



State of New Jersey

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

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May 11, 2022

The Honorable Philip Murphy
Governor of New Jersey

The Honorable Nicholas P. Scutari
President, New Jersey Senate

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

The Honorable Craig Coughlin
Speaker, New Jersey Assembly

The Honorable John DiMaio
Minority Leader, New Jersey Assembly

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

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

Pursuant to P.L. 2017, c.269 (c.30:1AA-9.1-9.3), I am submitting the attached annual report to you concerning the work done by our office during the 2021 calendar year. I am providing it to you electronically, but if you prefer, I will provide a hard copy version, too.

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

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

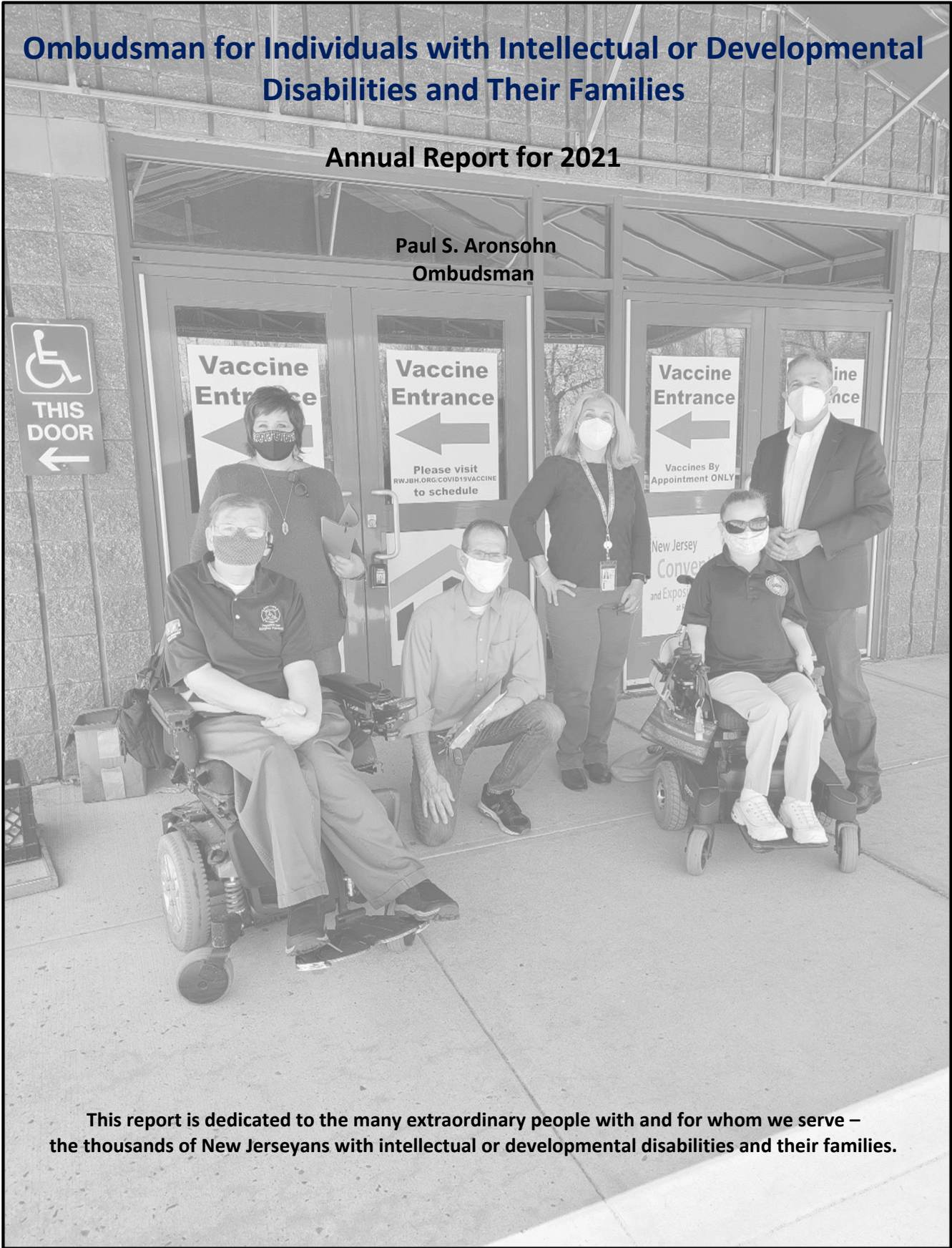
Sincerely,

Paul S. Aronsohn
Ombudsman

Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families

Annual Report for 2021

Paul S. Aronsohn
Ombudsman



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.

Pictured above outside the vaccine megasite in Edison are (left to right) Norman Smith of the NJ Statewide Independent Living Council, Carole Tonks and Luke Koppish of the Alliance Center for Independence, Christine Bakter of the Ombudsman's Office, Kelly Boyd of the NJ Office of Emergency Management and Paul Aronsohn of the Ombudsman's Office.

Preface

Reflecting back on the past year, I am filled with a lot of emotion. I think of the many people who contacted our office seeking assistance, justice, and a little peace of mind. I think of our conversations, which were usually filled with anxiety, anger or even tears. And I remember their stories – always personal, often painful.

I think, too, about how wonderful it felt when we were able to help someone – able to answer a question, connect them with the right resource or assist them in fixing a particular situation. I also think about the deep sense of frustration when we were unable to do so.

Our office is a place people turn to for advice, support or even just a sympathetic ear. Increasingly, our office is also a place people turn to when they are in crisis. A teenager engaging in self-injurious behavior. A young adult with complex medical needs not getting proper supports. A group home resident with unexplained injuries and bruises. An individual whose civil rights are not being respected. A parent not included in consequential decisions about their child.

These are the calls we most often receive. These are the people we most often serve.

Granted, I know none of this is easy. For those who staff our system of care for people with disabilities – in schools, government offices, provider agencies and homes – the work can be hard, time-consuming and emotionally demanding. For those who rely on the system – the individuals and families at the center of it all – it is even harder and even more demanding, because for them, the challenges are very personal and ever-present.

Understandably, we get emotionally invested in the individuals and families with whom we work. They invite us into their lives, often during stressful and defining moments. We listen. We try to help. And whether we are successful or not, we take it all to heart and often internalize their challenging situations.

This emotional investment, in turn, expresses itself in a variety of ways. It drives us to work harder and longer. It compels us to demand more of ourselves and of others. And it leads us to put a lot of time and thought into this annual report, knowing it is an important opportunity to say what needs to be said.

Taken together, we consider this to be our life's work. Like so many others, we have known disability in very personal, very painful ways. In some large measure, it defines and explains us. And so, we will always be grateful to Governor Phil Murphy for giving us this opportunity to serve others in such a meaningful way. We will also always be grateful to our colleagues – in the Administration, in the Legislature and in the larger disability community – for their partnership and for their understanding when we disagreed. And we will always be grateful to the many people – individuals and families – who reach out to our office for assistance, opening themselves up to us and sharing their extraordinary lives in the process. They inspire and strengthen us.



Paul Aronsohn
Ombudsman
May 11, 2022

Introduction

This is our 4th annual report.

As in previous years, we view this report as an opportunity to highlight issues of importance to the people we serve: New Jerseyans with intellectual or developmental disabilities and their families. That means going beyond the required summary of last year's work and making recommendations. It means also sharing the lessons learned through the lives, experiences and stories of the people for whom we work.

In fact, our discussion of these issues is informed by the daily conversations we have with those at the center of our State's large, robust and diverse disability community: people with disabilities and their parents, siblings, grandparents, aunts, uncles, cousins, spouses, children and friends.

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

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

In our [first two reports](#), we provided somewhat of a laundry list of topics, because frankly, a great many issues had been brought to our attention. [Last year](#), we took a more thematic approach.

For this report, we decided to keep it relatively focused. Although there are numerous topics to be addressed, we believe it is absolutely essential that readers of this report know and understand the issues most often brought to our attention last year – the issues that individuals and families would call, email and meet with us about on a weekly, if not daily, basis:

- Abuse & Neglect
- Autism / Severe Challenging Behavior
- Housing
- Self-Direction
- Appeals Processes
- Complex Medical Needs
- Managed Care Organizations
- Staffing

Prior to that discussion, we make some systemic observations and take a deep dive into an issue that we believe is central to the challenges faced by individuals and families, namely, the disconnect that often exists between those making decisions and those impacted by them. At the end of report, we focus on the one thing that would most help mitigate, if not eliminate, that disconnect.

In last year's report, we included several observations about the disproportionate impact the COVID-19 pandemic has had on the disability community, noting that it exposed the fault lines in our system of care. From the civil rights of people with disabilities to the challenges faced by students and their families to the outsized demands placed on educators and group home staff, everyone in the community has been negatively and significantly affected by this public health emergency. And while last year we fielded hundreds of emails and calls about pandemic-related issues – including vaccines, school closures, day program status and group home visitation - we decided not to call out the pandemic as a special focus of discussion in this report, because it is increasingly clear that the coronavirus is both our present and foreseeable future – our so-called “new normal.” We just need to move forward and find our way through it all, embracing the lessons learned (good and bad) and continuously working to improve our system of care for people with disabilities. We have no other choice.

Background

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

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

For the first two years, the Office had a staff of one – [me](#). Since February 2020, [Christine Bakter](#) has been helping me to carry out our 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.

The work of our office is driven by the understanding that while many of us have special needs, all of us – each and every single one of us – has special gifts and that we all deserve the opportunity to be safe, to be healthy and to reach our full potential. To that end, the work of our office is guided by the Murphy Administration’s commitment to make New Jersey a stronger, fairer place for everyone to live, work and raise a family.

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

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

According to the enabling legislation, the Ombudsman is required to “issue a written report annually to the Commissioner of Human Services and the Commissioner of Children and Families. The report shall include a summary of the services the ombudsman provided during the year, and any specific recommendations the ombudsman deems appropriate and necessary concerning the State’s implementation of procedures with respect to providing individuals with intellectual or developmental disabilities with services and supports. The ombudsman also shall issue the report prepared pursuant to subsection a. of this section to the Governor, and pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1) to the Legislature.”

This is that report.

Summary of 2021 Services Provided

Throughout 2021, our office remained small, but busy with the two of us directly and personally serving thousands of New Jerseyans with disabilities and their families in a variety of ways.

Although most of our time was spent troubleshooting problems for people, we also spent much of the year serving as a nexus between decision makers and those impacted by their decisions – working to make connections, promote understanding and bridge the divides that often exist. Sometimes that meant creating opportunities for direct communication among individuals, families, government officials and other stakeholders. Sometimes that meant working alongside Support Coordinators, Care Managers and others serving the disability community. Sometimes that meant helping individuals and families to raise questions, express concerns and speak truth to power.

Our office’s mandate is focused on individuals with intellectual or developmental disabilities and their families, but 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, which often involves connecting them with other offices or organizations.

Prior to the coronavirus pandemic, whenever possible, we would bring our office to the people we serve by visiting with them in their homes, their schools, their places of employment, their communities. This not only made it easier for the individuals and families; it also gave us a uniquely personal and valuable perspective. We could see, hear and feel their life experiences in a way not possible through emails or phone calls.

Last year, however, we had to continue working against the backdrop of the pandemic, requiring us again to adjust our approach, while doing everything possible to maintain our personal connection to the people we serve. When requested, we met in-person with individuals and families, but we spent most of our time talking by phone, communicating by email and meeting by video. As always, we would give people the choice to talk with us in whatever way worked best for them.

As in previous years, we worked with individuals and families throughout our State on a wide range of issues, including adult services, children services, civil rights, education, employment, housing, insurance, managed care, Medicaid, Medicare, mental health, physical health, public safety, Social Security, transportation and unemployment compensation. Most often, this work involved helping them navigate time-sensitive situations.

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

Accordingly, throughout 2021 –

- We worked daily with colleagues across the State’s Executive branch, including in the Departments of Children and Families, Corrections, Education, Health, Human Services, Justice, Labor, State and Transportation as well as the Motor Vehicle Commission.
- We worked regularly with State Legislators and their staffs, providing support to their constituents and collaborating with them on policy issues.
- We worked closely with the Board and Staff of the [New Jersey Council on Developmental Disabilities](#) (NJCDD) and participated in several meetings with them, including weekly phone calls with Executive Director Mercedes Witowsky.
- We participated in a series of weekly interagency working group meetings to discuss disability issues, which were organized and hosted by the Governor’s Policy Office.
- We participated in regular meetings of the Attorney General’s [steering committee](#) to strengthen coordination between law enforcement officers and members of the mental health and other special needs community.
- We participated in multiple meetings of the [NJ Statewide Independent Living Council](#) and worked closely with several leaders of [New Jersey’s Centers for Independent Living](#).

- We participated in multiple meetings of the [Regional Family Support Planning Councils](#).
- We participated in multiple meetings of the [New Jersey Association of County Disability Services](#) and worked closely with several of its members.
- We participated in quarterly meetings of the [New Jersey Legislative Disability Caucus](#).
- We worked closely with the leadership of [Autism New Jersey](#), Executive Director Suzanne Buchanan and Policy Director Eric Eberman.
- We met several times with [Disability Rights New Jersey](#) (DRNJ) and worked closely with Executive Director Gwen Orłowski.
- We met with the leadership of [Special Olympics New Jersey](#) and participated in some subsequent meetings with staff and families.
- We participated in a [legislative hearing](#) of the New Jersey Assembly Committee on Women and Children.
- We attended the 15th Annual [New Jersey Self-Advocacy Network](#) Luncheon as well as the 37th Annual New Jersey Self-Advocacy Network Fall Conference.
- We conducted site accessibility visits of all of New Jersey's COVID-19 vaccine megasites and offered suggestions for improvement.
- We joined Congressman Josh Gottheimer for a visit to a private pop-up vaccine clinic at [Eastern Christian Children's Retreat](#) and joined Governor Murphy and other colleagues for a vaccine event at [Matheny](#).
- I authored an [opinion piece](#) concerning the United Nations Convention on the Rights of Person with Disabilities.
- I spoke with Journalists on a [range of topics](#), including the [availability of COVID-19 vaccines](#) to people in the disability community.
- I did several presentations and interviews, including [a podcast](#) with a Bergen County Commissioner and a closing address to the first annual [NJ Youth Transition Conference](#).
- We attended or participated in about 150 events, including some of the important programs organized by [The Arc of New Jersey](#), the [Fair Lawn Sunrise Rotary Club](#), the [New Jersey Chapter of the American Academy of Pediatrics](#), the [Passaic County Parents of Adults with Disabilities](#), and the [REED Foundation for Autism](#).
- And most importantly, we had more than 1,000 one-on-one meetings and phone calls with individuals and families – in addition to many group meetings and email exchanges.

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

- We promoted our colleague, Christine Bakter, to the position of Deputy Director in our office. Having joined our team in February 2020 – just weeks before the Governor declared a public health emergency – Christine had to hit the ground running and has risen to the many challenges faced by our office and the people we serve.
- We hired a new member to our team, [Charles \(CJ\) Dodge](#), who began this past March. CJ brings to our office a wealth of personal and professional experience with disability, including a strong background in the independent living movement and will help us take our service to individuals and families to the next level.
- We launched a website which seeks to be a one-stop resource for individuals and families. Although still very much a work-in-progress, the website – with CJ's hard work – will become a useful tool for individuals and families.

Observations & Recommendations

In each of the first three reports, I observed that our system of care for people with disabilities is a tale of two systems – one good and one not good enough. Now, in my fourth year, I can state that with even greater certainty.

On the one hand, the system definitely has its strengths. Most notably, there are so many good, well-intentioned people working within the system – people who have dedicated themselves to serving others. Some work in government. Some work outside of government as Direct Support Professionals, Self-Directed Employees, Private Duty Nurses, Personal Care Assistants, Behavior Analysts, Educators, Support Coordinators, Care Managers, Providers, and Advocates. Individually and collectively, they make it possible for so many New Jerseyans with disabilities to live safe, fulfilling lives.

Yet, on the other hand, the system definitely has its shortcomings, too. Every day our office is contacted by those who are falling through the cracks. For some, the need is immediate and a matter of basic health and safety. For some, the need relates to housing, transportation, education, employment or some other quality of life determinant. And for still others, the need is longer-term and a matter of doing everything possible to make sure that vital supports and services remain in place for them or their loved one. This is particularly true for those parents who contact us, worrying about the future and asking “who will take care of my child when I’m gone.”

Moreover, as discussed in last year’s report, I have a haunting feeling that many adults who need supports and services are effectively being shut out of the system. Cultural barriers. Language barriers. Socio-economic barriers. For a host of reasons, I believe many adults with disabilities are aging out of the children’s system of school-based entitlements and are not just falling off the figurative “cliff,” but are actually falling off the “grid” and never making it into the adult system.

Taken together, the question is why – why does our system frustrate, if not fail, so many individuals and families.

- Why do so many parents find themselves having to fight for their child’s educational rights, often forcing them into a legal battle with their local school district?
- Why do so many parents find themselves without desperately needed in-home supports to keep their children and themselves safe, often forcing them to seek an out-of-home residential placement for their child – arguably the most painful decision for any mother or father?
- Why do so many individuals with severe challenging behavior – children as well as adults – find themselves in the back of police cars and taken to acute care hospitals, often forcing them to be restrained in emergency beds for days or weeks on end by medical professionals, who have little (if any) training to serve people with intellectual or developmental disabilities?
- Why do so many individuals with complex medical needs and/or behavioral challenges - children as well as adults - find themselves unable to get proper supports and services in the community, often forcing them to be institutionalized in hospitals and nursing homes?
- Why do so many high-skilled individuals with disabilities find themselves without meaningful employment, often forcing them to work in low-paying, low-skilled jobs?
- Why do so many individuals with disabilities find themselves without appropriate day programs, often forcing them to sit at home without any semblance of a meaningful life?
- Why do so many individuals with disabilities have little, if any, real access to proper medical and dental care?
- Why do so many individuals with disabilities find themselves living in sub-standard conditions with sub-standard supports, often forcing them to withstand otherwise unthinkable abuse and neglect?
- Why do so many individuals with disabilities live completely outside of our system of care, often forcing them to go without vital supports and services?
- Why are so many individuals and families left out of decisions that directly impact their lives?

Systemic Observations

In my first two reports, I highlighted several systemic factors that often make it difficult for people to access the supports and services they need and deserve. Chief among the culprits identified were the overwhelming complexity of the system, the seeming inflexibility of policies and procedures and the maddening lack of urgency by many people working in the system.

I am increasingly convinced, however, that the main problem – the primary culprit – is something that often runs deeper and is a root cause for these and other system weaknesses. It is the main reason for the complexity, the inflexibility and the lack of urgency. It is the main reason many individuals and families do not feel seen, heard, or served by those working in “the system.”

“We are hanging by a thread here trying to manage this dangerous situation on our own and we don’t know where to turn or what to do anymore.”

Parent of a teenager with severe autism, January 2021

Specifically, I am referring to the disconnect that often exists between the people making decisions and the people affected by them – the disconnect in perspective, motivation and expectations.

- People in authority often view situations through the prism of their professional experience and expertise; individuals and families, however, often view situations through their own personal experience and the real-life implications of living with lifespan disabilities.
- People in authority are often driven by bureaucratic and budgetary imperatives; individuals and families, however, are often driven by fundamental human imperatives – namely the person’s health, safety and quality of life.
- People in authority often develop, execute and change policies and procedures in a prescribed way; individuals and families, however, often need and expect decisions and accommodations in real time and based on real, individual needs.

Clearly, this is a generalization. Not all people in authority approach their work in the same way. Many of them bring their own personal, lived experiences to work, and many are also driven by a genuine sense of mission.

Regardless, it is clear that people on both sides of the decision-making dynamic – those making the decisions and those affected by them – often approach situations very differently. The problem, however, is not just that this disconnect often exists and that decision makers and individuals/families are often at odds. Rather, the bigger problem is that those in authority – namely school administrators, government officials or provider agency managers – do not always seem to understand the reason for the disconnect; nor do they always seem to care much about it.

Granted, I am sure that this seeming indifference is not intentional or indicative of any ill will. In fact, I genuinely believe that most people working in the disability community – both in and out of government – are well-intentioned and “in it” for the right reason. More often than not, their hearts are clearly in the right place.

However, I also believe that some people lose their way, becoming desensitized and detached - intellectually, physically and emotionally - from the people they are supposed to serve. Less understanding. Less empathy. And seemingly less concerned about the consequences of their decisions.

“When my adult child was denied SSI, I took him to my local Social Security Office to begin the appeal. As my son rocked back and forth and spoke to himself and couldn’t answer any questions directed at him, I handed over a copy of the guardianship order Social Security claimed they never received. The agent looked around, then leaned in and whispered “We deny almost everyone the first time - don’t worry about it.”

Parent an adult child with autism
February 2022

As a result, this disconnect rears its ugly, infuriating head continuously throughout the life of an individual with intellectual or developmental disabilities and expresses itself in myriad ways:

- This disconnect is felt by a parent when school district officials claim that their child with significant disabilities does not need therapies or any special accommodations.
- This disconnect is felt by a parent when government officials do not act with urgency to provide their family with intensive in-home supports or place their self-injurious child in an emergency residence.
- This disconnect is felt by a parent who is told to “just fill out the form” as if that parent has not already filled out numerous forms, including the one in question.
- This disconnect is felt by a parent who is asked to reaffirm – time and time again – that their child still has autism or some other lifelong developmental disability.
- This disconnect is felt by a parent who is told that their child does not qualify as “disabled” by the Social Security Administration despite having multiple disabilities since birth.
- This disconnect is felt when the family of an autistic child, who elopes into traffic, is denied safety fencing as a disability-specific home modification, because the fence “restrains” the child.
- This disconnect is felt when a managed care organization inexplicably and unexpectedly reduces a family’s personal care assistance/nursing hours or denies a request for a medically-necessary device.
- The disconnect is felt when a government official dismisses a parent’s concern about the lack of physicians available to people with intellectual or developmental disabilities – physicians who are willing to accept Medicaid and who are willing and properly trained to treat these individuals.
- This disconnect is felt by someone with disabilities when they are told about New Jersey’s status as an “[Employment First](#)” State, but not given the transportation resources needed to get to and from a job.
- This disconnect is felt when someone realizes that the New Jersey Comprehensive Assessment Tool (NJCAT) – which is used to determine the resources available to an adult with developmental disabilities - relies on a series of “black and white” questions to assess individuals whose disabilities usually present in shades of gray.
- This disconnect is felt when someone listens to webinars about the benefits of “person-centered” planning, but then told to accept a one-size-fits-all policy regarding the use of their individualized budget.
- This disconnect is felt when a loving couple realizes that their marriage would likely result in the elimination of much-needed government benefits, such as Supplemental Security Income (SSI) or Medicaid coverage.
- This disconnect is felt when someone hears aspirational talk about “self-determination” and “community integration” only then to be told that the resources are not available to hire personal aides or nurses to keep them safe, independent and in the least-restrictive environment.
- This disconnect is felt when someone in a congregate living setting consistently has unexplained injuries or health conditions, yet officials dismiss the possibility of abuse or neglect.

And this disconnect, which is a constant for so many individuals and families, has consequences. It not only causes a lot of frustrating conversations; it also leads to a lot of bad decisions and bad outcomes. Moreover, it also has a less obvious, yet insidious effect in that it traumatizes and re-traumatizes individuals and families who are already emotionally abused by a seemingly cold, uncaring system – one that makes them often beg, plead and fight for basic supports and services for themselves or their loved ones.

The cause of this disconnect is varied, but I have no doubt that much of it results from the lack of direct, personal interaction between decision makers and those impacted by their decisions – a point addressed at the end of this report.

Key Issue Observations

As noted, although numerous issues were brought to our attention last year, we are focusing our discussion in this report on only those brought to us on a weekly - sometimes daily - basis.

This is not to suggest issues omitted from this discussion are unimportant. Quite the contrary. Every issue brought to our attention is important to someone and therefore important to us. Again, in our [previous annual reports](#), we addressed a wide range of issues and encourage you to review them.

Abuse and Neglect

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

"I have the impression that this patient has been physically and mentally declining deconditioning [sic] probably related with poor care in her group home."

Hospital psychiatric evaluation of an 18-year-old group home resident
December 2021

There is also no question that the Murphy Administration takes this very seriously and has taken important steps to address it – to prevent abuse and neglect and to respond to situations brought to our attention. Most notably, beginning in 2018, the New Jersey Department of Human Services has been implementing the [Stephen Komninos' Law](#), the landmark law that established new policies and procedures for protecting those with intellectual or developmental disabilities. Specifically, the Department has put in place several important measures for helping to prevent abuse and neglect in residential and day programs – measures such as unannounced site visits, drug testing of direct care staff and strict notification requirements to parents/guardians when incidents occur.

Moreover, our office works closely with individuals and families, helping to connect them with the appropriate government officials, so that they can tell their stories and [report their allegations](#). We work closely with other Administration officials and State Legislators to address specific situations brought to our attention. And we work with everyone involved - individuals, families, our colleagues and our fellow advocates - to explore additional ways of preventing abuse and neglect in any form, in any place.

That said, there is clearly a disconnect here, because despite all of the good faith efforts, the abuse and neglect persists. And despite all of the information brought to light over the past couple of years – through legislative hearings, news stories and personal pleas from families – I am not aware of any new proactive initiatives to reduce, if not eliminate, abuse and neglect. No new punitive measures or other efforts to hold residential provider agencies more accountable. No new transparency measures to shine a brighter light on instances of abuse and neglect. And except for a very recent effort to develop “core competencies,” no new effort to meaningfully enhance compensation and training for Direct Support Professionals – something that would help ensure more and better staff. Even after the disturbing revelations associated with the [Bellwether Behavioral Health](#) situation in 2019, which led to the revocation of the company’s license to operate in New Jersey, no new programs or processes have been put in place to ensure that other provider agencies do not engage in the same egregious practices.

"I don't know why I didn't push more. Actually, I do know why. I was afraid of retaliation. The agency was very spiteful. But if I had pushed more, maybe he would still be here."

Parent of an adult child who died last year in a group home
March 2022

Going forward, this needs to change.

- The Administration should lead an open and frank discussion about abuse and neglect - a discussion that includes individuals, families, advocates, providers and legislators.
- We should have a zero tolerance policy with teeth. No excuses. No second chances.
- We should make it easier for individuals and families to report abuse and neglect, perhaps through one central phone number or web portal for anyone in New Jersey regardless of age, location, etc. - similar to the [new 988 nationwide lifeline](#) for suicide and crisis prevention
- And we should dramatically change the way we staff congregate settings. Specifically, we need to increase the salary, training and expectations for Direct Support Professionals. (See “Staffing” section below.)



Abuse and Neglect in Focus: Disturbing scene outside the bathroom of a State-licensed group home for children. In addition to the demeaning, abusive sign on the door, the sign to the left of the door warns against flushing certain items in the toilet, including “children.”

Appeals Processes

We often hear from individuals and families who have had their requests for supports and services denied. Unfortunately, the only recourse often available to them is to appeal the denial in court. This is true for matters involving children as well as adults.

For parents of students, it is referred to as a “due process” hearing. For adults, it is called a “fair” hearing. I put quotes around both, because the names are misleading. Both can be expensive and time-consuming, further depleting resources often not available to people with disabilities and their families, and both can seem unfair.

For special education cases, the Administrative Law Judge’s (ALJ) ruling is final. For all other cases, however, the Judge’s ruling is only a recommendation – **one that the State agency can actually reject**. In other words, for cases involving adults, despite the resources spent by a family - the time, the money and the emotional energy - **in the end, it does not matter if the Judge rules in their favor**. The State agency can “adopt, reject or modify what the ALJ decided.”

Last year, our office was involved in several such situations with family members appealing decisions by the NJ Department of Human Services. Here are the main takeaways:

- **The process is weighted against the individual / family.** While individuals/families often represent themselves, State agencies are represented by a taxpayer-funded Deputy Attorney General, who has significant resources – including time – at their disposal. Managed Care Organizations (MCO) are represented by in-house counsel.
- **The process can be long and expensive.** One case has been ongoing for almost 3 years; another has been for about 2 years. The appeals process often costs families a good deal of money - even if they do not hire an attorney - because of time off of work and expenses related to their appeal. The process also costs taxpayers, who pay for the Deputy Attorney General, the Administrative Law Judge and other related expenses.

The process is seemingly predetermined. Again, the Administrative Law Judge’s ruling is not binding. It has no force of law. And it is left to the State agency – which already declined the service in question – to accept or reject the Judge’s decision.

Granted, I have been impressed by and grateful for the Administrative Law Judges involved in the cases we have followed. Each has treated the families with patience and respect. Each has treated the matters with a great deal of sensitivity.

Nonetheless, the disconnect here is glaring. Despite what those in authority often say, for many people, the appeals process does not exist in any real or meaningful way. People often do not have the time or money or emotional bandwidth to challenge a school district, a State agency or MCO in court. And for those adults willing and able to take up the challenge, it can all be for naught, because the State agency does not need to accept the Judge’s ruling.

Going forward, we need to change this.

For special education students, although there is an alternative dispute resolution process – **mediation** – available to parents, more needs to be done to make the overall appeals process less adversarial and more family friendly. For adults, an intermediate step – between State agency denial and court hearing – should be made available to allow for an appeal to be heard and considered in a thoughtful, serious way. For example, DHS should consider an “intensive review” process whereby State officials actually meet – in person – with the individual, family, healthcare professional and anyone else involved before arriving at a final decision.

At the very least, for students as well as adults, our only answer to them should not be “take us to court.” That is not how it should work. Our taxpaying families deserve better than that.

“It is frustrating as parents with full guardianship awarded for their son with disabilities that we have to go through this for a SECOND time! It also feels like harassment at this point, as the MCO (Horizon) lawyers are now threatening with subpoenas for information that has no bearing. In addition, we are in no position to hire an attorney and are doing this Pro Se. However, Horizon is NOW using two attorneys on this case.”

Parent referencing a remand of a Judge’s favorable decision for their family
September 2021



State of New Jersey
OFFICE OF ADMINISTRATIVE LAW

INITIAL DECISION

OAL DKT. NO. HMA [REDACTED]

OAL DKT. NO. HMA [REDACTED]

[REDACTED],
Petitioner,
v.
HORIZON,
Respondent.

STATEMENT OF THE CASE AND PROCEDURAL HISTORY

(text omitted)

ORDER

It is hereby **ORDERED** that Horizon's determination that petitioner is not approved for PCA services is **REVERSED**.

I hereby **FILE** my initial decision with the **DIRECTOR OF THE DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES** for consideration.

This recommended decision may be adopted, modified or rejected by the **DIRECTOR OF THE DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES**, the designee of the Commissioner of the Department of Human Services, who by law is authorized to make a final decision in this matter. If the Director of the Division of Medical Assistance and Health Services does not adopt, modify or reject this decision within forty-five days and unless such time limit is otherwise extended, this recommended decision shall become a final decision in accordance with N.J.S.A. 52:14B-10.

Within seven days from the date on which this recommended decision was mailed to the parties, any party may file written exceptions with the **DIRECTOR OF THE DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES, Mail Code #3, PO Box 712, Trenton, New Jersey 08625-0712**, marked "Attention: Exceptions." A copy of any exceptions must be sent to the judge and to the other parties.

Appeals Process in Focus: A recent example of an Administrative Law Judge's decision in support of a family. Note the required disclaimer that the decision is only a "recommendation."

Autism / Severe Challenging Behavior

Our State has one of the highest prevalence rates of autism in the country – [1 in every 35 New Jersey children](#). That is astounding. In all, it is estimated by [Autism New Jersey](#) that there are about 122,000 New Jerseyans with autism today.

In each of our previous annual reports, I spoke of people with severe autism (a combination of autism, intellectual disability and severe challenging behavior) – people who are self-injurious, aggressive towards others and/or destructive of property. I spoke of the high prevalence. I spoke of the urgent need for more supports and services. And in our 2019 report, I noted that “of all of the things I have learned since becoming the State’s Ombudsman, nothing has been more eye opening and more worrying.”

Years later, I stand by that assessment. We have a full-fledged crisis on our hands.

According to [Autism New Jersey](#), there are approximately 20,000 people in our State – children as well as adults – who have severe autism. Moreover, [it is estimated](#) that about 1 in 3 New Jersey children with autism have likely punched themselves in the face, banged their own head against a wall, bitten themselves or engaged in some other self-injurious aggression – often as a pattern of ongoing behavior. (See ["A Voice for Severe Autism"](#) link at the end of the report.)

Without exaggeration, rarely a day goes by when we are not involved with a family trying to cope with the effects of severe autism. A self-injurious child in need of urgent treatment or residential placement. An adult with aggressive behavior taken from their home and restrained in a hospital emergency department. Parents and siblings fearing for their physical safety and that of their loved one. Individuals and families experiencing post-traumatic stress disorder.

Important steps have been taken across State government, and we are grateful to the Governor’s Office for a recently initiated conversation on this critical topic – a conversation that has included our Office, a cross-section of the Governor’s Office staff as well as experts from Autism New Jersey and elsewhere. We hope to continue those conversations and broaden them to include other government officials, community experts and family advocates, and to explore ways in which we can take a more holistic approach – one that addresses early identification / intervention, treatment, crisis response, out-of-home placements and intensive in-home supports, including vital house modifications, such as outdoor property fencing and indoor wall padding, if necessary.

“(My child) has been on a list for a crisis bed for eight months and her situation has become so serious to the point that we had to involve the police and ambulance last Friday. She had two ER visits last week. She has trashed our home and destroyed walls, doors, windows and numerous personal items. We are in desperate need of an in home placement where she can receive wrap around services and care.... We are constantly visiting the ER and as you are aware she is temporarily medicated and returns home to her exact behaviors that got her hospitalized.

Parent of teenage daughter with severe autism, April 2022

That said, there is clearly a disconnect here. Severe autism is not new; nor is it going away. If anything, the challenge seems to be getting larger, more complex and more dire. Yet, despite all we know about severe autism – the high prevalence and the devastating consequences – we have yet to “sound the alarms” and put in place the infrastructure needed to mitigate this human crisis.

Going forward, we should take a whole-of-government approach – one that involves senior level officials from across the Administration as well as individuals, families, advocates, behavior analysts, medical professionals, hospital officials, law enforcement officials, providers and legislators. The State’s increased focus on severe challenging behavior has been an important step forward, but we need to move much faster and much further. Time is not on our side. These individuals and families do not have months or years to wait for answers; their need is now – right now – and the longer we wait, the more permanent damage (physical, emotional, psychological and financial) will be done.

“I am not sure how to sound the alarm that there are families, such as, myself that are hanging on by a thread with phone in hand ready to call 911 for help; but knowing, calling 911 will only add to the trauma of their child.... We are in the trenches every day with no reinforcements in sight.”

Parent/Caregiver of an adult child with severe autism, March 2022



Autism / Severe Challenging Behavior in Focus: Disturbing scene inside the bedroom of a teenager with severe challenging behavior. This family has since installed padding on the walls throughout much of their home so as to lessen the physical injury caused by their child's head banging and wall punching.

Complex Medical Needs

Many New Jerseyans - children as well as adults - have disabilities that involve complex medical needs. Some have functional limitations. Some rely on technologies, such as feeding tubes and tracheotomies. Most require some level of specialized care and supports, often involving trained nurses and medical specialists.

Last year, we continued to hear concerns from people with complex medical needs and their families on topics important to them – from the scarcity of day programs to the unreliability of transportation options to the unpredictability of managed care organizations. Mostly, we heard about the desperate need for staff, housing and medical care.

- **Staff:** For people with complex medical needs to live safely and fully in the community, they often need Private Duty Nurses (PDN). As discussed in the “Staffing” section below, however, PDN are in dangerously short supply. This workforce shortage is due, in part, to the fact that the Medicaid salary rate for PDN in New Jersey – about \$28 per hour -- has reportedly not increased in more than a decade.

Moreover, the NJ Department of Human Services (DHS) does not have a program to meet the needs of adults who have both complex medical needs and severe challenging behavior. Families, like one featured below, who need to hire both PDN and “individual supports” are effectively forced to choose one or the other, because DHS’s [Community Care Program](#) - which includes individual supports - does not include nursing.

- **Housing:** Without access to PDN, many people with complex medical needs cannot live in their own home or even a family home. They need some type of congregate residential setting. However, there are not enough “medical” group homes or other privately-run congregate residences that have the capacity to provide nursing/medical support; nor is the State allowing (with few exceptions) new admissions to the Developmental Centers it runs. This often leaves many adults and their families with two bad, dangerous choices: live at home without proper supports or live in a congregate care setting, including a nursing home, without proper supports.
- **Medical Care:** Accessing quality healthcare is a serious challenge for many, if not most, people with disabilities. Many physicians/psychiatrists/dentists do not accept Medicaid. Many are not willing or trained to treat people with intellectual or developmental disabilities. And some of the top specialists are located in New York and Pennsylvania and are therefore not necessarily covered by New Jersey’s managed care organizations.

The disconnect here is serious. Despite all of the talk about “home and community based” services and supports, many people with complex medical needs and their families do not have access to the tools to make living in the community a safe, sustainable reality. Moreover, despite all of the talk about “de-institutionalization” over the years – including efforts to close down the Developmental Centers – the State has (inadvertently) fostered a “re-institutionalization” by effectively forcing many people with complex medical needs – children as well as adults – into hospitals and nursing homes.

Going forward, we must ensure that people with complex medical needs have the resources to live safely and independently in the communities of their choice.

- This means making Private Duty Nurses more readily available by paying them a more reasonable salary rate.
- This means making it possible for individuals with both medical and behavioral needs to get the supports they require through a Community Care Program that provides nursing care as well as individual supports.
- This means doubling-down on efforts to promote the development of more medical residences.
- This means making MCO network adequacy a priority by ensuring that more medical / dental professionals accept Medicaid and that they are trained to treat people with intellectual or developmental disabilities.
- This means expanding and mandating MCO coverage to “border providers” in adjacent States – similar to what is offered to New Jersey State employees through [their health plans](#).
- And once and for all, this means making sure that no one with an intellectual or developmental disability is living in a nursing home, unless it is determined by them and/or their families that it is the most appropriate setting.

From: [REDACTED]
Sent: Friday, January 21, 2022 6:58 AM
To: [REDACTED] (DHS)
Cc: Aronsohn, Paul [TREAS] <Paul.Aronsohn@treas.nj.gov>; Bakter, Christine [TREAS] <Christine.Bakter@treas.nj.gov>; [REDACTED]
[REDACTED] Seifried, Jonathan (DHS)
Subject: [EXTERNAL] Re: [REDACTED] transition

Thank you for taking the time to meet yesterday to continue talking about how to support [REDACTED] in his transition to adult life.

I understand that we will temporarily need to move from CCP to the Supports Program + PDN until we are able to come up with a solution to our nursing problem. I agree and consent to this change as a temporary measure.

To say that this is devastating cannot completely describe my feelings over this situation.

As a parent of a child with complex neurodevelopmental disabilities with medical problems I have learned to cope with loss: first it's the dreams you have for your child. Then you lose mundane things like going out to dinner because your child is disruptive and gags at the sight of food. You lose friends because you can't go out or join in activities like you once did. You lose your job because you're late waiting for staff to arrive, or to cover a call out, or because there are too many hospitalizations, appointments, obligations. Eventually you lose your family and you are alone trying to hold it all together.

[REDACTED] swallows air. That is what will kill him. Eventually. It causes an obstruction in his bowels. No one can stop him from swallowing the air. It's the nature of his disability. He gets skin infections that require surgery. He had MRSA on his scrotum twice in the last year. The first time we took him to CHOP- because no one in NJ can help us — and they lanced it in the ER. They sedated him and he stopped breathing for 30 minutes. They had to bag him, mechanically breathe for him, for 30 minutes before he could breathe on his own. The skin infections are a major problem because he has Ehlers Danlos syndrome. His skin breaks open, it bruises. His bones break, or just wear out. He wore out the top of his hip, it disappeared. The surgeon had never seen anything like it, [REDACTED] needed total hip replacement at 17. It lasts 10 years but we were told it probably can't be repeated because it he surgery is so hard to go through that he wouldn't endure it. But [REDACTED] can't tell you when he's sick or hurt. You have to know him to know the signs.

We have 4 nurses who will work with [REDACTED]. Give him daily enemas and suppositories and vent his tube every hour he is awake, because if he's awake he's swallowing air. Measure his stomach contents and hold a tube feed because if his gastric emptying slows down and you keep tube feeding- it kills a person. Tell me who will take this on? Who will come here and do this for \$25 an hour? With a man with Down syndrome, Ehlers Danlos, Autism, who breaks bones easily, who gets MRSA frequently, who is non compliant due to Oppositional Defiance and OCD.

No one.

Yet people hold this belief that nurses are lined up eager to do this work. Even when the nursing agency hasn't sent a new nurse in 2 YEARS. We can't find a new person to take one shift. One hour.

This care cannot happen in a group home. This care can't even happen in the hospital. This requires 1:1 Skilled nursing care. I need you to understand how terrifying Nursing Care denials are to us. The nurses worry too. They worry about open shifts because what if someone doesn't check his skin thoroughly? Doesn't get the enema done properly? We are desperately trying to hold this together but need more help.

I'll be here. The nurses will be here. For now. Until we collapse. The nurses are holding on to \$25 an hour, holiday pay, overtime. They don't want extra paperwork, requirements and no way to negotiate extra pay for covering someone else's shift. This is how the nursing agency covers shifts. They provide incentives. Will they be able to do that in the DDD system? No one knows and the nurses are saying they can't work in these conditions if they can never get the money they currently are paid. With no health benefits, sick time, retirement. They are saying they can't give anymore.

This is urgent. This is a problem created in part to the pandemic and we need a solution. We have no good choices here. Each choice results in someone getting hurt.

Please. Help us.
[REDACTED]

Complex Medical Needs in Focus: Recent email from a parent about an adult child transitioning into the adult system of care. The note says so much about the challenges faced by individuals and families.

Housing

Last year, many housing issues were brought to our attention. Mostly, the questions and concerns were raised in the context of an alarming shortage of residential options for individuals with severe challenging behavior or complex medical needs – children as well as adults.

For children, the situation is an absolute crisis. Since I started in this position nearly 4 years ago, parents have contacted our office about the desperate need for residential placements for their children with severe challenging behavior – children physically and emotionally hurting themselves and their families. Last year, however, it seemed as though parents were contacting us on a near daily basis.

For adults, the situation is very similar. Although there are many more “beds” available for adults, there is also much more need. Some adults with significant behavioral and/or medical needs are forced into substandard housing situations – often in understaffed State-licensed residences or personal homes. Some, as discussed below in the “Complex Medical Needs” section, apparently end up in nursing homes.

Simply stated, there are not enough safe, appropriate housing options for many of the most vulnerable people in our State, placing in harm’s way - on a daily basis - many New Jersey children, adults and families.

The disconnect here is that housing is a basic necessity for all people. Yet, here, in one of the most affluent places on earth, there is a housing shortage for people with the most significant behavioral and/or medical needs. Moreover, none of this new. The housing shortage and its serious repercussions have been widespread and well-known for many years. Yet, we have not done enough to increase the options available to these individuals and their families.

- By not effectively expanding the number and type of residential options for children – in New Jersey as well as out-of-state – we have not done enough to address the needs of families in crisis.
- By not adequately increasing salaries for Direct Support Professionals, Self-Directed Employees and Private Duty Nurses, we have not done enough to address staffing shortages in State-licensed residences and private homes.
- By not easing restrictions on the use of state-funded housing vouchers and by not more actively promoting diverse, innovative housing solutions - including intentional residential communities - we have not done enough to address the shortage of community-based housing options.
- And by not allowing adults to choose an out-of-state residence - even when no appropriate in-state option exists - we have not done enough to address the needs of some of our adults.

Going forward, we need to revisit old policies and double-down on the development of new residential options for children as well as adults. That means taking a new, more realistic approach to professional staff salaries. That means proactively encouraging new housing developments, including medical group homes, barrier-free apartments, campuses and other intentional communities made possible by [federal policies](#) (see below). That means making it easier for an individual to use a housing voucher. And that means supporting individuals with intellectual or developmental disabilities who want to live in out-of-state residences, if doing so best meets their needs. As one parent pointed out, when necessary, we allow students to attend out-of-district schools. The same principle should apply for adults whose needs can best be met in out-of-state housing.

“NJ needs to do a lot more in terms of having crisis beds for situations like this and also have campus based settings like Woods Services to keep residents safe and provide the clinical and therapeutic interventions using a multi-disciplinary approach.”

I am currently beside myself in complete trepidation that my innocent child may be placed in harm’s way and I may have no way to stop it.”

Parent of an adult child
August 2021

“We don’t have PTSD. We have chronic traumatic stress disorder. I’m worried all the time.”

Parent who wants her two adult children with autism to live in a campus residential setting
January 2022

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-26-12
Baltimore, Maryland 21244-1850



June 11, 2021

The Honorable Brian K. Fitzpatrick
U.S. House of Representatives
Washington, DC 20515

Dear Representative Fitzpatrick:

Thank you for your letter regarding the scope of the home and community-based services (HCBS) settings rule. I appreciate your concern about specific characteristics of settings in which Medicaid-funded HCBS can be delivered.

I would like to first clarify that the HCBS settings rule does not prohibit HCBS funding in farmsteads, intentional communities, and campus settings, nor does the settings rule require that individuals receive services in other setting types prior to choosing to receive services in a compliant farmstead, intentional community, or campus setting. The settings criteria contained in the regulation require that individuals receiving Medicaid-funded HCBS have the same degree of access to the community as individuals not receiving Medicaid-funded HCBS; there is no numerical threshold defining this requirement. The degree of interaction with the community should be determined by each individual, as outlined in his or her person-centered service plan.

With regard to settings that are presumed to be institutional, the March 22, 2019 guidance that you reference outlines the characteristics of settings that isolate HCBS beneficiaries from the broader community. In your letter, you outline four characteristics of home and community-based settings; however, those will not alone meet all of the settings criteria outlined in the regulation. The state must assess each setting to determine that all of the settings criteria are met in order for a setting that meets the characteristics of isolation to overcome its institutional presumption.

Lastly, CMS does not believe that there is a threshold number of individuals receiving services beneath which it can be presumed that a setting would meet the HCBS settings criteria, or above which it can be presumed that a setting would not meet the criteria. Therefore, there is no cap as mentioned in your letter on the number of individuals who can receive services in a setting. In determining a setting's compliance with the regulatory criteria, the focus should be on the experience of the individuals in the setting. This applies to both residential and non-residential settings in which individuals receive Medicaid-funded HCBS.

We continue to engage with our state partners, Medicaid beneficiaries and their families, and other stakeholders to discuss the settings criteria in the HCBS final rule. Your questions are helpful for informing this ongoing work.

Housing in Focus: Letter underscoring the federal government's flexibility on using Medicaid monies for people with disabilities, noting that the emphasis with respect to housing should be on a person's "experience" rather than the size or location of a residence.

Managed Care Organizations

Last year, we received multiple questions and concerns about the [Managed Care Organizations](#) (MCO) that participate in New Jersey's Medicaid program. Specifically, people reached out to us regarding MCO decisions to reduce or eliminate nursing and personal care assistance hours as well as decisions to deny requests for other supports and services. Toward the end of the year, we also started hearing from several people concerned with the "slow pace" at which MCOs were providing therapeutic coverage for children with autism, particularly applied behavior analysis (ABA).

More generally, we have had our own questions and concerns about the work of the MCOs, their decision-making authority and the public monies paid to them. As such, we used the opportunity presented by the State's effort last year (October) to renew the Medicaid program and the Children's Health and Insurance Program – [the NJ FamilyCare Comprehensive Draft Renewal](#) – to seek clarifications on some of these important issues.

"I can personally attest to the fact that MCO's are making it almost impossible to keep a disabled loved one at home.... We must stop giving the MCO's free reign with tax dollars and no oversight or accountability to the State. This abuse of authority needs to stop now."

Parent of an adult child with complex medical needs
October 2021

Among [the questions we asked](#):

- How are MCOs compensated for the work they do in the context of our Medicaid programs?
- Is the amount of compensation ever affected by decisions made by an MCO about whether specific services are permitted for an individual?
- Do MCO representatives or care managers receive additional compensation or bonuses for reducing Private Duty Nursing hours or any other benefit for their members?
- What office in our State government oversees the work of the MCOs in our Medicaid programs and how is that oversight exercised?
- Short of taking a matter to court, what recourse does an individual have to challenge an MCO's decision?

We are hoping that detailed answers to such questions will help us – and the individuals and families we serve – to better understand [the relationship](#) between the State and the MCOs.

Regardless, there often seems to be a disconnect between decisions taken by MCOs and the needs of the people who depend on them for supports and services. There also seems to be a disconnect between the authority delegated to the MCOs and the public's belief that State government officials – not private business representatives – are ultimately responsible for coverage decisions. In fact, right or wrong, there is a widespread belief that MCOs operate without any real concern for the individuals they are paid public money to support and without any meaningful controls.

Central to this disconnect is the definition of "medically necessary." MCOs often seem to rely on a much more narrow definition than individuals and families – one that provides them a rationale for not covering a service or supply and one that seems to be generally accepted by government officials.

Going forward, we need to ensure that people are getting the supports and services they need and deserve and that the State is exercising adequate oversight. To that end, a comprehensive review should be undertaken to examine our State's relationship with the MCOs – a review that, among other things, could be used to clarify the responsibilities of everyone involved. And, of course, individuals and families should play a meaningful role in such a review.

Amerigroup

An Anthem Company

<https://providers.amerigroup.com>

November 12, 2021

[REDACTED]
[REDACTED]
[REDACTED]

Member name: [REDACTED]
Member ID number: [REDACTED] Medicaid
Reference number: [REDACTED]
Appeal ID number: [REDACTED]
Dates of service: [REDACTED]
Service requested: full powered (total electric) Sleep Safe Bed

Subject: Appeal upheld

Dear [REDACTED]

Thank you for taking time to contact Amerigroup Community Care. We received your appeal request on 10/15/2021. After reviewing the information you submitted, we have decided to uphold the previous denial for the following reason: Not Medically Necessary.

Member was evaluated for a full electric bed. According to the guideline, full electric beds are a matter of convenience. We have approved services for this member where he has a paid aide to assist him. The member is not getting out of bed independently. Therefore denial of full powered (total electric) Sleep Safe Bed is UPHELD.

This review was done by the health plan's Medical Director, who is a Medical Doctor that is board certified specializing in Pediatrics, reviewed the documentation submitted for the date(s) above. This review was done in accordance with New Jersey state laws, which are consistent with appeal decisions.

The decision is based on recognized medical standards; we used the Amerigroup: Clinical UM Guidelines: Hospital Beds and Accessories (CG DME-15) to make this decision. This decision does not exhaust the member's right to appeal.

As a participating provider, please be advised that the member may not be held financially responsible; therefore, you may not bill the member for the denied service. If you disagree with this decision, and would like to file an external appeal with the Independent Health Care Appeals Program (IHCAP), please complete and return the external appeal application by mail or by email within 60 days

NJPEC-2138-20

NJAP0061 Provider Appeal Upheld Letter May 2020

Managed Care Organizations in Focus: Letter denying – for a second time – a family's request for an electric powered bed for someone with tetraplegia and other disabilities. (Following outreach to the State Medicaid Office, the MCO approved the 3rd request.)

Self-Direction

In New Jersey, individuals can choose to "self-direct" some or all of their home and community-based supports and services – an alternative approach to the more traditional agency-based service model. The idea is to give these individuals and families more responsibility, more independence, more control and more choice. And this self-directed service model can be a more person-centered, less expensive approach – one that allows people with disabilities to live safely and fully in the least restrictive environment.

However, the State does not always make it easy.

In my [2019 annual report](#), I discussed some of the challenges faced by individuals and families who have chosen self-direction. Here, I am focusing on the one challenge most often brought to our attention last year: the State's decision to impose a salary threshold for Self-Directed Employees (SDE) – the people hired to care for and support people with disabilities.

Indeed, throughout the past year, we worked closely with several self-directing families – individually and collectively; we joined them in meetings with other State officials; and we even supported some families appealing this salary threshold in Administrative Law Court hearings. It is an important issue that goes to the heart of families' ability to care properly and effectively for their loved ones in the least restrictive settings. And it is a complex issue, so I am discussing it here at a high level.

In April 2020, the State announced and began implementing a "reasonable and customary" salary threshold of \$25 per hour for families to pay SDEs who care for their loved ones, including those with the highest level of need or (in clinical language) the highest level of acuity. This threshold, which is lower than what many families were previously allowed to pay staff, seems more "arbitrary" than "reasonable" and is problematic on multiple levels:

- **The SDE salary threshold is not fair to the individuals involved:** The threshold does not take into account the fact that some individuals need a higher-level of care than can be provided by someone making only \$25 per hour. The threshold therefore not only makes it difficult to hire a professional with the right mix of expertise and training; it makes it difficult to retain them. Moreover, the threshold not only jeopardizes the health and well-being of individuals; it also sometimes forces them into the unenviable and uncomfortable position of having to be cared for – in a very personal way – by a rotating mix of people, including strangers.
- **The SDE salary threshold is not fair to families:** To make matters worse, this salary threshold is in place for families, but not for provider agencies. In fact, to support the same individual with the highest level of need / highest acuity, the State pays home health agencies **\$53.16 per hour or up to \$1,275.84 per day**. (Note: This is not a threshold; it is the flat, bottom rate.) Moreover, if that same individual lives in a State-licensed residence, the provider agency is paid up to **\$999.36 per day**.

"The decision to cap (my adult child's) personal aide's salary was done in a very subjective and uninformed manner. There was no discussion with (the aide) and no meeting with (my adult child). No consideration was given to the fact that she had been assessed by DDD to be in Tier Da, meaning that her needs are significant and serious. This does not align with the more than \$50:00 per hour given to provider staffing agencies for the same purpose."

Parent/Caregiver
October 2021

When asked about this discrepancy, the State's response has been that these agencies only pay staff about \$13 - \$16 per hour and use the remaining money to cover administrative overhead costs, including benefits.

This, however, seems neither right nor fair. Not only is it hard to believe that these agencies have such exorbitant overhead costs – up to \$41 per hour per staff member – the policy does not take into consideration the overhead expenses incurred by families, including those associated with hiring and training new staff. Moreover, the significant rate differences put self-directing families at a disadvantage by making it much harder for them to compete with home health agencies, who can provide higher salaries and benefits to staff.

- **The SDE salary threshold is not realistic:** Although \$25 per hour may seem like a lot of money, it really is not. For a full-time employee, it only comes to about \$52,000 per year – before taxes are withheld and without any benefits, including health insurance. As discussed below in the “Staffing” section of this report, this is not a realistic, sustainable salary for a professional, who is responsible for the health and well-being of someone with significant disabilities.

The disconnect here is very real and very regrettable. It is a disconnect between the promise of self-direction and the reality faced by many individuals and families. Despite what they are told, self-directing families are not allowed to establish their own salary rates, thereby calling into question [the control and choice](#) promised to them and their loved ones and thereby calling into question the long-term viability of this service model. (Similarly, individuals and families often do not have the ability to use their designated budget as they see fit in a truly person-centered manner.)

Going forward, to ensure that New Jerseyans with disabilities are safe, healthy and living in the least restrictive environment, we should take the following steps to strengthen the self-directed service model.

- **Parity:** There should be parity between families and provider agencies or at least, there should not be any artificial threshold imposed on families. Like agencies, families should be constrained only by the parameters of the budget assigned to them alongside the oversight exercised by the State.
- **Transparency:** There should be a transparent process for SDE salary requests – one that clarifies the information the State uses in making its decision.
- **Intensive Review:** There should be an “intensive review” step added to any denied SDE salary request, ensuring that all of the information relevant to the request - including the need to retain quality employees and the need to ensure the health, safety and quality of life of the individual - have been considered. As part of this intensive review, State officials should actually meet – in person – with the individual, employee, etc.
- **Advisory Committee:** There should be an advisory committee, comprised of at least 50% self-directing family members, whose responsibility is to review and make recommendations regarding all aspects of the self-directed model, including the need to eliminate the seemingly arbitrary salary threshold.

All of this is particularly important in light of the fact that self-direction is often the only “choice” for some families, who fear placing their loved one in a State-licensed residence or who are effectively forced from such a residence due a lack of adequate supports.

Just prior to the release of this report, a family member raised concerns about future planning for self-directing families, namely:

- Who will care for my adult child when we are gone?
- Who will serve as guardian or assist with legal issues?
- Will my child be able to remain in her/his own home in the community?

Clearly, this is a topic that needs to be discussed thoroughly and thoughtfully – perhaps in the context of the advisory committee recommended above. Indeed, there is a real sense of urgency, particularly for families with aging parents and/or without other natural supports, such as other family members who are willing and able to play a meaningful role in the individual’s life.



State of New Jersey

DEPARTMENT OF HUMAN SERVICES
DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES
PO Box 712
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PHILIP D. MURPHY
Governor

SHEILA Y. OLIVER
Lt. Governor

SARAH ADELMAN
Acting Commissioner

JENNIFER LANGER JACOBS
Assistant Commissioner

**STATE OF NEW JERSEY
DEPARTMENT OF HUMAN SERVICES
DIVISION OF MEDICAL ASSISTANCE
AND HEALTH SERVICES**

█, PETITIONER,

V.

DIVISION OF MEDICAL ASSISTANCE
AND HEALTH SERVICES,
RESPONDENTS.

ADMINISTRATIVE ACTION

ORDER OF REMAND

OAL DKT. NO. HMA █

As Assistant Commissioner for the Division of Medical Assistance and Health Services

(DMAHS), I have reviewed the record in this case, including the OAL case file, the Initial Decision and both Petitioner's and Respondent's exceptions.

(text omitted)

That said the issue transmitted to the OAL was an appeal of DDD's denial of Petitioner's request for a wage increase because the proposed rate was not reasonable and customary. DDD has argued that a reasonable and customary rate cap for SDEs is \$25/hr. DDD asserts that it arrived at this rate after researching private-agency employees, the majority of which pay staff between \$12 and \$15 per hour. While I agree provider agency rates are not comparable to individual direct service provider rates, largely due to the costs and overhead associated with running the business, I feel that the record is lacking documentary evidence of DDD's research into the reasonable and customary rates for SDEs similarly employed to █.

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Self-Direction in Focus: An official explanation regarding the higher rates paid to provider agencies compared to families. The State provides these private agencies as much as \$53.16 per hour – the rate paid to them for staffing someone with acute needs – even though these agencies reportedly pay their staff only up to \$15 per hour.

Staffing

Even before the COVID-19 pandemic, we had a staffing crisis in the disability community. Now, the situation is dire. People's lives are literally at stake. We regularly learn of State-licensed residences (group homes and apartments) with dangerously reduced staffing levels. We regularly learn of families unable to hire and retain desperately needed Self-Directed Employees and Private Duty Nurses.

Simply stated, our system of care for people with disabilities cannot survive without the professionals who staff it on the frontlines – the professionals who make it possible for people with disabilities to live safely and fully in the least restrictive environment. Yet, we do not pay these professionals nearly enough. That is why we have high staff turnover and staff vacancies. That is why we have people living in seemingly dangerous situations without the staff support they need and deserve – again, a situation made even worse by the crushing workforce challenges brought about by the pandemic.

In my 2019 annual report – prior to the public health emergency – I spoke about the staffing crisis, noting that many frontline staff are paid so little that they need to rely on government assistance and / or need to hold down multiple jobs.

- **Direct Support Professionals (DSP):** For many people with disabilities, DSPs play an indispensable role in their lives – one that is often very personal, very physical and very demanding. Yet, most DSPs are underpaid, undertrained and underappreciated. According to the NJ Department of Human Services, the salary last year for most DSPs was only between \$13 and \$16 per hour, which is barely above the State's minimum wage and about the same [rate paid to a child](#) employed by a retail store. Indeed, working a full-time, 40-hour week, this wage is only between \$27,000 and \$33,000 per year - before taxes are deducted.
- **Self-Directed Employees (SDE):** As discussed, SDEs play a similar role in private homes and now have a salary threshold of \$25 per hour, although many earn much less. Indeed, many full-time SDEs hired to care for someone with acute behavioral and/or medical needs can earn only up to \$52,000 per year - before taxes are deducted and without any health or retirement benefits.
- **Private Duty Nurses (PDN):** Many PDNs working in the Medicaid-funded system of care for people with disabilities have not received a salary increase in over a decade and earn [no more than \\$28 per hour](#). In other words, despite all of their training and responsibilities working with individuals with complex medical needs, PDNs are often paid no more than \$58,000 per year - before taxes are deducted.

Clearly, there is a dangerous disconnect here. We expect professionals – DSPs, SDEs, PDNs and others, including Behavior Analysts – to provide first-rate care and support to people with significant medical, physical and/or behavioral needs; yet we often pay them at sub-standard rates and often give them minimal training. In so doing, we are effectively setting the system up for failure. Moreover, the disconnect is even more disturbing when consideration is given to the significant amount of [money paid to many provider agencies](#) to support just one individual – again, up to \$1,275.84 per day for home health agencies and up to \$999.36 per day for residential provider agencies.

Granted, the Administration's effort in recent years to ensure DSPs earn more than the minimum wage has been a good, important start, but it cannot be the end of the story.

Going forward, we must invest the necessary resources to pay our professionals a reasonable salary and give them the training commensurate with the level of care expected from them. That means revisiting wage/salary rates. That means revisiting qualifications and training requirements. The Administration, alongside [The Boggs Center on Developmental Disabilities](#), recently launched an important effort to develop core competencies and skills for DSPs, but without a meaningful increase in compensation, the effort will likely be limited in its effect. We need to raise salaries and raise standards together, simultaneously. There is no way around it.

"Without notifying us, the staff shut down the group home's plumbing for 24 hours. This left (our adult child) and the others without the ability to use the bathroom for a whole day, and this caused a behavioral crisis, including (our adult child) screaming and running around the house naked and twice using the bedroom garbage can as a toilet."

Parent of an adult child, March 2022



PHILIP D. MURPHY
Governor

SHEILA Y. OLIVER
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ANDREW J. BRUCK
Acting Attorney General

MICHELLE L. MILLER
Director

November 9, 2021

VIA Regular Mail

Re: [REDACTED] v. DMAHS
OAL DOCKET NO.: [REDACTED]

Dear Judge [REDACTED]

Please accept this letter brief from Respondent, Division of Medical Assistance and Health Services (DMAHS), as a Closing Statement in support of its position in the above-named case.

(text omitted)

In setting this reasonable-and-customary rate, DDD has looked at private-agency DSPs across the spectrum of service providers, and what the DDD has found is that a DSP is paid the same rate regardless of whether he or she is working with someone who has minimal-to-moderate needs or someone who has a higher level of need. There are very few exceptions to this rule, even for those individuals with medical or behavioral needs.

Staffing in Focus: This is a revealing admission that Direct Support Professionals and Self-Directed Employees are NOT paid at rates commensurate with the level of care needed or expected from them.

Recommendations

Again, none of this easy.

For those staffing New Jersey's system of care for people with disabilities as well as for those who depend on it, the challenges are great and numerous. In this report, we only discussed some of the issues important to people with intellectual or developmental disabilities and their families. There are plenty more. And while we can offer suggestions on each of them, the most important thing we should do is encourage – if not insist – on more direct, personal interaction between those making decisions and those affected by them.

I say this, because again, I genuinely believe that most people who work in this space – in education, in government, in the provider community – are “in it” for the right reasons. They have chosen this line of work because they really care, and they really want to make a difference in people's lives. However, somewhere along the way, something often gets in the way, causing some of these otherwise mission-driven people to lose their way.

My belief is that our system has created too much space – physical, intellectual and emotional – between the people in authority and the people who depend on them. And it is that space that is the “something” causing the disconnect and most of the problems – the “something” that often prevents decision makers from genuinely understanding and effectively responding to the needs of people they are responsible for serving.

Indeed, even the most well-intentioned decision maker can lose perspective without real, meaningful, regular connection to the people affected by their decisions.

And so, going forward, we need to bridge the divide that too often leads to bad policies and bad outcomes. We need to create more understanding. We need to create more human connection. And in so doing, we need to make sure that the voices of people with disabilities and their family members are heard in a meaningful way.

To that end, I have two no-cost, easy-to-implement recommendations:

- **People in authority should personally spend time with people with disabilities and their families.**

Rather than always relying on outsourced case managers, small advisory boards with unchanging membership or other intermediaries, our system's decision makers should talk directly and regularly with individuals and their families. By phone. By video. Or in person. Decision makers should make it a point to spend quality time with the people they are serving. I generally recommend home visits, but anything personal, anything meaningful will do. Somehow, we need to break down the silos that too often exist between decision makers and those affected by their decisions.

- **People in authority should hire and appoint people with disabilities and their families.**

Diversity in the workplace should include people with disabilities and their families. We need their input, their perspective, and their leadership. We need to have them “at the table” asking questions, providing insights and informing - if not driving - the conversation. Working alongside, if not under, people with disabilities and their family members inevitably leads to more inclusive work environments and more effective policy outcomes. This is true in government as well as throughout the larger community. Indeed, going forward, offices, committees, and organizations that focus on people with disabilities should be largely staffed, if not led, by professionals with personal, lived experience - the same standard widely embraced by offices, committees, and organizations focused on other segments of the population. And since the disability community - like any community - is robust and diverse, that means having more than one individual or family member representing more than one set of disabilities.

Taken together, I am absolutely convinced that these two recommendations – more than anything else – would help fix what is broken with our system of care and would help ensure future policies are better informed and better meet the needs of individuals and families. Indeed, if faithfully implemented, these two recommendations could be real game changers, because they would help ensure that those of us who work in this important human services field come to work each day with the same sense of urgency and the same sense of mission as the individuals and families we serve.

Moreover, I am also convinced that we are at an inflection point – that New Jersey’s system of care for people with disabilities is in the process of going from good to great. Indeed, here in New Jersey, we have some of the best minds and biggest hearts, and together, we have made important progress in recent years, placing greater focus on the needs of people with disabilities and their families.

Yes, we still have very serious challenges - some of which were outlined above - but we also have very real opportunities. Namely, we have substantial resources, human as well as financial. We have a vibrant, diverse, dedicated community of advocates, educators and providers. And we have the support of public officials in both political parties and at all levels of government.

Now, as we find our way through the pandemic, we just need to have the wisdom and the will to do the right things and to do them in the right way. That means more inclusive decision making. That means more inclusive workplaces. That means working in real partnership with the individuals and families at the center of it all to make the changes that need to be made, to develop the policies that need to be developed.

Too many lives are at stake for us not to seize this moment.

Postscript

This year could be especially significant for New Jersey’s disability community. With the coronavirus pandemic increasingly in our rearview mirror, we have an opportunity as well as an obligation to embrace the lessons learned – good and bad – over the past two years and build a stronger, safer, better future. Indeed, in the coming months, decisions will be made on a whole range of important issues - including special education, employment, healthcare, housing, public safety, and transportation - and it is incumbent on us to get it right.

One such issue currently being discussed and debated is the future of virtual programming.

Prior to the public health emergency, most of us had never heard of “Zoom” or “Microsoft TEAMS” or any of the other video platforms that allow people to meet and learn through their computers, tablets and smartphones. In fact, many of us would never have thought it possible or desirable to engage each other – personally or professionally – through such mediums. But here we are. So much has changed.

Clearly, people have different views about the use of video technology. For some, it has been a godsend. For some, it has been a disaster. And for still others, the feelings are mixed, depending on the context.

It is therefore absolutely essential that policies about the future of virtual programming be made with everyone having a seat at the decision making table, including people with disabilities and their families. That is true with respect to school districts and their virtual learning policies. That is true with respect to local governments and their public meeting practices. That is true with respect to State government and its day program policies, telemedicine regulations and community meeting practices.

My personal view is that we should take a balanced, hybrid approach – one that recognizes the invaluable accessibility made possible through video technology, but one that also recognizes that, when possible, there really is no substitute for the in-person experience. I know it may not be easy. I know it may require some logistical and financial adjustments. But in the end, it will mean more choice, more accessibility and more opportunity for people with disabilities and their families, and that will make it all worthwhile.

Regardless, at a minimum, all decisions affecting the disability community - this year and every year - should be driven, shaped and guided by the input and needs of the individuals and families at the center of it all.

Now, more than ever, “Nothing about us without us.”

Acknowledgements

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

Many of our colleagues across the Murphy Administration, particularly in the Governor's front office and in the Departments of Banking & Insurance, Children & Families, Education, Health, Human Services, Labor and Workforce Development, Law and Public Safety, Transportation, and Treasury (including in the Office of the Long Term Care Ombudsman) with whom we worked on a regular – sometimes daily – basis. In this context, we are especially grateful to the leadership and staff of the NJ Division of Developmental Disabilities (DDD) and the NJ Children's System of Care (CSOC) with whom we work the most: Assistant Commissioner Jonathan Seifried and Assistant Commissioner Mollie Greene and their teams, respectively.

Members of the State Legislature and their staffs, particularly in the offices of Senate President Sweeney, Senate Republican Leader Kean, Senator Bucco, Senator Corrado, Senator Gopal, Senator Vitale and Senator Weinberg as well as Assembly Speaker Coughlin, Assembly Republican Leader Bramnick, Assemblyman Benson, Assemblyman Conaway, Assemblywoman Downey, Assemblywoman Dunn, Assemblywoman Swain, Assemblyman Tully and Assemblywoman Vainieri Huttie.

Many organizations and providers across the state, particularly the Arc of New Jersey, Autism New Jersey, Disability Rights New Jersey, the New Jersey Association of County Disability Services, the New Jersey Council on Developmental Disabilities, New Jersey's Centers for Independent Living, and the New Jersey Statewide Independent Living Council.

And most importantly, individuals and families from communities across our State with whom we had the opportunity to work – extraordinary people living extraordinary lives who inspire us in profoundly important ways.

"A Voice for Severe Autism"

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