Medical Review Team at the Division of Medical Assistance & Health Services

NJ WorkAbility Premium Chart*

Tier Levels	Countable Income - % of Federal Poverty Level	Equivalent Annual Earned Income**	Monthly Premium Amount
None	≤250%	<$76,332	None
Tier 1	251 - 350%	>$76,332 - $106,452	$175
Tier 2	351 - 450%	>$106,452 - $136,572	$350
Tier 3	451 - 550%	>$136,572 - $166,692	$525
Tier 4	551 - 650%	>$166,692 - $196,812	$700
Tier 5	651 - 750%	>$196,812 - $226,932	$875
Tier 6	>750%	>$226,932	$1050

*Reflects 2024 figures

**With no unearned income.

Note: Portions of both earned and unearned income are not counted for the *NJ WorkAbility* program. Because everyone's situation is different, the only way to know for sure where they fall in the premium chart is to apply.

Questions? Call us.

We're here to help.

Division of Disability Services

1-888-285-3036

We look forward to hearing from you and helping you determine if ***NJ WorkAbility* can work for you!**

Question: Are premiums / fees really necessary?
Question: Are they fair?

Health Care

Access to quality health care is vital – regardless of disability status. Access to quality health care, however, is an unrelenting challenge for many individuals with intellectual or developmental disabilities.

Indeed, myriad limitations prevent people with lifespan disabilities from accessing the care they need and deserve. Among those most often brought to our attention by individuals and families:

- Many medical professionals are not trained and/or are not willing to serve people with disabilities, who often require additional time for appointments as well as other accommodations.
- Many people with disabilities rely on Medicaid for their health care coverage, which limits the number of medical providers available to them, due to relatively low reimbursement rates.
- Many people have expressed concerns that staff in State-licensed residences (group homes and supervised apartments) often fail to meet the health needs of those in their care – harmful food choices, missed medical appointments, slow responses to health conditions, improper medication administration, etc.

An Important Individual/Family Perspective

"My daughter — a vibrant young woman who was excellent at grooming horses and could correctly identify all the birds of North America by sight or sound — was not a burden. The idea that her death at age 21 this summer provided relief grossly belies the love and purpose we found in caring for her….

Our daughter required several specialists to manage her chronic conditions. This meant the presence of a parent or guardian and travel, plus the out-of-pocket costs of private insurance copays or deductibles. Few physicians see patients with Medicaid because the reimbursement rate is lower than it is with private insurance."

Lynne Moronski Writing about Her Daughter, Katie,
Who Died Within Days of Moving into a State-Licensed Group Home
Philadelphia Inquirer
February 2025

Clearly, these barriers to quality health care can and should be addressed. There is not only a moral imperative to ensure people with disabilities have meaningful access to quality health care; there are also practical and financial imperatives, too. Simply stated, better access will lead to better care and less need for costly medical interventions, including hospital visits. And in some cases, it means the difference between life and death.

Going forward, we offer the following few recommendations:

- **Access to Medical Professionals:** Many, if not most, New Jerseyans with intellectual or developmental disabilities rely on one of the State's five Medicaid managed care organizations (MCO) to obtain health care coverage. We should therefore ensure that the MCOs maintain "network adequacy" – that they guarantee their plan members have real access to the full array of medical professionals. We should also require the MCOs to extend coverage to "border providers" (healthcare professionals and hospitals) in adjacent States, similar to the coverage offered to New Jersey State government employees.

An Important Individual/Family Perspective

"I'm the mom who brought up the issue with my daughter's Medicaid not covering critical doctors in NYC, or services at the new Williams Syndrome (ACE) Center on the UPenn campus in Philadelphia.

This gap in coverage is something I've now officially added to my "Shit That Keeps Me Up at Night" list.
It's frustrating, disheartening, and deeply concerning as a parent trying to get the safest care possible for her daughter.

Parent of a Young Adult with Complex Medical Needs
October 2024

- **Medicaid Rates**: We need to revisit our Medicaid reimbursement rates, requiring that they be more reasonable and more aligned with Medicare and private (commercial) insurance rates. The recently announced raise in rates for pediatricians and primary care physicians should be extended across all medical professionals. This would likely incentivize more medical, mental, and dental health professionals to become Medicaid providers and to be more willing and able to treat people with intellectual or developmental disabilities.

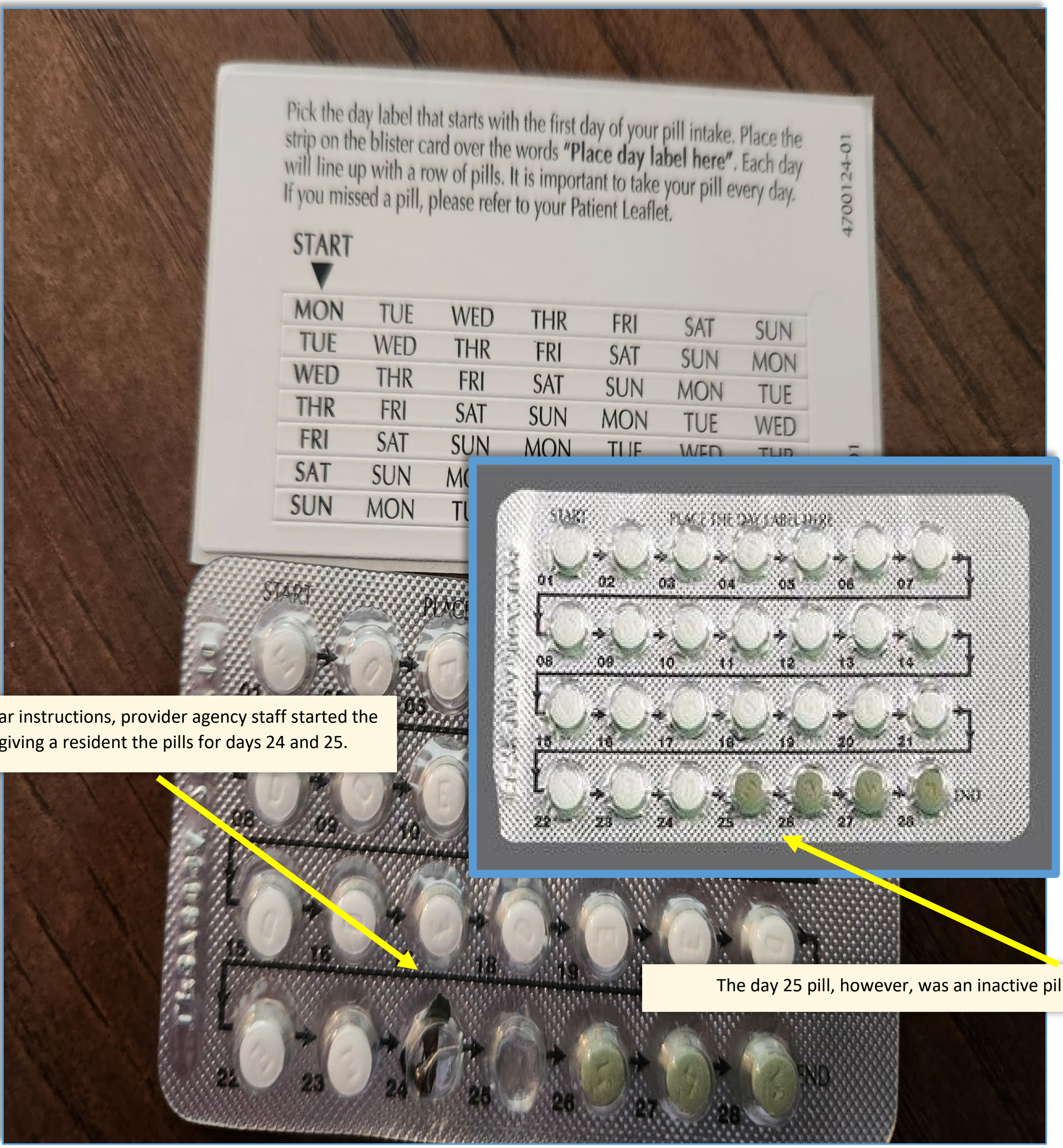
- **Provider Agency Staff**: Simply stated, provider agencies need to be held more accountable for the health needs of the residents in their care. That means better training and oversight of direct care staff. That means nurse involvement with the administration of medication* – a requirement that exists in practically every other setting for every other community – such as schools, assisted living homes, prisons, and developmental centers – and that exists in other States, including New York.

Important note about medication administration: It was recently acknowledged there have been 1,620 cases of reported medication errors in State-licensed residences for adults with disabilities over the last five years. The actual number, however, is undoubtedly much larger, because in our experience, families have come to accept this dangerous reality as "a given" of life in a State-licensed setting – one that is not often reported due to its frequency and general acceptance. Indeed, many families share stories about medication errors as an afterthought when talking with us about another situation in the group home.

Moreover, medications errors also occur in State-licensed residences for youth under the age of 21. And just like with the adult system, there is no requirement that a nurse be involved with the administration of medication in residences licensed by the NJ Department of Children and Families.

All of this is particularly concerning and needs to be fixed.

Medication Errors in Perspective



Pick the day label that starts with the first day of your pill intake. Place the strip on the blister card over the words **"Place day label here"**. Each day will line up with a row of pills. It is important to take your pill every day. If you missed a pill, please refer to your Patient Leaflet.

Despite clear instructions, provider agency staff started the month giving a resident the pills for days 24 and 25.

The day 25 pill, however, was an inactive pill.

Question: Shouldn't nurses be involved in the administration of medicine?

Housing

As we discussed in last year’s annual report, 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.

- 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 treatment 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.

In last year’s report, we made several concrete recommendations –

- **Housing Web Portal**: Develop a one-stop easy to use website that provides access to useful information about the resources available to individuals, families, providers, and developers – one that includes information about licensed and unlicensed opportunities as well as information about vouchers, grants, legal services, and advocacy organizations.
- **Housing Vouchers**: Increase flexibility regarding local rent standards/levels as well as the use of rental vouchers in family-owned homes.
- **Housing Technology**: Increase the use of video cameras and “smart” technology.
- **Housing Modifications**: Increase flexibility with respect to permitted home modifications.
- **Accessory Dwelling Units**: Increase the ability of home owners to build housing structures on their property.
- **Out-of-State Placements**: Increase the availability of out-of-state residential options for youth and adults, when necessary due to a lack of needed specialized residential services in-state.
- **Intentional Communities**: Explore the development of intentional residential communities, such as campuses – independent, yet fully supportive communities for people with the full range of behavioral and/or medical needs.

Going forward, we offer the following few additional recommendations concerning the safety, well-being, and fair treatment of people with disabilities.

- **Licensed Residences**: For youth and adults with significant support needs, there are a variety of State-licensed residences available.

    - Through the NJ Department of Children and Families, there are less than 300 placements available for youth (under age 21) in licensed residential settings in New Jersey – much less than the number of placements available when I started this job in 2018.

    - Through the NJ Department of Human Services, there are about 8,400 placements available for adults (aged 21 and over) in licensed group homes and apartments – representing a significant increase in recent years.

    - The NJ Department of Children and Families (DCF) occasionally places youth in out-of-state locations. The NJ Department of Human Services, however, does not.

  Clearly, we need more residential treatment options available for youth whose needs cannot be met at home. Indeed, we have been involved in countless situations whereby a youth desperately needs an out-of-home placement – for their safety and well-being as well as that of their families – but nothing is available due to a scarcity of “beds” as well as due to New Jersey’s refusal to pay certain rates.

  Clearly, too, we need to make out-of-state options available to adults whose needs cannot be met in New Jersey. In fact, Medicaid regulations may make it possible to fund such placements with a mix of State and Federal funds.

  Beyond that, we need to do a lot more to ensure the safety and well-being of individuals – of all ages – living in our State-licensed settings. As discussed in the “Abuse & Neglect” section above, we need better staffing. We need investigations of abuse and neglect to be more thorough, more credible, and more meaningful. And we need more accountability from the agencies paid – with taxpayer money – to manage these State-licensed settings.

- **Unlicensed Residences**: Most New Jerseyans with intellectual or developmental disabilities live in unlicensed settings. Personal homes. Family homes. And increasingly in supportive housing communities and accessible set aside apartments. All of this is good, except we have occasionally learned of problems with the latter and that there is a real need for more oversight, if not regulation, in such residential settings for people with disabilities.

An Important Individual/Family Perspective

“While the school has been supportive, we have realized that (my child) needs an intensive, residential educational program, due to the nature of his violent behavior.

We are working with [redacted] CMO and (my child) is on a "waiting list" for … housing. Again, our CM with [redacted] has been great, but they unfortunately are unable to provide us with information on timing (where my child is on the waitlist), and the type of program we are "waiting" for.

I am also very surprised and disturbed by the protocol we need to follow to have my son moved up on the said waitlist.”

Parent of a Teenager with Significant Disabilities
May 2024

“I am writing to formally document a recent incident involving my son, [redacted], whose urgent need for residential educational placement remains unresolved after a year and a half of advocacy.

Attached is a picture and video recorded on Saturday, May 17, 2025 in which (he) pushes me into a pile of broken glass from a vase that he threw into the ceiling during a behavioral escalation. This resulted in injury and further demonstrates the severity of our current home situation.”

The Same Parent
May 2025
(One Year Later)

Indeed, we have learned of questionable practices by landlords, including:

- Treating residents with disabilities different than residents without disabilities by enforcing specific requirements on the former, but not the latter.
- Exceeding their authority as landlords by making demands for personal health information and support plans.
- Allowing service providers to effectively coerce residents into utilizing their services.
- Disregarding the role of legal guardians.

A Questionable Landlord Perspective

> "We now require the ISP along with all housing applications and because the ISP is updated annually, we are also requesting the most current plan be submitted along with the annual update to the Support Services agreement.
> These are now required attachments to the lease."
>
> Landlord Representative for a Supportive Housing Community,
> Demanding a Copy of Individualized Service Plans, Which Contain Very Sensitive Personal Information
> November 2024

We clearly need to do more to protect the rights of people with disabilities living in unlicensed settings.

Although I truly believe that many of the people involved in the development and operation of our State's supportive housing residences/communities are very well-intentioned, it currently seems like "the wild west" in that some of these landlords are making up their own rules without much involvement / oversight by State government.

We have raised our concerns with the U.S. Department of Health and Human Services. We have raised our concerns with the NJ Department of Human Services. And we have begun exploring these concerns with Disability Rights New Jersey and Legal Services of New Jersey.

Together, we need to find a better way forward – one that facilitates the development of much-needed supportive housing residences, while protecting the civil and human rights of people with disabilities.

One additional thought with respect to housing: Recent statements and actions by senior officials in the NJ Department of Human Services related to private duty nursing and overnight staffing have been raising both questions and concerns – questions about the meaning of their opaque statements, concerns that they are part of an effort to compel people with significant disabilities to live in more restrictive settings, including State-licensed group homes and institutions.

- With respect to nursing, senior Department leadership recently testified in support of New Jersey's policy to allow only up to 16 hours per day of private duty nursing in unlicensed settings, such as personal homes or family homes. In so doing, the official publicly questioned whether "24-hour around the clock care for every individual in their home" is cost effective.
- With respect to overnight staffing, as discussed below in the "self-direction" section of this report, Department officials have been telling people that a policy change is in the works – one that would make it more difficult, if not impossible, to hire overnight staff in personal and family homes.

Taken together, along with existing policies and practices that have led to new admissions in the State-run Developmental Centers as well as State-licensed nursing homes, there is a real concern that a re-institutionalization is underway in New Jersey – something discussed in our 2021 and 2023 annual reports. Moreover, in last year's report, we also highlighted Department policies that have favored group home providers at the expense of self-directing individuals and families.

This is an issue that requires clarification and close scrutiny.

Managed Care Organizations

In New Jersey, there are nearly 1.9 million people enrolled in Medicaid. Most of them — approximately 95% — are enrolled in one of the State's five managed care organizations (MCO). Over the past five fiscal years (2020 through 2024), the MCOs participating in New Jersey's Medicaid program have been paid approximately $70 billion. The Governor's proposed FY2026 projects that they will receive about $22.5 billion over the coming year.

Not surprisingly, the MCOs play a central role in the lives of many New Jerseyans with disabilities. They get paid with Medicaid dollars – Federal and State – to provide healthcare coverage as well as host of other vital services, such as personal care assistance and private duty nursing.

There are rules and regulations about the services they must cover, but there is a lot of discretion built into the system – discretion that effectively allows the MCOs to make many coverage decisions themselves. Indeed, we have worked with several individuals and families, who have been on the receiving end of decisions to reduce or terminate their coverage of specific services – often without real justification.

We share the concern often expressed by these individuals and families, namely that coverage decisions seem driven more by the financial interests of the MCOs than by the clinical needs of the individuals – a concern rooted in two troubling, undeniable realities: (1) the financial incentive built into the process whereby MCOs are often paid a lump sum of taxpayer money (capitation) every month and are able to keep all unused dollars; and (2) the often-inexplicable decisions made by MCOs using an "internal" assessment tool not readily available to individuals and families.

A Questionable Government Admission

"We are concerned that Horizon is cutting services to lower costs knowing that the members aren't even receiving what Horizon themselves deemed to be needed."

NJ Department of Human Services Official
Referring to One Family's Situation
September 2024

For instance, for each plan member in the Medicaid Managed Long Term Services and Supports (MLTSS) program, the MCOs get paid about $8,5000 per month by the State of New Jersey. The money is to pay for services needed by that individual. However, the MCO has the discretion to determine if a person qualifies for Private Duty Nursing coverage, and if so, how many hours should be permitted per week. The MCO also has the discretion to reduce or eliminate that coverage, and they are able to keep all of the unused dollars paid to them.

Granted, there is an appeals process – including a so-called "fair" hearing – but the process has several obvious flaws:

- **Initial Appeal**: The initial appeal available to MCO plan members is an "internal" appeal, meaning that the decision to reduce or eliminate services by the MCO is then reviewed by … the MCO itself.

- **External Appeal**: An external appeal is often available to MCO plan members and entails a third-party organization (Maximus) contracted by the State, which reviews the MCO's decision. [Despite multiple requests, the NJ Department of Human Services has not provided information about the percentage of situations in which Maximus upholds the MCOs' decisions.]

- **Administrative Law Court Hearing**: Following that, the MCO plan member can take the matter to a NJ Administrative Law Court for a "fair" hearing – one in which the individual or family must face off against a lawyer hired by the MCO and effectively paid for with their taxpayer Medicaid dollars. Moreover, the Judge's decision is not actually binding, but merely a recommendation to the NJ Department of Human Services, which makes the "final" decision.

- **Superior Court Hearing**: Following that, the MCO plan member can take the matter to NJ Superior Court, where – for the first time – the MCO's decision will be reviewed with genuine objectivity.

Going forward, we offer the following common-sense recommendations —

- **Transparency**: First and foremost, we need to shine a bright light on these organizations and the State's role in overseeing them. The money paid to MCOs. The decisions made by MCOs. The controls placed on MCOs.

  For example, the "internal" assessment tool used by MCOs to determine Private Duty Nursing coverage raises a lot of questions, because of the secrecy surrounding it and the impact it has on peoples' lives:

  1. Who designs the "internal" tool?

  2. Who gets to review the "internal" tool?

  3. Why isn't the "internal" tool and its results shared immediately with the individual assessed?

  4. How often and under what authority is the "internal" tool changed?

  5. And why does this "internal" tool carry more weight than an individual's medical professionals, who may have known the individual for many years?

  Over the past year, families have been telling us that their MCOs have claimed that reductions and eliminations in coverage are due to a "new" version of the assessment tool being used and that assessments are now being conducted more frequently. One parent, already in the appeals process, was able to get copies of the "internal" tool used to assess a family member, and it was clear that the tool was changed even within the few months between assessments. The questions had changed. The scoring scale had changed. And perhaps not surprisingly, the overall score had changed (See page 60).

  When asked about the assessment process, the NJ Department of Human Services, which oversees the MCOs, said, "*There has been no change in DMAHS's (State Medicaid Division) policy with respect to these assessments, and there is no new tool being used at this time.*"

  Hence the need for transparency.

- **Appeals Process:** As discussed above, the appeals process is deeply flawed. This is particularly true with respect to the so-called "fair" hearing, which is anything but fair. Although the Judges we have worked with seem unquestionably impartial, thoughtful, and considerate to the families, the process is flawed in that their decisions are not actually binding. Regardless how they rule, the final decision is made by the Department.

  This, in turn, raises an important question – Why include such a hearing as part of the appeals process? After all, it seems like it is a big waste of time and money – for the individuals, the government (executive and judicial branches), and the taxpayers who pay for much of it.

  Our recommendation is to reform the overall appeals process, by (among other things) giving Administrative Law Judge's the authority to make binding decisions – a policy changethat can and should be made by our State government.

A Questionable MCO Admission

"The PDN (Private Duty Nursing) Acuity tool is an internal document used to assist Medical Directors in deciding the amount of PDN hours medically necessary for each member. The purpose of a fair hearing is to be able to review, question, correct, or even supplement all the information that [the MCO] received to make its determination of medical necessity.

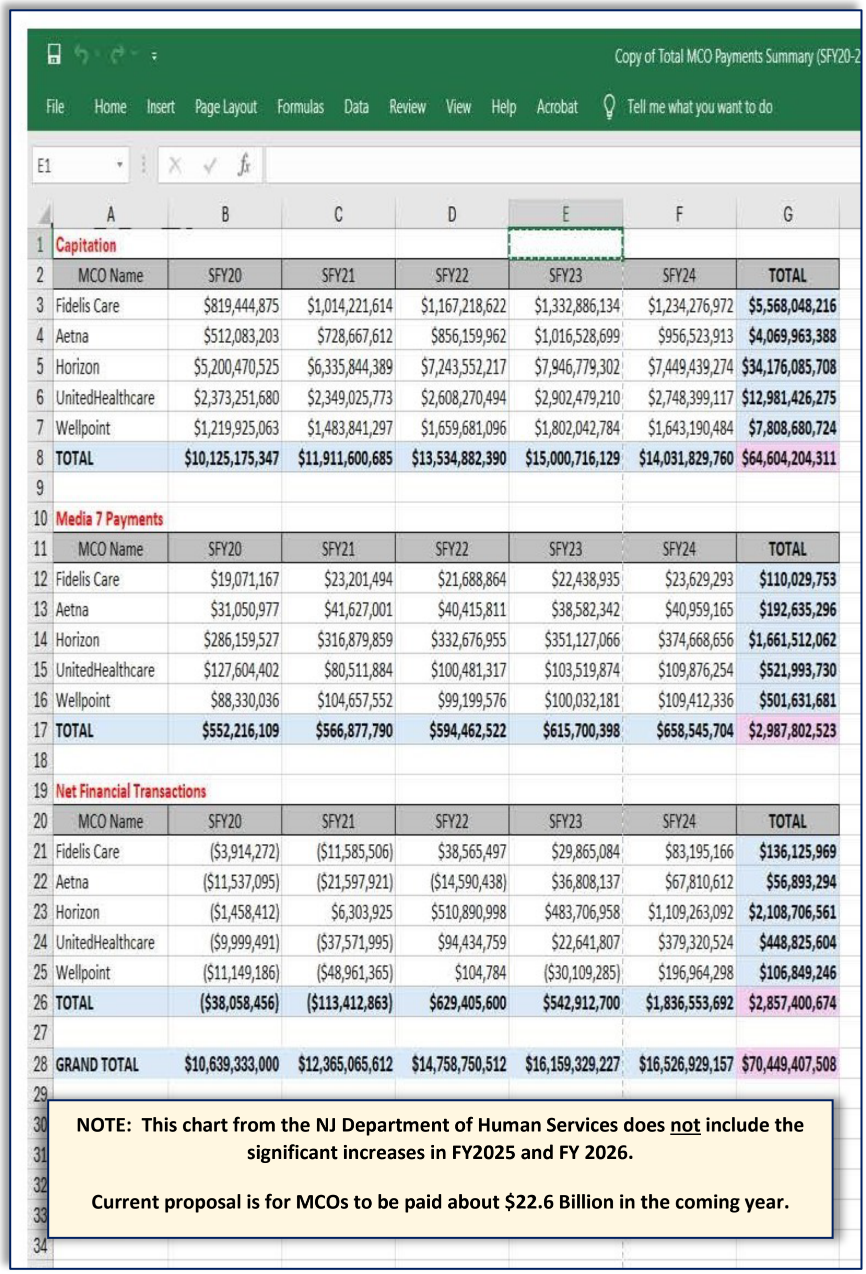
Legal Counsel for a Managed Care Organization
Explaining Why the Results of Its Assessment Were Not Previously Shared with the Guardian
March 2025

Managed Care Organizations in Perspective

In recent years, the number of NJ Medicaid enrollees has fluctuated, but is now almost back down to pre-pandemic levels. In recent years, however, the amount paid to MCOs has continued to increase significantly.

In FY20 (largely pre-pandemic), the MCOs – which provide coverage to about 95% of enrollees – received $10.6 billion. That came to about $6,625 per each of the 1.6 million MCO enrollees.

In FY26, the MCOs are expected to receive about $22.6 billion. That comes to about $12,520 per each of the nearly 1.8 million MCO enrollees.



Capitation

MCO Name	SFY20	SFY21	SFY22	SFY23	SFY24	TOTAL
Fidelis Care	$819,444,875	$1,014,221,614	$1,167,218,622	$1,332,886,134	$1,234,276,972	**$5,568,048,216**
Aetna	$512,083,203	$728,667,612	$856,159,962	$1,016,528,699	$956,523,913	**$4,069,963,388**
Horizon	$5,200,470,525	$6,335,844,389	$7,243,552,217	$7,946,779,302	$7,449,439,274	**$34,176,085,708**
UnitedHealthcare	$2,373,251,680	$2,349,025,773	$2,608,270,494	$2,902,479,210	$2,748,399,117	**$12,981,426,275**
Wellpoint	$1,219,925,063	$1,483,841,297	$1,659,681,096	$1,802,042,784	$1,643,190,484	**$7,808,680,724**
TOTAL	**$10,125,175,347**	**$11,911,600,685**	**$13,534,882,390**	**$15,000,716,129**	**$14,031,829,760**	**$64,604,204,311**

Media 7 Payments

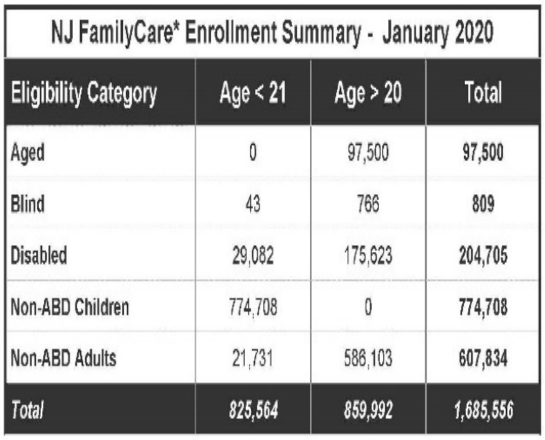
MCO Name	SFY20	SFY21	SFY22	SFY23	SFY24	TOTAL
Fidelis Care	$19,071,167	$23,201,494	$21,688,864	$22,438,935	$23,629,293	**$110,029,753**
Aetna	$31,050,977	$41,627,001	$40,415,811	$38,582,342	$40,959,165	**$192,635,296**
Horizon	$286,159,527	$316,879,859	$332,676,955	$351,127,066	$374,668,656	**$1,661,512,062**
UnitedHealthcare	$127,604,402	$80,511,884	$100,481,317	$103,519,874	$109,876,254	**$521,993,730**
Wellpoint	$88,330,036	$104,657,552	$99,199,576	$100,032,181	$109,412,336	**$501,631,681**
TOTAL	**$552,216,109**	**$566,877,790**	**$594,462,522**	**$615,700,398**	**$658,545,704**	**$2,987,802,523**

Net Financial Transactions

MCO Name	SFY20	SFY21	SFY22	SFY23	SFY24	TOTAL
Fidelis Care	($3,914,272)	($11,585,506)	$38,565,497	$29,865,084	$83,195,166	**$136,125,969**
Aetna	($11,537,095)	($21,597,921)	($14,590,438)	$36,808,137	$67,810,612	**$56,893,294**
Horizon	($1,458,412)	$6,303,925	$510,890,998	$483,706,958	$1,109,263,092	**$2,108,706,561**
UnitedHealthcare	($9,999,491)	($37,571,995)	$94,434,759	$22,641,807	$379,320,524	**$448,825,604**
Wellpoint	($11,149,186)	($48,961,365)	$104,784	($30,109,285)	$196,964,298	**$106,849,246**
TOTAL	**($38,058,456)**	**($113,412,863)**	**$629,405,600**	**$542,912,700**	**$1,836,553,692**	**$2,857,400,674**
GRAND TOTAL	**$10,639,333,000**	**$12,365,065,612**	**$14,758,750,512**	**$16,159,329,227**	**$16,526,929,157**	**$70,449,407,508**

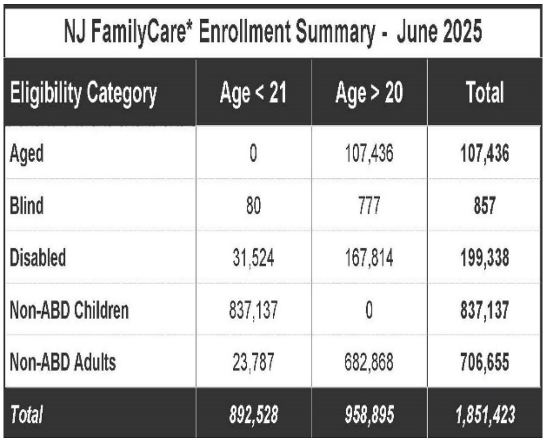
NOTE: This chart from the NJ Department of Human Services does not include the significant increases in FY2025 and FY 2026.

Current proposal is for MCOs to be paid about $22.6 Billion in the coming year.



NJ FamilyCare* Enrollment Summary - January 2020

Eligibility Category	Age < 21	Age > 20	Total
Aged	0	97,500	**97,500**
Blind	43	766	**809**
Disabled	29,082	175,623	**204,705**
Non-ABD Children	774,708	0	**774,708**
Non-ABD Adults	21,731	586,103	**607,834**
Total	*825,564*	*859,992*	*1,685,556*



NJ FamilyCare* Enrollment Summary - June 2025

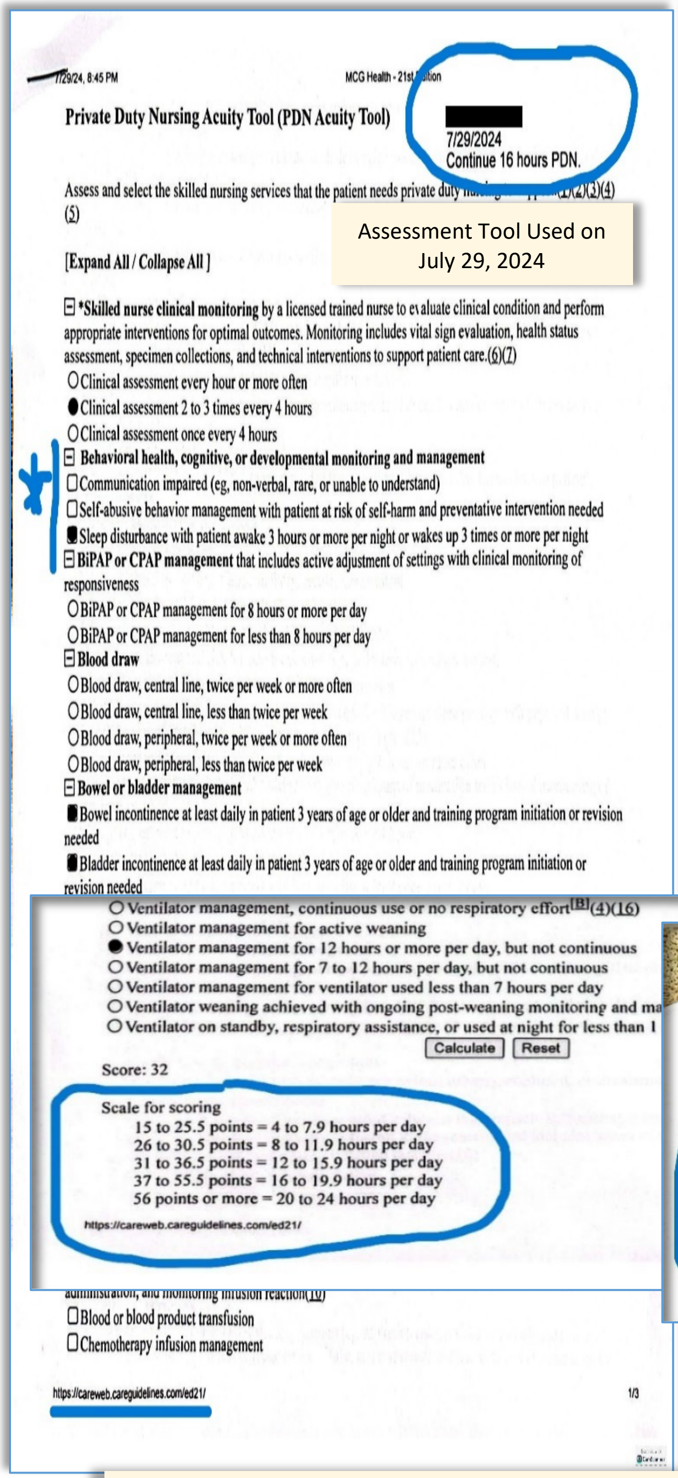
Eligibility Category	Age < 21	Age > 20	Total
Aged	0	107,436	**107,436**
Blind	80	777	**857**
Disabled	31,524	167,814	**199,338**
Non-ABD Children	837,137	0	**837,137**
Non-ABD Adults	23,787	682,868	**706,655**
Total	*892,528*	*958,895*	*1,851,423*

Question: Why have there been such large annual increases in public outlays to the five MCOs?
Question: With a similar number of people to support, why are the MCOs now getting paid much more taxpayer money?

Managed Care Organizations in Perspective

Below are samples of two versions of the "internal" assessment tool used to determine Private Duty Nursing coverage. These tools were used by one MCO to assess and downgrade one individual within a six-month period.

NOTE: The questions are different. The scoring scales are different.



7/29/24, 8:45 PM MCG Health - 21st Edition

Private Duty Nursing Acuity Tool (PDN Acuity Tool)

[redacted]
7/29/2024
Continue 16 hours PDN.

Assessment Tool Used on July 29, 2024

Assess and select the skilled nursing services that the patient needs private duty [illegible] (1)(2)(3)(4) (5)

[Expand All / Collapse All]

⊟ ***Skilled nurse clinical monitoring** by a licensed trained nurse to evaluate clinical condition and perform appropriate interventions for optimal outcomes. Monitoring includes vital sign evaluation, health status assessment, specimen collections, and technical interventions to support patient care.(6)(7)

○ Clinical assessment every hour or more often
● Clinical assessment 2 to 3 times every 4 hours
○ Clinical assessment once every 4 hours

⊟ **Behavioral health, cognitive, or developmental monitoring and management**

☐ Communication impaired (eg, non-verbal, rare, or unable to understand)
☐ Self-abusive behavior management with patient at risk of self-harm and preventative intervention needed
☒ Sleep disturbance with patient awake 3 hours or more per night or wakes up 3 times or more per night

⊟ **BiPAP or CPAP management** that includes active adjustment of settings with clinical monitoring of responsiveness

○ BiPAP or CPAP management for 8 hours or more per day
○ BiPAP or CPAP management for less than 8 hours per day

⊟ **Blood draw**

○ Blood draw, central line, twice per week or more often
○ Blood draw, central line, less than twice per week
○ Blood draw, peripheral, twice per week or more often
○ Blood draw, peripheral, less than twice per week

⊟ **Bowel or bladder management**

☒ Bowel incontinence at least daily in patient 3 years of age or older and training program initiation or revision needed
☒ Bladder incontinence at least daily in patient 3 years of age or older and training program initiation or revision needed

○ Ventilator management, continuous use or no respiratory effort[B](4)(16)
○ Ventilator management for active weaning
● Ventilator management for 12 hours or more per day, but not continuous
○ Ventilator management for 7 to 12 hours per day, but not continuous
○ Ventilator management for ventilator used less than 7 hours per day
○ Ventilator weaning achieved with ongoing post-weaning monitoring and ma
○ Ventilator on standby, respiratory assistance, or used at night for less than 1

Calculate Reset

Score: 32

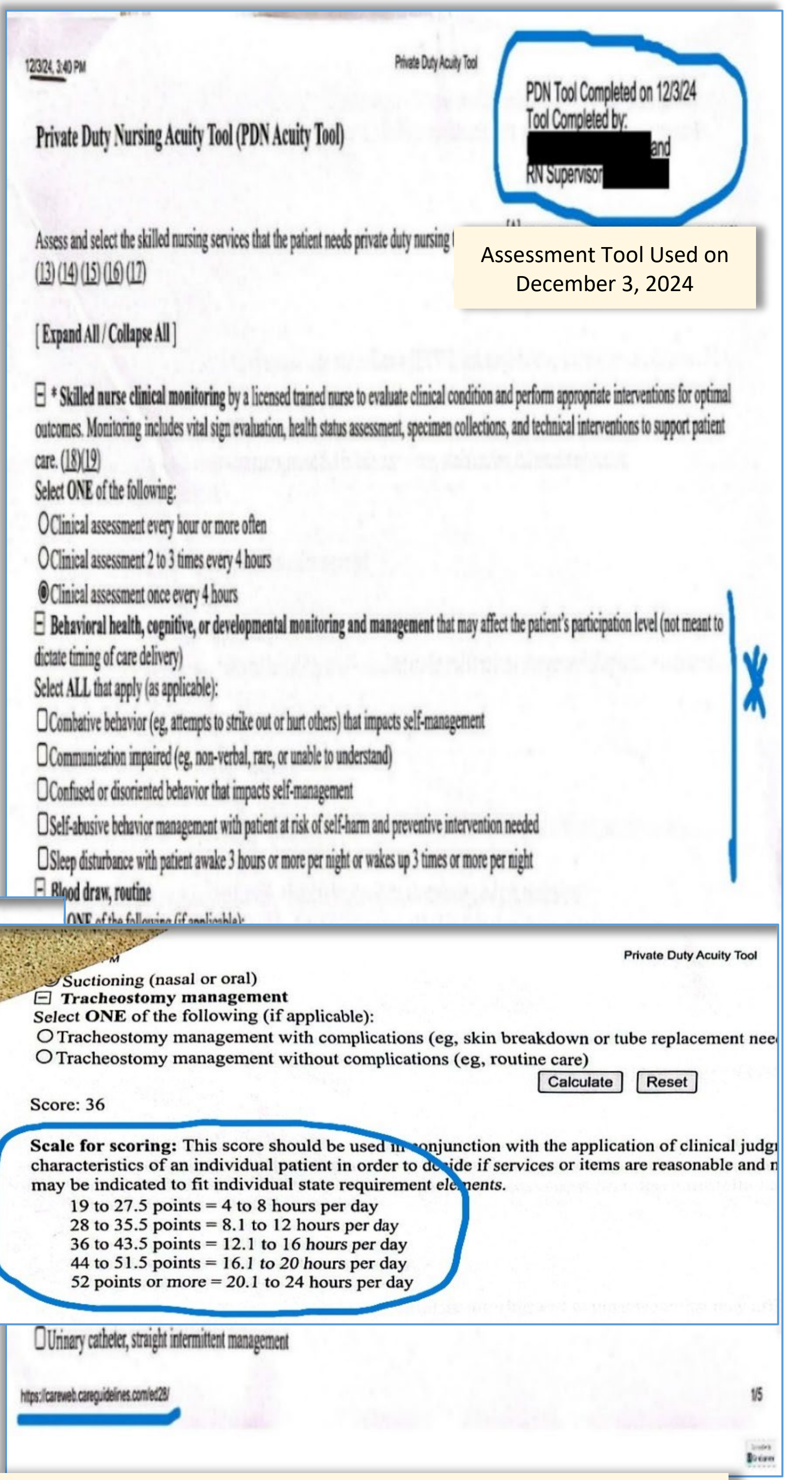
Scale for scoring
15 to 25.5 points = 4 to 7.9 hours per day
26 to 30.5 points = 8 to 11.9 hours per day
31 to 36.5 points = 12 to 15.9 hours per day
37 to 55.5 points = 16 to 19.9 hours per day
56 points or more = 20 to 24 hours per day

https://careweb.careguidelines.com/ed21/

administration, and monitoring infusion reaction(10)

☐ Blood or blood product transfusion
☐ Chemotherapy infusion management

https://careweb.careguidelines.com/ed21/ 1/3



12/3/24, 3:40 PM Private Duty Acuity Tool

Private Duty Nursing Acuity Tool (PDN Acuity Tool)

PDN Tool Completed on 12/3/24
Tool Completed by:
[redacted] and
RN Supervisor [redacted]

Assessment Tool Used on December 3, 2024

Assess and select the skilled nursing services that the patient needs private duty nursing
(13) (14) (15) (16) (17)

[Expand All / Collapse All]

⊟ * **Skilled nurse clinical monitoring** by a licensed trained nurse to evaluate clinical condition and perform appropriate interventions for optimal outcomes. Monitoring includes vital sign evaluation, health status assessment, specimen collections, and technical interventions to support patient care. (18)(19)

Select ONE of the following:

○ Clinical assessment every hour or more often
○ Clinical assessment 2 to 3 times every 4 hours
● Clinical assessment once every 4 hours

⊟ **Behavioral health, cognitive, or developmental monitoring and management** that may affect the patient's participation level (not meant to dictate timing of care delivery)

Select ALL that apply (as applicable):

☐ Combative behavior (eg, attempts to strike out or hurt others) that impacts self-management
☐ Communication impaired (eg, non-verbal, rare, or unable to understand)
☐ Confused or disoriented behavior that impacts self-management
☐ Self-abusive behavior management with patient at risk of self-harm and preventive intervention needed
☐ Sleep disturbance with patient awake 3 hours or more per night or wakes up 3 times or more per night

⊟ **Blood draw, routine**

ONE of the following (if applicable):

Private Duty Acuity Tool

○ *Suctioning (nasal or oral)*

⊟ ***Tracheostomy management***

Select **ONE** *of the following (if applicable):*

○ Tracheostomy management with complications (eg, skin breakdown or tube replacement nee
○ Tracheostomy management without complications (eg, routine care)

Calculate Reset

Score: 36

Scale for scoring: This score should be used in conjunction with the application of clinical judg characteristics of an individual patient in order to decide *if services or items are reasonable and* n may be indicated to fit individual state requirement *elements.*
19 to 27.5 points = 4 to 8 hours per day
28 to 35.5 points = 8.1 to 12 hours per day
36 to 43.5 points = 12.1 to 16 *hours per* day
44 to 51.5 points = 16.*1 to 20 hours* per day
52 points or more = 20.1 to 24 hours per day

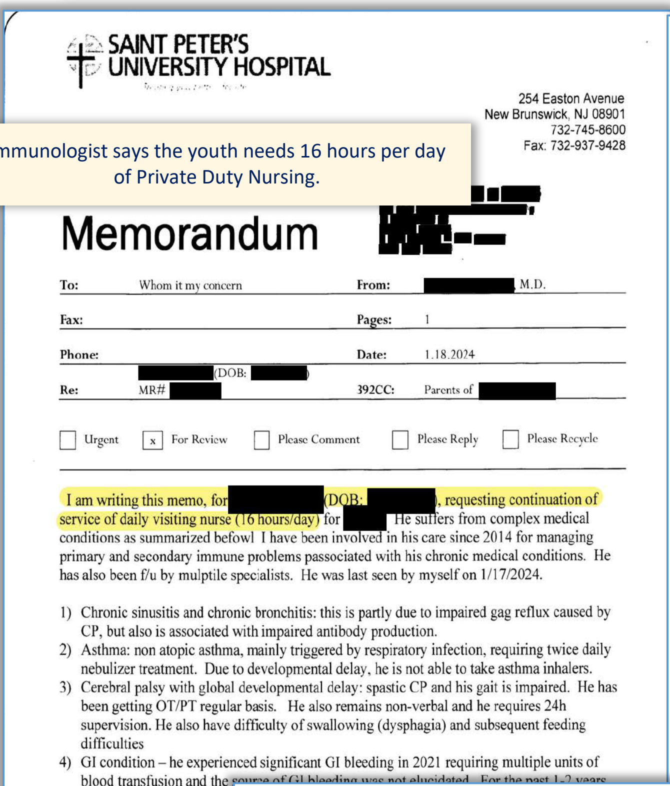
☐ Urinary catheter, straight intermittent management

https://careweb.careguidelines.com/ed28/ 1/5

Question: Why is this allowed?

Managed Care Organizations in Perspective

Immunologist says the youth needs 16 hours per day of Private Duty Nursing.



SAINT PETER'S UNIVERSITY HOSPITAL

254 Easton Avenue
New Brunswick, NJ 08901
732-745-8600
Fax: 732-937-9428

[redacted]

Memorandum

To:	Whom it my concern	**From:**	[redacted] M.D.
Fax:		**Pages:**	1
Phone:		**Date:**	1.18.2024
Re:	[redacted](DOB: [redacted]) MR# [redacted]	**392CC:**	Parents of [redacted]

☐ Urgent ☒ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

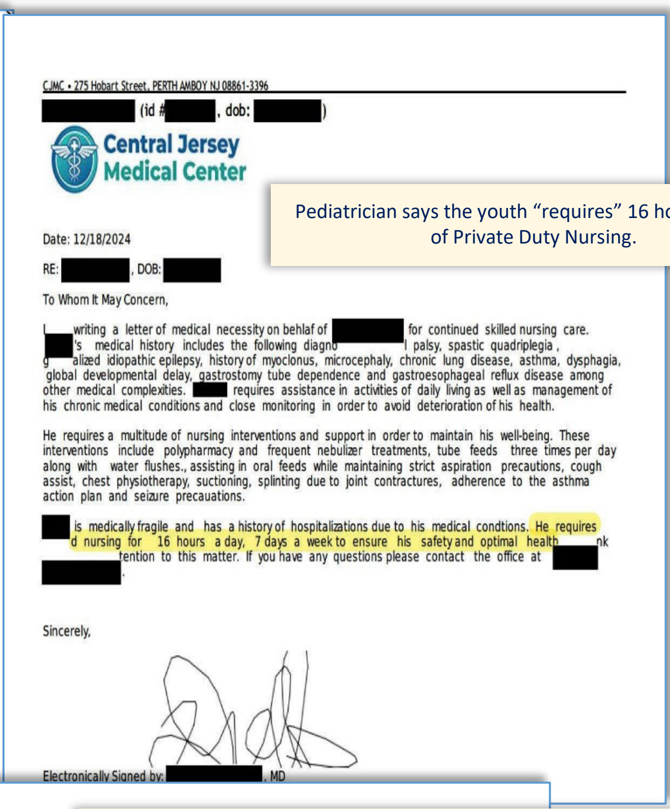
I am writing this memo, for [redacted](DOB: [redacted]), requesting continuation of service of daily visiting nurse (16 hours/day) for [redacted] He suffers from complex medical conditions as summarized befowl I have been involved in his care since 2014 for managing primary and secondary immune problems passociated with his chronic medical conditions. He has also been f/u by mulptile specialists. He was last seen by myself on 1/17/2024.

1) Chronic sinusitis and chronic bronchitis: this is partly due to impaired gag reflux caused by CP, but also is associated with impaired antibody production.
2) Asthma: non atopic asthma, mainly triggered by respiratory infection, requiring twice daily nebulizer treatment. Due to developmental delay, he is not able to take asthma inhalers.
3) Cerebral palsy with global developmental delay: spastic CP and his gait is impaired. He has been getting OT/PT regular basis. He also remains non-verbal and he requires 24h supervision. He also have difficulty of swallowing (dysphagia) and subsequent feeding difficulties
4) GI condition – he experienced significant GI bleeding in 2021 requiring multiple units of blood transfusion and the source of GI bleeding was not elucidated. For the past 1-2 years he is losing weight → rece
causes chronic GI inflamn
gastroenterologist and still

Given his above-described me
h/day) is medically indicated.

[redacted] M.D.

Pediatrician says the youth "requires" 16 hours per day of Private Duty Nursing.



CJMC • 275 Hobart Street, PERTH AMBOY NJ 08861-3396

[redacted] (id #[redacted], dob: [redacted])

Central Jersey Medical Center

Date: 12/18/2024

RE: [redacted], DOB: [redacted]

To Whom It May Concern,

I writing a letter of medical necessity on behlaf of [redacted] for continued skilled nursing care. [redacted]'s medical history includes the following diagno l palsy, spastic quadriplegia, g alized idiopathic epilepsy, history of myoclonus, microcephaly, chronic lung disease, asthma, dysphagia, global developmental delay, gastrostomy tube dependence and gastroesophageal reflux disease among other medical complexities. [redacted] requires assistance in activities of daily living as well as management of his chronic medical conditions and close monitoring in order to avoid deterioration of his health.

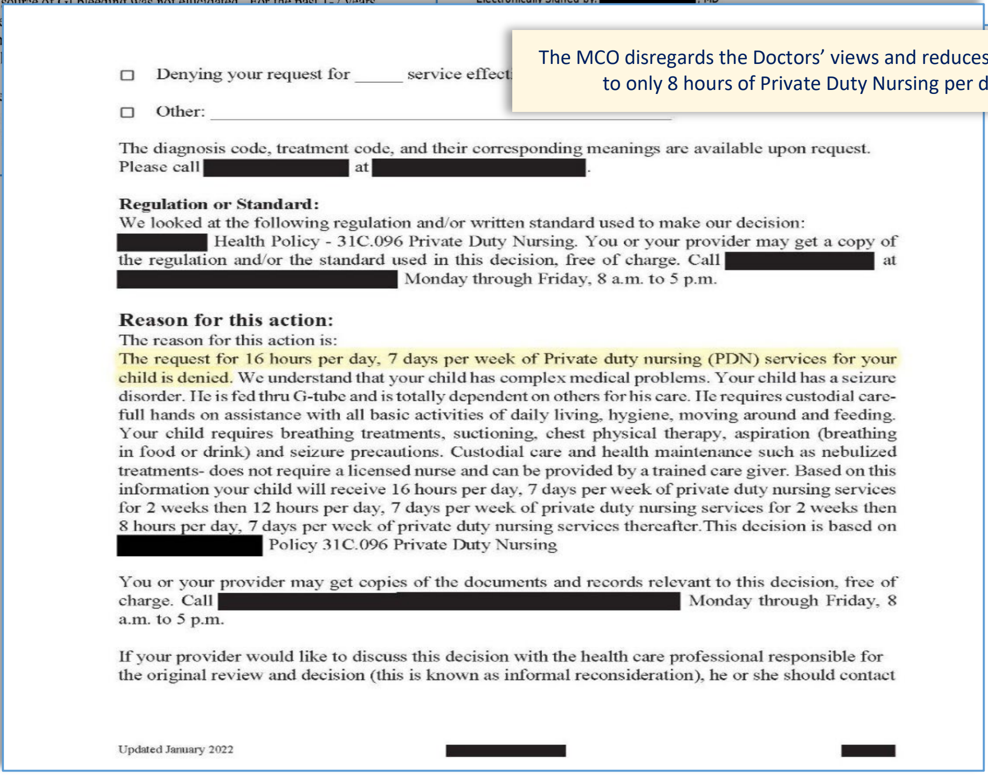
He requires a multitude of nursing interventions and support in order to maintain his well-being. These interventions include polypharmacy and frequent nebulizer treatments, tube feeds three times per day along with water flushes., assisting in oral feeds while maintaining strict aspiration precautions, cough assist, chest physiotherapy, suctioning, splinting due to joint contractures, adherence to the asthma action plan and seizure precaautions.

[redacted] is medically fragile and has a history of hospitalizations due to his medical condtions. He requires d nursing for 16 hours a day, 7 days a week to ensure his safety and optimal health nk tention to this matter. If you have any questions please contact the office at [redacted] [redacted].

Sincerely,

Electronically Signed by: [redacted], MD

The MCO disregards the Doctors' views and reduces the youth to only 8 hours of Private Duty Nursing per day.



☐ Denying your request for _____ service effect

☐ Other: ______________________________

The diagnosis code, treatment code, and their corresponding meanings are available upon request. Please call [redacted] at [redacted].

Regulation or Standard:
We looked at the following regulation and/or written standard used to make our decision: [redacted] Health Policy - 31C.096 Private Duty Nursing. You or your provider may get a copy of the regulation and/or the standard used in this decision, free of charge. Call [redacted] at [redacted] Monday through Friday, 8 a.m. to 5 p.m.

Reason for this action:
The reason for this action is:
The request for 16 hours per day, 7 days per week of Private duty nursing (PDN) services for your child is denied. We understand that your child has complex medical problems. Your child has a seizure disorder. He is fed thru G-tube and is totally dependent on others for his care. He requires custodial care-full hands on assistance with all basic activities of daily living, hygiene, moving around and feeding. Your child requires breathing treatments, suctioning, chest physical therapy, aspiration (breathing in food or drink) and seizure precautions. Custodial care and health maintenance such as nebulized treatments- does not require a licensed nurse and can be provided by a trained care giver. Based on this information your child will receive 16 hours per day, 7 days per week of private duty nursing services for 2 weeks then 12 hours per day, 7 days per week of private duty nursing services for 2 weeks then 8 hours per day, 7 days per week of private duty nursing services thereafter. This decision is based on [redacted] Policy 31C.096 Private Duty Nursing

You or your provider may get copies of the documents and records relevant to this decision, free of charge. Call [redacted] Monday through Friday, 8 a.m. to 5 p.m.

If your provider would like to discuss this decision with the health care professional responsible for the original review and decision (this is known as informal reconsideration), he or she should contact

Updated January 2022 [redacted] [redacted]

Question: Why is the MCO's seemingly secret, ever-changing assessment tool given more weight than the Doctors who know the individual and have long worked with him?

Self-Direction

In theory, self-direction is a great option available to adults and their families enrolled in the NJ Division of Developmental Disabilities. It aims to give individuals and families the ability to better control their lives through better control of their resources. You choose your support staff. You choose your programs and services in the community. You choose how to spend the budget dollars assigned to you by the NJ Department of Human Services.

In practice, however, self-direction is not as great as it could or should be. And for many families, it is not a real option.

Although the Department established up the Office of Education on Self-Directed Services to help people understand and enroll in this approach, the Department has chosen to put in place many limitations that can make self-direction difficult, if not impossible.

I spoke to many of those limitations in last year's annual report.

- Unrealistic salary caps for self-directed employees.
- Unreasonable labor practices, including a general overtime prohibition.
- Unfair budget restrictions relative to provider agencies.

Indeed, as discussed in last year's report, many of the limitations placed on self-directing individuals and families are not also placed on provider agencies – a questionable, counter intuitive approach that makes it more difficult for people with disabilities to live in least restrictive settings, which can lead to better overall outcomes and can be more cost effective.

Moreover, the fiscal administration of self-direction is often ridiculously complex and frustrating. Indeed, you would think that the fiscal intermediary role – particularly the onboarding of staff and the issuing of paychecks to them – would be relatively easy and straightforward. After all, businesses (large and small) do it all the time. Yet, throughout my seven years in this position, I have regularly learned of situations whereby direct care staff have not been paid on time or have been paid the wrong amount or that a "glitch" in the fiscal intermediary's system has caused some other inexplicable delay or problem — all of which often leads to staff resignations and other additional hardships for individuals and families already overburdened and overwhelmed.

An Important Individual/Family Perspective

"While DDD provides us with a large budget for [my child's] care at home, the agency then limits our ability to fully use it for his care. More specifically, the current SDE program limits hourly pay, does not allow us to hire salaried caregivers or overnight support ([my child] requires venting and ostomy care overnight), limits PTO, does not provide annual pay increases, and restricts hours worked/week. This makes it impossible to attract qualified professionals and provide 24/7 care at home.

Provider agencies that manage group homes receive a daily rate and do not have these restrictions or limitations.

Furthermore, only a portion of the funds DDD provides to these provider agencies actually goes to patient care vs. administrative cost or profit. In contrast, 100% of the SDE budget goes directly to patient care."

A Self-Directing Parent of a Young Adult with Significant Disabilities
February 2025

The latest shoe to drop on self-directing families and others choosing not to live in a licensed setting has to do with overnight staffing.

Earlier this year, families and Support Coordinators started raising concerns that the Department would no longer allow overnight staff to be paid. There was no actual announcement by the Department, just various conversations with Department staff leading to various versions of this "new" policy being circulated. Some people were reportedly being told absolutely no overnight staff would be allowed in unlicensed settings, such as a personal or family home. Some were reportedly being told that overnight staff would be allowed to get paid only when they engaged with the individual, for example to take them to the bathroom or roll them over in bed. Some were reportedly being told that staff could only get paid when the individual under their care was awake.

Aside from the unnecessary anxiety and uncertainty that such conversations caused, the potential policy changes, as described, have raised serious questions:

- How could the Department deny someone with very significant behavioral and/or medical needs overnight staffing support, particularly when the Department itself had previously assessed and determined the need for full, 24/7 support?
- How could the Department expect direct care staff to work an overnight 8-hour shift, but only get paid for the minutes/hours they actually physically engaged the individual or for the time that the individual in their care was awake?
- And how could the Department implement such a restrictive policy only on individuals and families living in unlicensed settings – holding them to a different standard than that applied to provider agencies that run State-licensed group homes and supervised apartments? Does that seem fair? Does that seem right?

I tried repeatedly to get clarification on the policy from the Department's leadership, sending them weekly requests for information. In late March, the Department clarified the policy, noting in an email that nothing had changed and that the policy was the same for both licensed and unlicensed residential settings.

> "Overnight staffing is permitted when it meets the service definitions of Individual Supports or Community Based Supports. The individual does not need to be awake during the entire shift, but the staff person does need to be awake and providing some type of active support, such as conducting routine checks, completing documentation, or undertaking a range of other ADL activities. Examples of when overnight staffing may be permitted include, but are not limited to: an individual has a pattern of waking up multiple times throughout the night, wandering around the house, and leaving the home or engaging in unsafe behavior while awake; an individual has a pattern of waking up several times throughout the night and engaging in disruptive behaviors such as clogging the toilet; an individual engaging in behaviors where they pull at their g-tube while asleep; or an individual requiring frequent positioning throughout the night. Evidence of such activities is expected to be present and documented, and planning team meetings should discuss such needs as well as any actions that could mitigate the need for staff, such as assistive technology, etc."

Recognizing the importance of this information — and the anxiety caused by weeks of uncertainty — we immediately shared the clarification directly with those who had contacted us about a possible "new" policy as well as more generally through our website and social media.

A week later, however, the Department asked us to remove the information from our public platforms, pending further clarification, which we have yet to receive.

Although, in the end, this overnight staffing issue may turn out to be more of a scare, rather than an all-out policy change, I am highlighting it here because it underscores a couple key points:

- As evidenced by a draft policy paper recently circulated to a small group of family members, some type of change in policy or change in implementation of policy is being considered for individuals not living in State-licensed settings – a change that could be devastating for many individuals and families for whom overnight staffing is an absolute necessity for their health and safety <u>and</u> that would likely force more individuals to live in State-licensed group homes, developmental centers, or even nursing homes. In addition to the draft policy paper, there have been just too many instances of people – families as well as Support Coordinators – being told by Department staff about apparent changes in policy to think otherwise. In fact, I participated in a meeting in which a Department official clearly suggested such changes to a family and their support team. This is very, very concerning.
- There needs to be more transparency in the policy-making process – both in the making of policy and in the roll-out (announcement) of policy. With respect to the latter, new ideas or policies should not trickle out of the Department in such informal ways, and once it is noted — by our Office or in other ways — that confusion regarding a policy is widespread, the Department should make it a point to issue a statement of clarification.

Going forward, we offer these simple, albeit important recommendations:

- Let us make it easier, not harder, for adults with intellectual or developmental disabilities to live in unlicensed, less restrictive settings whether they self-direct and/or use a provider agency.

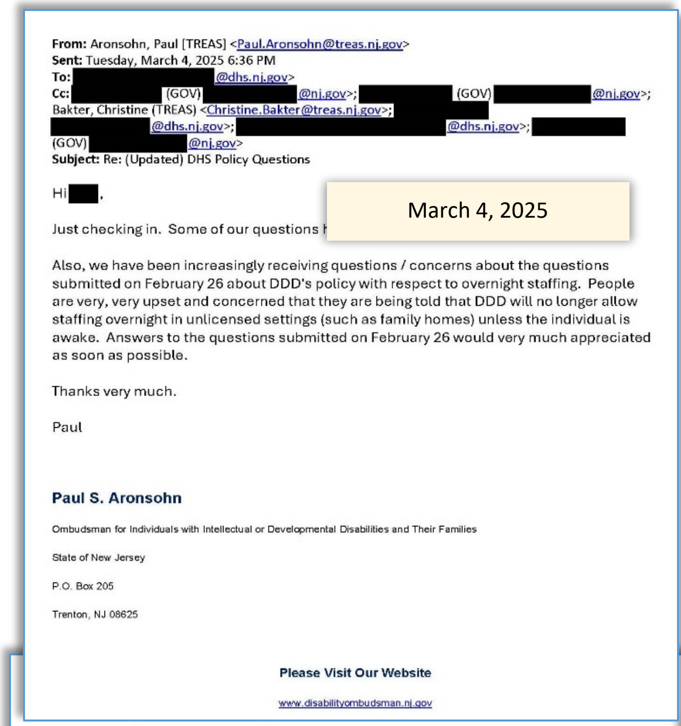
- Let us engage individuals and families in the policy-making process – soliciting and considering their input <u>before</u> policies are made.

- And let us take great care when rolling out new policies – formally announcing new policies in a manner that is clear, consistent, and ensures everyone involved is provided all of the necessary information.

After all, we know living in an unlicensed setting can result in a better quality of life for some individuals <u>and</u> cost savings for the State. And we know the importance of informed policy-making as well as the importance of accurate information, clear communication, and real transparency.

Overnight Staffing in Perspective

A policy in question.



March 4, 2025

From: Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>
Sent: Tuesday, March 4, 2025 6:36 PM
To: [redacted]@dhs.nj.gov>
Cc: [redacted] (GOV) [redacted]@nj.gov>; [redacted] (GOV) [redacted]@nj.gov>; Bakter, Christine (TREAS) <Christine.Bakter@treas.nj.gov>; [redacted]@dhs.nj.gov>; [redacted]@dhs.nj.gov>; [redacted] (GOV) [redacted]@nj.gov>
Subject: Re: (Updated) DHS Policy Questions

Hi [redacted],

Just checking in. Some of our questions

Also, we have been increasingly receiving questions / concerns about the questions submitted on February 26 about DDD's policy with respect to overnight staffing. People are very, very upset and concerned that they are being told that DDD will no longer allow staffing overnight in unlicensed settings (such as family homes) unless the individual is awake. Answers to the questions submitted on February 26 would very much appreciated as soon as possible.

Thanks very much.

Paul

Paul S. Aronsohn

Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families

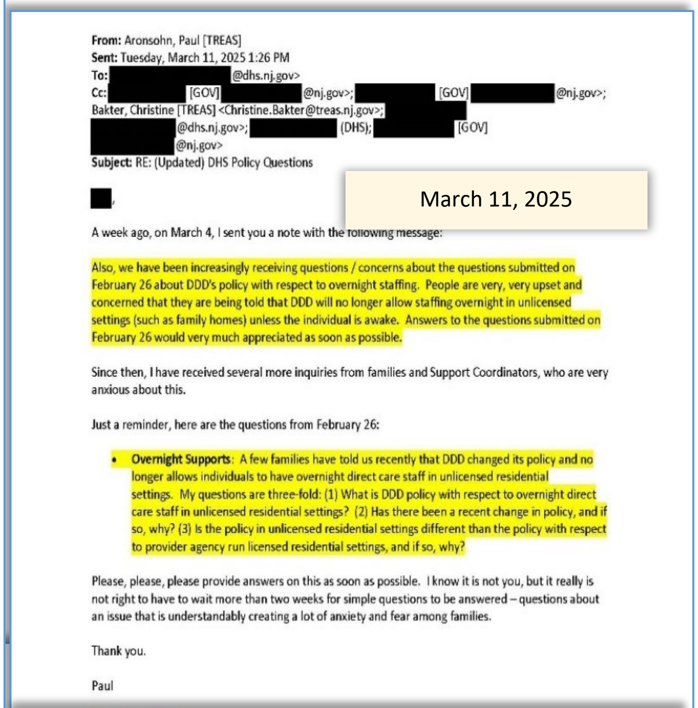
State of New Jersey

P.O. Box 205

Trenton, NJ 08625

Please Visit Our Website

www.disabilityombudsman.nj.gov



March 11, 2025

From: Aronsohn, Paul [TREAS]
Sent: Tuesday, March 11, 2025 1:26 PM
To: [redacted]@dhs.nj.gov>
Cc: [redacted] [GOV] [redacted]@nj.gov>; [redacted] [GOV] [redacted]@nj.gov>; Bakter, Christine [TREAS] <Christine.Bakter@treas.nj.gov>; [redacted]@dhs.nj.gov>; [redacted] (DHS); [redacted] [GOV] [redacted]@nj.gov>
Subject: RE: (Updated) DHS Policy Questions

[redacted],

A week ago, on March 4, I sent you a note with the following message:

Also, we have been increasingly receiving questions / concerns about the questions submitted on February 26 about DDD's policy with respect to overnight staffing. People are very, very upset and concerned that they are being told that DDD will no longer allow staffing overnight in unlicensed settings (such as family homes) unless the individual is awake. Answers to the questions submitted on February 26 would very much appreciated as soon as possible.

Since then, I have received several more inquiries from families and Support Coordinators, who are very anxious about this.

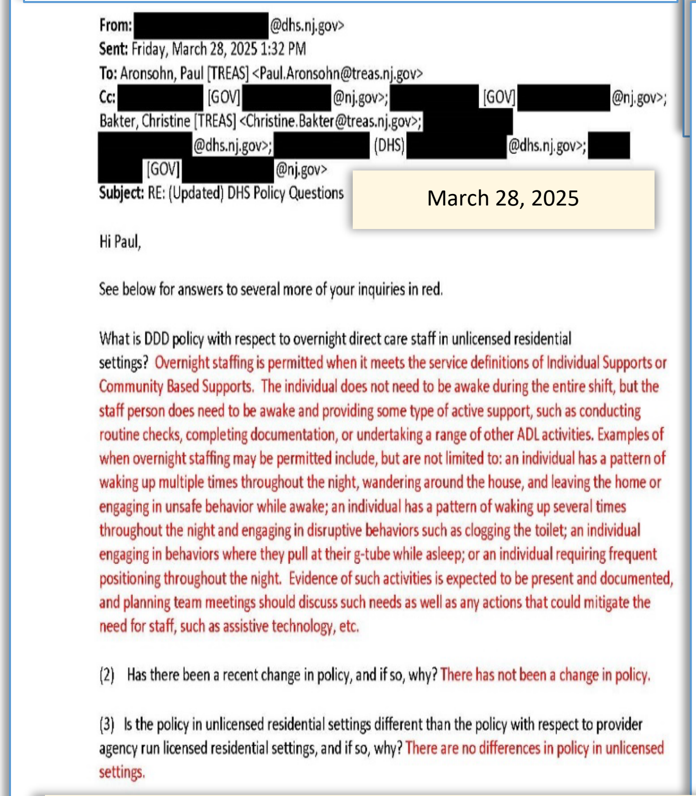
Just a reminder, here are the questions from February 26:

- **Overnight Supports**: A few families have told us recently that DDD changed its policy and no longer allows individuals to have overnight direct care staff in unlicensed residential settings. My questions are three-fold: (1) What is DDD policy with respect to overnight direct care staff in unlicensed residential settings? (2) Has there been a recent change in policy, and if so, why? (3) Is the policy in unlicensed residential settings different than the policy with respect to provider agency run licensed residential settings, and if so, why?

Please, please, please provide answers on this as soon as possible. I know it is not you, but it really is not right to have to wait more than two weeks for simple questions to be answered – questions about an issue that is understandably creating a lot of anxiety and fear among families.

Thank you.

Paul



March 28, 2025

From: [redacted]@dhs.nj.gov>
Sent: Friday, March 28, 2025 1:32 PM
To: Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>
Cc: [redacted] [GOV] [redacted]@nj.gov>; [redacted] [GOV] [redacted]@nj.gov>; Bakter, Christine [TREAS] <Christine.Bakter@treas.nj.gov>; [redacted]@dhs.nj.gov>; [redacted] (DHS) [redacted]@dhs.nj.gov>; [redacted] [GOV] [redacted]@nj.gov>
Subject: RE: (Updated) DHS Policy Questions

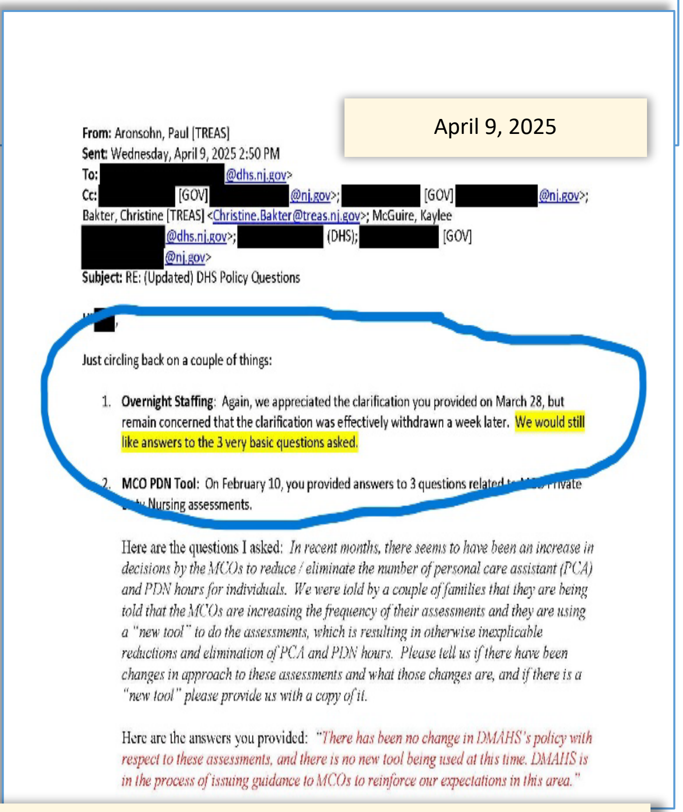
Hi Paul,

See below for answers to several more of your inquiries in red.

What is DDD policy with respect to overnight direct care staff in unlicensed residential settings? Overnight staffing is permitted when it meets the service definitions of Individual Supports or Community Based Supports. The individual does not need to be awake during the entire shift, but the staff person does need to be awake and providing some type of active support, such as conducting routine checks, completing documentation, or undertaking a range of other ADL activities. Examples of when overnight staffing may be permitted include, but are not limited to: an individual has a pattern of waking up multiple times throughout the night, wandering around the house, and leaving the home or engaging in unsafe behavior while awake; an individual has a pattern of waking up several times throughout the night and engaging in disruptive behaviors such as clogging the toilet; an individual engaging in behaviors where they pull at their g-tube while asleep; or an individual requiring frequent positioning throughout the night. Evidence of such activities is expected to be present and documented, and planning team meetings should discuss such needs as well as any actions that could mitigate the need for staff, such as assistive technology, etc.

(2) Has there been a recent change in policy, and if so, why? There has not been a change in policy.

(3) Is the policy in unlicensed residential settings different than the policy with respect to provider agency run licensed residential settings, and if so, why? There are no differences in policy in unlicensed settings.



April 9, 2025

From: Aronsohn, Paul [TREAS]
Sent: Wednesday, April 9, 2025 2:50 PM
To: [redacted]@dhs.nj.gov>
Cc: [redacted] [GOV] [redacted]@nj.gov>; [redacted] [GOV] [redacted]@nj.gov>; Bakter, Christine [TREAS] <Christine.Bakter@treas.nj.gov>; McGuire, Kaylee [redacted]@dhs.nj.gov>; [redacted] (DHS); [redacted] [GOV] [redacted]@nj.gov>
Subject: RE: (Updated) DHS Policy Questions

[redacted],

Just circling back on a couple of things:

1. **Overnight Staffing**: Again, we appreciated the clarification you provided on March 28, but remain concerned that the clarification was effectively withdrawn a week later. We would still like answers to the 3 very basic questions asked.

2. **MCO PDN Tool**: On February 10, you provided answers to 3 questions related [illegible] rivate [illegible] Nursing assessments.

   Here are the questions I asked: *In recent months, there seems to have been an increase in decisions by the MCOs to reduce / eliminate the number of personal care assistant (PCA) and PDN hours for individuals. We were told by a couple of families that they are being told that the MCOs are increasing the frequency of their assessments and they are using a "new tool" to do the assessments, which is resulting in otherwise inexplicable reductions and elimination of PCA and PDN hours. Please tell us if there have been changes in approach to these assessments and what those changes are, and if there is a "new tool" please provide us with a copy of it.*

   Here are the answers you provided: *"There has been no change in DMAHS's policy with respect to these assessments, and there is no new tool being used at this time. DMAHS is in the process of issuing guidance to MCOs to reinforce our expectations in this area."*

Question: What is the status of the overnight staffing policy?
Question: Why has there been such a lack of clarity about the policy?

Overnight Staffing in Perspective

A process in question.

"As a SCA (Support Coordination Agency) we were advised that overnight hours … the individual is asleep are not billable…."

A Support Coordinator
February 26, 2025

"[My Support Coordinator] told me that DDD told him that if I wanted overnight supervision for my sons, they needed to live in a licensed group home. That is highly restrictive and discriminatory."

A Self-Directing Parent
March 6, 2025

"I, personally, have been going back and forth with DDD about this for several weeks (at least).

A Support Coordinator
March 29, 2025

"Thank you. Rumors were wild."

A Self-Directing Parent,
Following Our Office's Announcement that Overnight Staffing is Still Allowed
March 29, 2025

"[Our Agency] wants to thank you directly for your post outlining current policy regarding overnight staffing. [Our Agency] strives to provide excellence; having black and white guidance and language to share with our families makes the team stronger."

A Leader of a Support Coordination Agency,
In an Email to Our Office Following the Posting of the Overnight Staffing Policy on our Social Media Platforms
March 31, 2025

"I am reaching out in regards to a Facebook post that was shared on Friday 3/28 regarding guidance from The Department of Human Services clarifying what is allowed in regards to Individual supports providing Overnight care.

We have since seen this post has been removed or hidden from the NJ Ombudsman Facebook, so we are looking for some more information and clarification on what care and billable hours of Individual Supports are allowed."

A Leader of a Provider Agency,
April 11, 2025

"I know overnight can't be billed when someone is sleeping."

A Support Coordinator
May 21, 2025

"As parents, we need to have an opportunity to publicly comment on this proposed May 2025 policy! When will parents be able to comment on this?

A Family Member
June 18, 2025

Question: How can we avoid such unnecessary and harmful uncertainty in the future?

Transitioning (Youth to Adult)

There are multiple transitions in the course of a person's life. For someone with an intellectual or developmental disability, that includes the key transition (often at age 21) from the children's system to the adult system – from a system of legally required supports and services provided largely by local school districts to a system of supports and services offered, but not required, by various State government offices.

Many people refer to this transition as "aging out" or more negatively as "falling off the cliff," because supports and services are no longer entitlements stipulated in both Federal and State law. After age 21, a person is no longer legally entitled to assistance; rather, they need to seek it out and be eligible for it.

As such, transitioning into the adult system requires a lot – a lot of information, a lot of decisions, a lot of planning, a lot of everything. It involves knowing what is available. It involves knowing what is required. It is a critical time in a young person's life, because the decisions made (and not made) can have long lasting implications.

We often counsel individuals and families that while the two systems are very different and legal entitlements end at age 21, there are still many resources – if not more – for New Jersey adults with intellectual or developmental disabilities. Educational. Financial. Medical. Residential. Vocational. The potential resources are substantial.

Unfortunately, however, not everyone is aware of all of this, 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."

In our 2023 annual report, we spoke again to this unfortunate and unacceptable reality, noting that literally thousands of young people with intellectual or developmental disabilities likely "fall off the grid" entirely, leaving them without vital supports and services. Indeed, the numbers provided by the NJ Department of Education and the NJ Department of Human Services suggest that many young people — who would otherwise qualify — do not end up enrolling in the NJ Division of Developmental Disabilities (DDD) and therefore do not receive critical supports and services.

Granted, transitioning involves so much more than the resources available through DDD. Decisions need to be made about a full range of important issues, including: Social Security, Medicaid, legal status, doctors, dentists, jobs, day programs, colleges, and living situations. 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 last year, the Murphy Administration came together to host a comprehensive webinar about transitions, which is now available on our Office's website.

Going forward, we offer the following recommendations, which were included in previous annual reports:

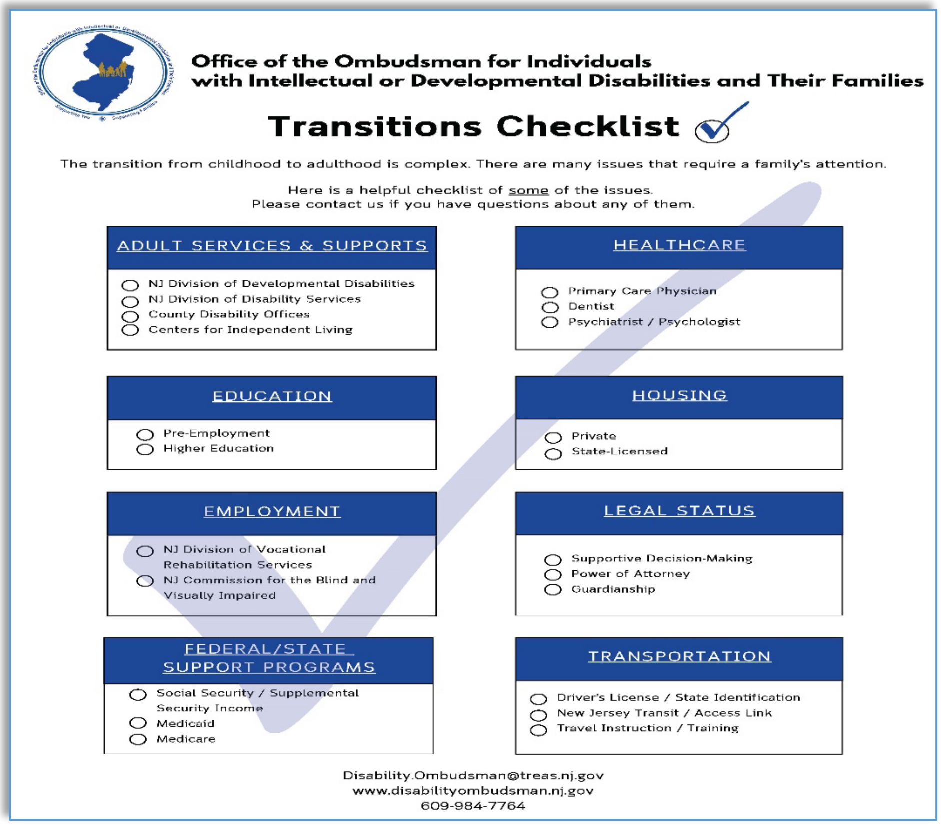
- **State-Funded Support Coordinators**: Beginning at about age 16, every "classified" special education student should be assigned a State-funded Support Coordinator — someone who knows the challenges and opportunities facing young adults with disabilities and who could be available as a resource through 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 student and family – regardless of zip code – has access to the information needed to make important decisions, including those related to DDD supports and services.

- **Earlier Transitions**: For those with complex behavioral and/or medical needs, we need to do everything possible to make the transition seamless. This should include an earlier start to the transitioning process.

    - 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, the transition is often far from seamless. Accessing specialized medical care is hard. Finding employment opportunities or day programs is hard. And, as noted above, trying to manage a likely reduction in nursing support is beyond hard. Taken together, for some of these individuals and their families, the transition can be a devastating experience, and for them and their families, we need to start the process earlier and with more intentionality.

- "**Transition Corps:**" To help facilitate this all-important transition, we should explore the establishment of a "Transition Corps" 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 Corps" could be a volunteer peer-support organization for families of special needs students.



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

HEALTHCARE
○ Primary Care Physician
○ Dentist
○ Psychiatrist / Psychologist

EDUCATION
○ Pre-Employment
○ Higher Education

HOUSING
○ Private
○ State-Licensed

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

LEGAL STATUS
○ Supportive Decision-Making
○ Power of Attorney
○ Guardianship

FEDERAL/STATE SUPPORT PROGRAMS
○ Social Security / Supplemental Security Income
○ Medicaid
○ Medicare

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

Disability.Ombudsman@treas.nj.gov
www.disabilityombudsman.nj.gov
609-984-7764

Transportation

In New Jersey, transportation is often not easy – regardless of a person's disability status. Traffic congestion. Public transportation shortcomings. And, of course, the high cost of tolls and gas.

For people with disabilities, there are those challenges and more. Much more.

First, many, if not most, people with intellectual or developmental disabilities do not drive. They require the assistance of family, friends, and private agencies/companies to get to and from work, to and from day programs, to and from anywhere and everywhere. Those that do drive often require specialized vehicles, such as wheelchair accessible vans.

Second, although there are important public transportation options available, they only provide limited access to the community for a limited number of people. Limited in terms of times of operation. Limited in terms of geography. Indeed, for many people, particularly for those living in more remote areas, public transportation is not really an option at all.

Third, although the NJ Division of Developmental Disabilities allows individuals and families to use some of their State-issued budgets to cover the costs of transportation, current policies and practices often make it difficult. Most frequently, we are told that individuals and families have the needed funds in their budget, but are unable to use them for transportation because of inflexible, non-person-centered rules that prevent them from doing so. In other words, they do not need more money from the State; they just need more flexibility in how it is spent. This is particularly true with respect to those who have specialized transportation needs and/or who live in more remote areas of the State.

Taken together, transportation is certainly a complex challenge with no single right answer. There are, however, a few things we can do to help mitigate this challenge.

Going forward, we offer the following few recommendations:

- **Access Link**: The biggest challenge for those who would like to use New Jersey's paratransit service is that it does not serve many people living in the State. Indeed, it only serves those who can be picked up and dropped off within ¾ mile of a fixed NJ Transit bus route or light rail system. This not only leaves out people with disabilities in Hunterdon, Warren, and Sussex counties; it also leaves out many people living in all of the other 18 counties. NJ Transit should explore the possibility of expanding their service area. Indeed, the ¾ mile federal regulation is only a minimum requirement. We can and should do more. As noted by the Federal Transit Administration, "…nothing in the ADA prohibits a transit system from operating service above and beyond the minimum ADA requirements."

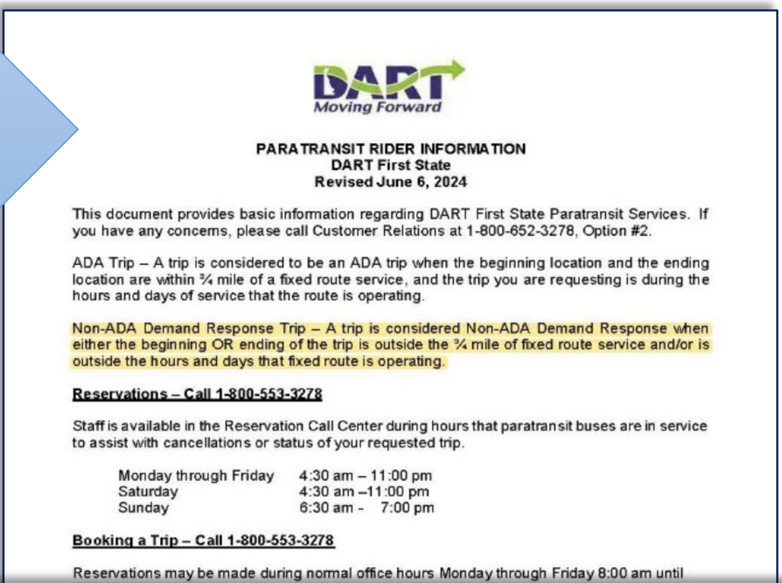
  Community Transportation: Each county provides its own paratransit service for people with disabilities. Each county, however, does it differently, presumably to meet the specific needs of their residents. However, there seems to be an important opportunity for the county services to better coordinate with Access Link, so that they are complementing – rather than duplicating – the respective service areas. This could make a public transportation option available to more people with little or no additional cost.

  Accessible Vehicles: The NJ Department of Human Services permits individuals enrolled in its Division of Developmental Disabilities to use some of their allotted budget for vehicle modifications – for example, to transform a typical van into one that is wheelchair accessible. This is an important offering, but it requires the individual to have a van in the first place. As discussed in last year's annual report, we should allow for the actual 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 similar to Medicaid's "estate recovery" policy that would help ensure recovery of the funds used for this purpose.

  NJ Division of Developmental Disabilities: The policies regarding the use of State-issued budgets should be more person-centered. That means more budget authority/flexibility given to individuals and families. That means higher rates for those with more specialized needs and/or who live in remote areas of the State.

Access Link in Perspective

Delaware is one State that has chosen to go beyond the ADA bare minimum requirement.



DART
Moving Forward

PARATRANSIT RIDER INFORMATION
DART First State
Revised June 6, 2024

This document provides basic information regarding DART First State Paratransit Services. If you have any concerns, please call Customer Relations at 1-800-652-3278, Option #2.

ADA Trip – A trip is considered to be an ADA trip when the beginning location and the ending location are within ¾ mile of a fixed route service, and the trip you are requesting is during the hours and days of service that the route is operating.

Non-ADA Demand Response Trip – A trip is considered Non-ADA Demand Response when either the beginning OR ending of the trip is outside the ¾ mile of fixed route service and/or is outside the hours and days that fixed route is operating.

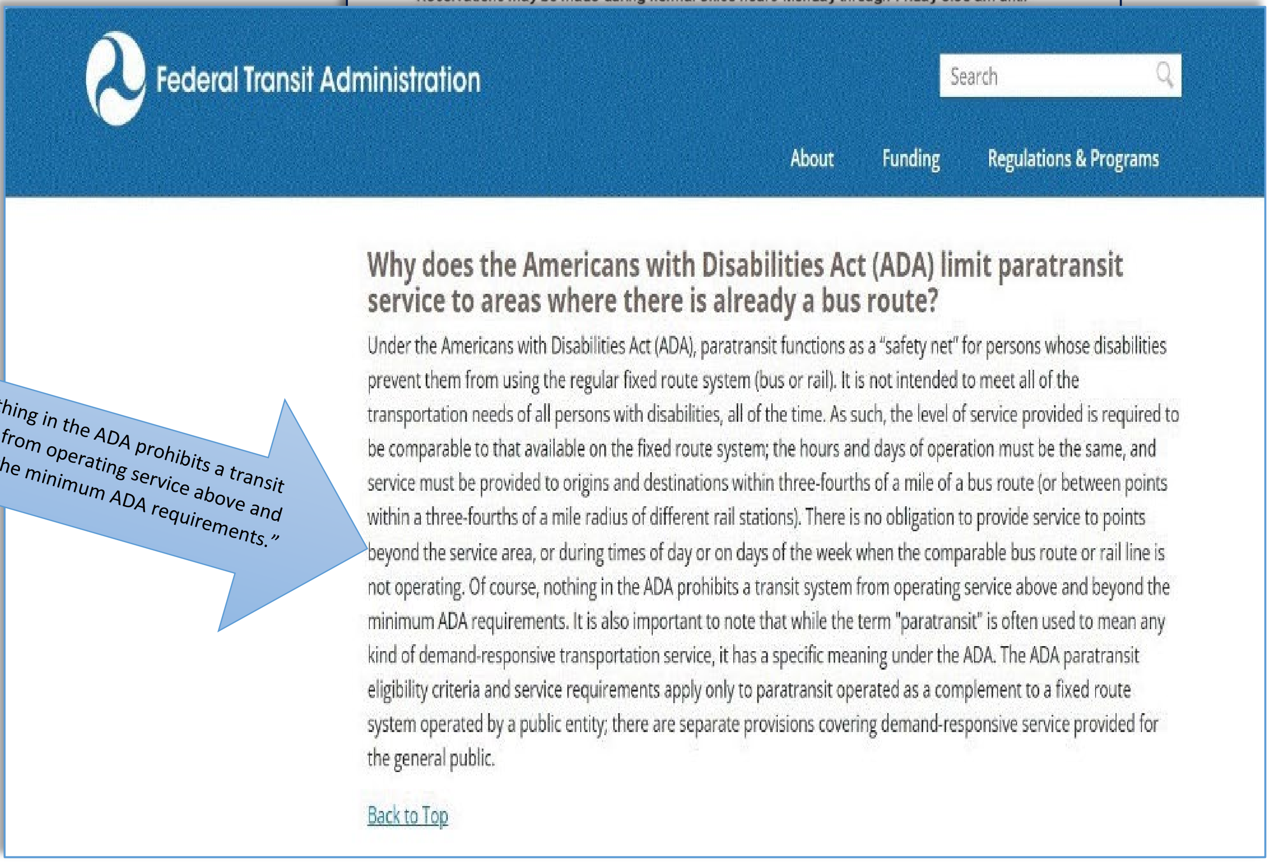
Reservations – Call 1-800-553-3278

Staff is available in the Reservation Call Center during hours that paratransit buses are in service to assist with cancellations or status of your requested trip.

Monday through Friday	4:30 am – 11:00 pm
Saturday	4:30 am –11:00 pm
Sunday	6:30 am - 7:00 pm

Booking a Trip – Call 1-800-553-3278

Reservations may be made during normal office hours Monday through Friday 8:00 am until



Why does the Americans with Disabilities Act (ADA) limit paratransit service to areas where there is already a bus route?

Under the Americans with Disabilities Act (ADA), paratransit functions as a "safety net" for persons whose disabilities prevent them from using the regular fixed route system (bus or rail). It is not intended to meet all of the transportation needs of all persons with disabilities, all of the time. As such, the level of service provided is required to be comparable to that available on the fixed route system; the hours and days of operation must be the same, and service must be provided to origins and destinations within three-fourths of a mile of a bus route (or between points within a three-fourths of a mile radius of different rail stations). There is no obligation to provide service to points beyond the service area, or during times of day or on days of the week when the comparable bus route or rail line is not operating. Of course, nothing in the ADA prohibits a transit system from operating service above and beyond the minimum ADA requirements. It is also important to note that while the term "paratransit" is often used to mean any kind of demand-responsive transportation service, it has a specific meaning under the ADA. The ADA paratransit eligibility criteria and service requirements apply only to paratransit operated as a complement to a fixed route system operated by a public entity; there are separate provisions covering demand-responsive service provided for the general public.

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"…nothing in the ADA prohibits a transit system from operating service above and beyond the minimum ADA requirements."

Question: Should we explore an expansion of Access Link to underserved parts of New Jersey?

CONCLUSION

Going Forward / Building Trust

In October 2017, during the last weeks of that year's gubernatorial campaign, a few of us organized a meeting for parents of children with disabilities to share some of their family stories with Tammy Murphy. The purpose of the meeting was to give the soon-to-be First Lady and trusted advisor to the incoming Governor a sense of what thousands of families across New Jersey were experiencing – thousands of families whose lives are often challenging even on a good day.

Some holding pictures of their children, the parents took turns sharing some of their family's story – some of their experiences, some of their concerns, some of their hopes, some of their fears. Towards the end of the meeting, one parent said something that painfully resonated with most of us in the room: "Unlike other parents, we want to outlive our children."

His words were met with quiet nods of agreement. After all, while his statement might confuse or even shock a typical parent, all of us from disability families knew what he meant and why he would say something so otherwise outrageous.

Simply stated, many disability families do not trust "the system" to care for their loved ones when they are gone – when they are no longer around to watch, to listen, to advocate, to protect, to love their children.

After all –

- Why trust a system that promises your child a "free appropriate public education," but fights you at every turn?
- Why trust a system that compels you to place your special needs child on a school vehicle with no real safeguards and no real accountability?
- Why trust a system that promises to support you and your family, but effectively tells you to "wait" — for weeks, months, even years — when your child is experiencing a behavioral and/or medical crisis?
- Why trust a system that gives managed care organizations (MCO) the authority to determine a person's level of need, despite their financial incentive to downplay that level of need?
- Why trust a system that has a "fair" hearing process whereby the Judge's decision is not binding and is only a recommendation to the NJ Department of Human Services, which can completely disregard that decision?
- Why trust a system that gives provider agencies the authority to investigate themselves in situations that involve allegations of abuse and neglect against them … and then does not allow families to see the investigation report?
- Why trust a system that decides an allegation of abuse and neglect is "unsubstantiated" despite obvious physical injuries to your loved one?
- Why trust a system that gives provider agency leadership the authority to determine if its own policies advance/protect the civil and human rights of people living in their taxpayer-funded group homes?
- Why trust a system that allows seemingly anyone – with limited training – to administer medications to children or adults with intellectual or developmental disabilities living in group homes?
- Why trust a system that does not automatically investigate deaths in group homes, even if the deaths are unexpected or otherwise suspicious?
- Why trust a system that allows group home providers to spend taxpayer money as well as people's personal money — such as their supplemental security income — with no real transparency or accountability?
- Why trust a system that promotes integrated, competitive employment — a so-called "Employment First" approach — only to pay little attention to the very real transportation needs of people with disabilities?

- Why trust a system that promotes "self-direction" but puts in place rules and regulations that make it likely that your loved one will end up in an agency-run licensed residence or even an institution?

- Why trust a system that promises to be "person-centered" but consistently compels you to fit your round lives into square holes?

Granted, most of this is not new. With good reason, people have been mistrusting the system for a very long time. Granted, too, the examples above may be more the exception than the rule for many people, because their experience overall has been positive. But we all know that it does not take much to lose someone's trust and confidence, particularly when they are let down in a moment of need.

Going forward, our objective should be to give everyone a reason to trust our system of care for people with disabilities. More empathy. More flexibility. More information. More sense of urgency. More simplicity. More transparency. The work to be done is considerable, but is certainly achievable. And the investment of time, energy, and priority would certainly be worth it. Without trust, we are setting the system up for failure.

Staffing the Government

To this end, the most important thing that the next Administration can do is to ensure that people with lived experience – people with disabilities and family members – play a meaningful role in the governing of our State. After all, when it comes to disability, no one knows better than them, and their participation will not only lend much needed perspective to the decisions made; they will also lend much needed credibility.

Here are three reasonable, common-sense ways to make that happen:

- Require that State offices specifically focused on disability matters are led by and largely staffed by people with lived disability experience, helping to ensure that people who best know the issues are actually driving the conversations about those issues.

- Require that the staff of these disability-focused offices get from behind their desks and actually spend time with people with disabilities and their family members, helping to ensure a more realistic understanding of the disability community's challenges and opportunities. Again, this does not mean making speeches to large audiences. This does not mean stopping by large events. This means spending quality, one-on-one time with individuals and families – visiting people where they live, work, school, or socialize – and listening, rather than talking.

- Require that people with lived disability experience are placed in key policy-making positions throughout State government, helping to ensure their important perspectives are part of the mix on <u>all</u> issues, not just those specific to disability.

In other words, the next Administration should treat people with lived disability experience the same way we treat other communities by including them, by engaging them, by listening to them, and by taking direction from them. This would not only result in better policy; it would give them more reason to trust the decisions made.

In 2019, in our first annual report, I referenced the debate then over whether to ban plastic straws in commercial settings – an idea advanced nationally and here in New Jersey by those genuinely concerned about the environment. The point of the example was that the development and advancement of this well-intentioned policy proposal probably did not include people with lived disability experience – people who would have likely been more sensitive to the fact that an outright ban on plastic straws could have serious, potentially life-threatening implications for those with physical limitations who require them for hydration and nourishment. (Ultimately, NJ lawmakers and the Murphy Administration heard from and responded to the disability community and included important accommodations in the new law.)

Simply stated, we need to ensure that people with lived disability experience are "in the room" and "at the table."

Leveling the Playing Field

In our 2020 annual report, I spoke of a power dynamic that often places individuals and family members at a disadvantage when advocating for supports or services.

> "Part of the problem is that the power dynamic is balanced against families. Government officials and provider agency representatives have the authority to make decisions that directly impact their loved one's lives – in positive or negative ways. Conversely, families often feel relatively powerless and stuck in the uneasy position of having to quietly accept others' decisions or risk that their advocacy will result in negative repercussions."

I believe this unbalanced power dynamic is central to the lack of trust felt by many individuals and family members. Simply stated, many people believe that the system is largely stacked against them – that others have the power and that others make the decisions, often with little regard for their needs or preferences.

Yes, there are certainly good educators, good doctors, good providers, and good public officials – people who do not abuse their positions and who earnestly work with (not against) people with disabilities and their family members. But lurking around every corner it seems is someone — not so good — who has the ability, authority, and inclination to make their challenging lives even more challenging.

Indeed, we have often been told of and have often witnessed this dispiriting dynamic at play, particularly in the context of our work with individuals and families involved in disputes with local school districts, State government offices, managed care organizations, and residential provider agencies.

As a result, individuals and family members often feel as though they must be prepared to fight, while recognizing that their weakened position means that they must also be prepared to lose. It is a distressing way to live, but for many within the disability community, it is the only way they know.

The next Administration should do its best to rebalance the power dynamic by placing a check on some of the authority now vested in the system's decision-makers, while making clear that the voices of individuals and families matter. Granted, the government's ability to change questionable behavior is limited, but there are certainly steps that can be taken.

For example, alongside the suggestions above related to staffing the government, we should take a good, hard look at local school districts, managed care organizations, and residential provider agencies — and ask some basic questions:

- Do local school districts have too much authority with respect to special educations decisions? Should State government play a more hands-on role? Should we seek to make the IEP process less contentious by making State-led facilitation more readily available and by revisiting the role of taxpayer-funded lawyers hired by school districts to fight families?

- Do managed care organizations have too much authority with respect to health coverage decisions? Should State government play a more proscriptive role? Should we revisit the appeals the process, including the rules governing the "fair" hearing process that currently undermine the role of Administrative Law Judges by rendering their decisions as non-binding?

- Do residential provider agencies have too much authority with respect to the treatment of their residents? Should State government play a more active, more proscriptive role? Should we explore whether a "too big to fail" mindset has resulted in too much discretion being given to large provider agencies – a mindset that has seemingly resulted in an unspoken permission structure that allows some agencies to do as they please without fear of reprisal?

After all, as it currently stands —

- Residential provider agencies <u>never</u> have to pay civil monetary penalties for misconduct.
- Residential provider agencies accused of abuse and neglect are often allowed to investigate themselves.
- Residential provider agencies have been given the authority to decide on matters of human rights.
- Residential provider agencies are able to spend taxpayer money and residents' personal money with seemingly few guardrails and very little transparency.

An Important Individual/Family Perspective

"… we are tired of this situation and DDD has not done anything. It seems the [*Provider Agency*] has some DDD connection and the [*Provider Agency*] is untouchable."

Parent of Adult Child Living in a State-Licensed Group Home
March 2025

Rebalancing these power dynamics could result in some helpful changes in policy and practice. At a minimum, it would help demonstrate to people with disabilities and their family members that we — their government — are on their side, and it would likely give them more reason to trust "the system."

Following the Money

Another step to be taken to build trust would be to follow the money poured into the system in recent years – the billions of dollars allocated to provide care for millions of New Jerseyans, but that does not always seem to make its way to the people it was intended to support.

For their part, Governor Murphy and the State Legislature have appropriated a considerable amount of money to help people with disabilities live safe, healthy, full lives. For that, they should certainly be commended. Yet, individuals and families have often raised questions about "where" that money actually goes and "how" it is actually spent – good questions that we have raised in previous annual reports and in our day-to-day conversations with government and provider community colleagues.

In fact, throughout my seven years in this role, I have rarely – if ever – advocated for more money to be appropriated to the system. Rather, our focus has been on "how" the money in the system is spent … and not spent.

This explains our relentless focus on transparency and accountability. This explains our persistent focus on provider agencies' spending practices – from direct care staff salaries to executive compensation. And this explains our determined focus on the large, taxpayer-funded private organizations at the center of our system of care, namely the managed care organizations, which receive billions of taxpayer dollars every year.

Our view is simple: To strengthen our overall system, we need to shine a big, bright light on the money flows to <u>and</u> within the system. As discussed in last year's report –

> "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.
>
> 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."

To this end, the next Administration should undertake some type of systemwide transparency initiative that requires all disability-related organizations doing business with the government to open their books and make budget information readily available for all to see. Revenues. Expenses. Administrative costs. Personnel costs. Topline information about the money flows to and within these organizations should be made available – in plain language – in one accessible, user-friendly location, such as our Office's website. This would likely lead to more accountability, more cost-effectiveness, and more trust.

Closing Thoughts

Taken together, there is certainly reason to take pride in the good, important work done by the Murphy Administration and its Legislative partners in recent years. Together, we have made good progress with respect to several key issues. We have served many people. We have helped many people. And I sincerely believe that we will be leaving New Jersey's system of care for people with disabilities better than we found it.

That said, our job in our Office is not to take victory laps. Although there is certainly much to applaud with respect to our collective record, there is even more work that still needs to be done, and that is – and always should be – the focus of our Office.

Going forward, there is much we can and should do to improve New Jersey's system of care for people with disabilities – to make it better, stronger, more person-centered, and more family-friendly. Systemic reforms, issue-specific changes, and trust building efforts – none of which would necessarily require more money or new funding. Rather, they would just require more commitment, more compassion, and more common-sense.

Granted, I realize that this report is being written against the backdrop of much concern and consternation about impending changes coming out of Washington — changes that include a significant reduction in Medicaid funding, which literally provides a lifeline for many people with intellectual or developmental disabilities. But I also realize and take comfort in the fact that New Jersey is a State known for its bipartisan, nonpartisan commitment to human services. Here, disability is not a political issue, and I am confident — working together — we will find our way forward.

Last year, I ended the annual report with one of my mother's oft-expressed pearls of wisdom – "Where there's a will, there's a way." The point was that we have the ability and the resources to "get this right" – to do what needs to be done. We just need to stay focused and determined.

This year, I am closing out the annual report with another Margot Aronsohn favorite – "If you're going to do a job, do it right; otherwise, don't do it all."

Sage advice from a woman, who – like many other New Jersey parents – found herself unexpectedly playing the role of lifelong, tireless advocate for her child with disabilities. Always loving. Always worrying. Always fighting. Always trying to do it right.

Going forward, let's heed my mother's advice and example.

Government officials. Educators. Providers. Direct Care Professionals. Advocates. Working together and alongside the individuals and families at the center of it all, let's make our good system great. Let's fix what needs to be fixed. Let's strengthen what needs to be strengthened. Let's demonstrate the "will" to do everything we know we should do.

Simply stated, let's do our jobs right.

POSTSCRIPT

Continuous Improvement

Years ago, while working in the private sector, I learned of an important organizational concept – "continuous improvement." The idea is that successful organizations cannot remain static. They must continue to evolve, and they must always strive to become more efficient and more effective.

Although called different names by different people, "continuous improvement" is a concept central to the long-term sustainability of many organizations. Unfortunately, however, that does not generally include governments.

Indeed, based on my many years in government — at various levels — "continuous improvement" is rarely part of the conversation, much less a requirement. Outdated programs and processes continue. Old approaches are made to fit new challenges. And if a new idea is actually pursued, it is often laid on top of the old machinery, leaving in place yesterday's way of doing business.

The next Administration will have the opportunity to change this – to revisit the way our State does disability policy-making and service delivery. To this end, they could consider a possible paradigm shift that would fundamentally change our overall approach or, at a minimum, they could just consider smaller, more incremental improvements.

Reforming the System

In June 2016, almost two years before I was appointed to this position. I wrote an opinion piece for the Star Ledger newspaper. The premise of the piece was that the "system" was failing many people with disabilities and their families, and there was a need to reform State government's role – to take a zero-based budgeting approach that "would streamline and consolidate the disability bureaucracy, making it more practical, more user-friendly and more comprehensive."

Based on the experiences of individuals and families with whom I had been working as well as some of my own personal experience, the thinking behind the piece was that there was likely a better way to provide disability supports and services – better for the individuals and families, better for taxpayers more generally.

Nine years later and seven years into this job, my view remains unchanged. Actually, if anything, I am even more convinced that major reform is warranted. The overwhelming complexity of the system alone is reason enough.

- Maybe a wholesale restructuring should be explored – one that results in a newly-created Department of Disability Services that houses key policy-making and service delivery offices involved in the full range of disability issues for children and adults, including education, employment, healthcare, housing (licensed and unlicensed), and transportation. This could allow for more informed, more coordinated, more holistic approaches to disability policies and practices by breaking down silos. It would also make it easier for individuals and families to engage the process – a critical consideration for any system reform effort.

- Maybe a more modest, albeit still meaningful approach should be taken – one that reviews current policies, practices, and programs with an eye toward implementing important reforms with respect to "what" we are doing and "how" we are doing it. This could result in some responsibilities being shifted among departments. This could result in a more efficient, more effective use of our limited resources.

Among the ideas to be explored would be whether responsibility for youth (up to age 21) with intellectual or developmental disabilities should be transferred back to the NJ Department of Human Services, where it resided prior to 2013. As discussed in our 2022 annual report, this is an idea often raised by colleagues in government as well as families, advocates, and providers. As one mother recently put it, "The children's system is broken" – a sentiment often shared with our Office.

Moreover, serious consideration should be given to the establishment of an independent agency responsible for investigations of abuse and neglect as well as deaths in State-licensed settings – one possibly modeled after the New York Justice Center for the Protection of People with Special Needs. As discussed, our current approach is not working. It is not thorough. It is not credible. It does not hold provider agencies accountable. It does not inform policy-making or training – a key by-product of New York's approach whereby investigations are used for educational purposes, too.

At a minimum, it will be incumbent upon the next Administration to take a good, hard look at the way New Jersey develops disability policy and delivers disability services – one that could result in program improvements and cost savings, two objectives that are not mutually exclusive, but rather, mutually reinforcing. After all, a fundamentally different approach should not necessarily mean more government; it should just mean better government.

Strengthening the Ombudsman's Office

Our Office has been an experiment of sorts. There are other Ombudsman offices, but nothing quite like our organization has existed here in New Jersey or elsewhere in the country. This is true with respect to our enabling legislation. This is true with respect to the way we have executed against that legislation – the way in which we have done our work for these past seven years. And while I think we have done a good job with limited resources and limited authority, there is certainly room for improvement.

Going forward, irrespective of our recommendation to reform the entire system above, the next Administration should work with the Legislature to make changes to our Office. Changes that would make it more effective. Changes that would allow it serve more people. Changes in line with the original intentions of the legislative sponsors.

More Resources: When the Office was envisioned, the original fiscal analysis that accompanied the legislation estimated that the cost of running the Office could require an annual budget of up to $1.9 million, noting that "the actual cost to implement this bill will largely depend on the design, operation, and implementation of the office." However, our current annual budget is $573,000, which supports only five full-time staff – including me – to provide support to the thousands of New Jerseyans with intellectual or developmental disabilities and their families.

In both absolute and relative terms – relative to some of the other Ombudsman offices – these resources are minimal.

The next Administration should review the work of our Office and consider its potential return on investment. With a larger staff, the Office would be able to serve more people in more effective ways. Better response time. Better data analysis. Better advocacy. Better outcomes for individuals and families.

More Independence: According to the enabling legislation, this was to be a largely independent office. As stated in the first paragraph of the law, "…the office is to be independent of any supervision or control by this department (Treasury) or any board or officer thereof, or any other cabinet-level department, board, or officer thereof." However, in practice, that has not often been the case.

Understandably, there have been growing pains with our new office. Having an internal advocate for people with disabilities and their families was somewhat new for the executive branch. Indeed, I recall a colleague sitting me down during the review of our first annual report in 2019 and telling me, "Paul, you're not supposed to be an advocate." I responded with a reference to the language in the law and to the language used in the Administration press release issued at the time of my appointment – a press release that said I would be "the administration's lead advocate and ally for New Jersey residents in need of critical services ranging from early childhood through adulthood."

Even in those early days, it was clear to me that this job required a level of independence. Over the years, that requirement has become increasingly clear. To ask decision-makers to revisit their decisions. To ask policy-makers to revisit their policies. To advocate for changes in our imperfect system of care. All of that requires some level of independence.

The next Governor should therefore consider steps to strengthen the Office – ensuring that it has the authority and ability to advocate effectively. The Office would still be part of the Administration's team, but its unique role and function on that team would be more fully recognized.

More Access to Information: The first responsibility outlined in our enabling legislation charges the Ombudsman "to serve as a source of information for individuals with intellectual or developmental disabilities and their families and interested members of the public, to help them better understand State and federal laws and regulations governing individuals with intellectual or developmental disabilities." Yet, gaining access to such information has often been a challenge.

This has been particularly true with respect to the NJ Department of Human Services. Although, importantly, the Department has been very responsive with respect to our day-to-day exchange of information about particular individuals and families, it has often been difficult to obtain clear, current policy-related information – a problem discussed in previous annual reports. And while we have been working with the Department and the Governor's office in recent months to facilitate a better flow of information, the new process is not working effectively – not working for our Office, and most importantly, not working for the people we serve.

Going forward, the next Administration should require that all requests for policy-related information from this Office – or any office or member of the public, for that matter – be processed quickly and thoroughly. Indeed, information about existing policies, practices, and regulations should be readily available to everyone.

A Broader Mandate: Early on, I had the opportunity to talk with some of the Legislators behind the creation of our Office. I learned their intentions. I learned their expectations. And importantly, I learned the reason behind the Office's focus on those with intellectual or developmental disabilities, the so-called lifespan disabilities. After all, as noted in my 2016 Star Ledger piece, my thinking was that all people with disabilities – lifespan or otherwise – needed and deserved a senior level advocate and a seat at the policy-making table.

The Legislators all shared that perspective, but felt that the creation of our Office was a good, important first step – that individuals with intellectual or developmental disabilities and their families live in "the system" their whole lives and thus our first priority was to provide them some support and relief.

Their reasoning made sense to me then, but now, having taken that important first step, I think a conversation should be had about expanding the scope of our Office to include all people with disabilities. Yes, that would certainly require additional resources, but a broader mandate would extend the important person-centered services of our Office to many New Jerseyans, who are often on their own to navigate the system and to advocate for themselves and their loved ones.

Going forward, the next Administration should explore such a broader mandate for this Office, using as a guide the bipartisan legislation introduced in 2021 that sought to expand the Office's responsibilities, reaffirm its independence, and ensure its access to information.

Again, the next Administration will have the opportunity to improve our system of care – to build on progress made and take our State's commitment to the disability community to the next level. With new energy, new ideas, and new approaches, the next Administration can reform State government's role in policy-making and service delivery to make our good system great – to make it better, stronger, more person-centered, and more family-friendly. And by strengthening the Ombudsman's office, the next Governor would be able to serve more people, more effectively.

And who knows, in so doing, the next Governor could also save money in the process.

ACKNOWLEDGEMENTS

Thank You

Throughout the year, the work of our office continued to benefit from the partnership and leadership of so many people throughout New Jersey's disability community and beyond, including –

- Many of our colleagues across the Murphy Administration, particularly in the Governor's office and in the Departments of Children & Families, Community Affairs, Education, Health, Human Services, Labor and Workforce Development, Law and Public Safety, 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) with whom we have worked most often and most closely. We always appreciate their passion, professionalism, and partnership.
- Our colleagues in the New Jersey Office of the State Comptroller.
- 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 Tracy Gillespie
- Members of the State Legislature and their staffs, particularly in the offices of Senate President Scutari, Senate Republican Leader Bucco, Senator Corrado, Senator Diegnan, Senator Gopal, Senator Lagana, Senator Schepisi, Senator Singleton, and Senator Zwicker as well as Assembly Speaker Coughlin, Assembly Majority Leader Greenwald, Assembly Minority Leader DiMaio, Assemblyman Barlas, Assemblywoman Dunn, Assemblywoman Haider, Assemblywoman Matsikoudis, 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 Community Living Education Project at Rutgers, the National Council on Severe Autism – New Jersey Chapter, 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.