



# State of New Jersey

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

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March 11, 2019

The Honorable Philip Murphy  
Governor of New Jersey

The Honorable Stephen M. Sweeney  
President, New Jersey Senate

The Honorable Thomas H. Kean, Jr.  
Minority Leader, New Jersey Senate

The Honorable Craig Coughlin  
Speaker, New Jersey Assembly

The Honorable Jon M. Bramnick  
Minority Leader, New Jersey Assembly

The Honorable Carole Johnson  
Commissioner, New Jersey Department of Human Services

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

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 2018. I can also provide you with an online copy with live links to some of the information referenced.

The report has been reviewed by the Department of Children and Families and the Department of Human Services, which will issue responses in the coming days.

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. And I 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 2018**

Submitted March 11, 2019

Paul S. Aronsohn  
Ombudsman

# **Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families Annual Report for 2018**

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According to P.L. 2017, c.269 (c.30:1AA-9.1-9.3), the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families (“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.”

## **Background**

The Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families (“Office of the Ombudsman”) was [established](#) on January 8, 2018.

On April 16, 2018, Governor Phil Murphy [appointed](#) me to the position of Ombudsman.

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

- (1) Assisting individuals and families to navigate New Jersey’s system of care to get the services and supports they need and deserve;
- (2) Working with individuals and families to identify opportunities for improving the system; and
- (3) Helping to ensure 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.

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

To this end, I have been working with people throughout New Jersey’s vibrant and diverse disability community to help ensure that the “system” is both responsive and effective. That includes many of my colleagues in the Murphy Administration as well as in the State Legislature. That includes everyone from providers to educators to advocates. And that, of course, includes many individuals and their families – the unsung heroes at the center of it all, whose lives are at once challenging and inspiring.

Together, we have accomplished a great deal. Together, we have a lot more work to do.

## Summary of 2018 Services Provided

During our first year (8 ½ months), my primary focus was two-fold: (1) helping individuals/families get the services and supports they needed; and (2) working to improve the system. One was immediate. One was longer-term. Both required a great deal of outreach to people throughout our State -- people who could benefit from more services and supports as well as people who could provide them assistance and expertise.

Since this is a new office, such outreach was -- and remains -- essential.

To that end, I tried to be anywhere and everywhere. Meeting with people. Participating in events. Visiting day programs, worksites, schools, hospitals and family living rooms. Sometimes I spoke. Most often, I just tried listening.

Through this outreach, I visited with families where they live and met with government officials, advocates, providers and school officials where they work. In fact, during the first 8 ½ months of our office's operation --

- I drove more than 23,000 miles and visited about 130 towns in all 21 counties.
- I met and worked with 57 state legislators or their staffs as well as most county disability directors and a few municipal officials.
- I met and worked with more than 20 advocacy organizations and more than 60 providers.
- I participated in about 70 events.
- I visited two [Developmental Centers](#) in New Jersey and the [Kennedy Krieger Institute](#) in Maryland.
- I co-authored 3 opinion pieces concerning [Bergen County's Disability Services Division](#), the one year anniversary of the [Stephen Komminos law](#) and the Administration's commitment to [employment opportunities](#) for people with disabilities.
- And most importantly, I directly connected with more than 150 individuals/families.

The purpose of my outreach to individuals and families was to make them aware of our office and our mission to serve them. It was also to give me the opportunity to learn their stories and experiences. And when possible, it was to work through issues important to them -- issues ranging from special education for children to day programs for adults, from in-home supports to residential placements, from employment resources to transportation challenges. I worked to connect the individuals and families with the right government officials or community resources. I worked to help them resolve disagreements or find alternative solutions. I worked to help ensure that their voices were heard by all of us charged with serving them.

The purpose of my outreach to everyone else was to introduce myself and extend my hand in partnership. This allowed me to tap into the experience and expertise of people, whose commitment is real and deep and whose knowledge of disability issues is invaluable. This also led to several opportunities to collaborate on a range of issues important to specific individuals and families as well as the disability community as a whole.

Below is a discussion of some of those issues.

## **Observations & Recommendations**

New Jersey's system of care for individuals with intellectual or developmental disabilities is a tale of two systems – one good, one not good enough.

To begin, the system benefits from some really great, really dedicated people, who come to work each day determined to make a positive difference in people's lives. Some work in government. Some work in our non-profit community and in our schools, our hospitals, our provider agencies and our homes. Collectively as well as individually, they are the lifeblood of our system of care. They are passionate. They are purposeful. They are the reason that so many New Jerseyans with disabilities live safe, fulfilling lives.

We also have many really good, really necessary programs and services. That's true for children as well as adults. Some are provided through our school districts. Some are provided through departments and agencies at all levels of government. And while a straightforward state-by-state comparison is not easy to accomplish, it is clear that New Jersey devotes a significant amount of resources – money, time and people – to supporting and improving the lives of individuals with intellectual or developmental disabilities.

However, good is certainly not good enough, and there is a real need for improvement – a real need to address shortcomings and repair cracks in the system through which many individuals and families fall. In fact, fixing the system must be an imperative, because frankly, lives depend on it. This is particularly true with respect to the way government – at all levels – provides services and supports.

Fortunately, this is a view shared throughout the Murphy Administration as well as the State Legislature. Everyone seems committed to “getting it right” – to building on successes, while making necessary changes. And everyone seems to recognize that this will take a real partnership among the key players in Trenton as well as with other government officials, advocates, providers, educators, individuals and families throughout our State.

But let's be clear -- we have our work cut out for us. After years of systemic changes and resource cuts, the Murphy Administration was handed a system in considerable disrepair – one that was far from meeting the needs of many New Jersey individuals and families.

It was against this backdrop that the Office of the Ombudsman was established by the legislature “to serve as a resource to provide information and support to individuals with intellectual or developmental disabilities and their families.” And it was against this backdrop that I and my colleagues in the Administration began our work.

### **General Observations**

Again, during my first year (8 ½ months) in office, I had the opportunity to connect with numerous individuals and families. Through them, I learned so much about New Jersey's system of care – about its strengths as well as its weaknesses. I also had the opportunity to work with numerous other stakeholders, including my colleagues in the Administration and the State Legislature. With them, I have had many discussions about what needs to be done to make the system better, stronger and more responsive to the people it is supposed to serve.

Granted, I recognize that people generally reach out to the Office of the Ombudsman when there is a problem or a concern, rather than when things are going well. That is how it should be. That is why the office exists. But that means my focus has been largely on the challenges faced by individuals and families – their frustrations as well as their unmet needs – instead of the many success stories.

Based on all of this, I offer the following general observations – in no particular order.

**Need for Simplification:** New Jersey's system of services and supports is too confusing. There are so many programs with so many names and so many acronyms offered by so many offices in so many departments in so many different ways with so many differences in timelines, requirements and eligibility criteria. This is true at every level of government, but most pronounced in Trenton. And this bureaucratic complexity often leaves everyone – people who work in the system as well as those who depend on it – confused, frustrated and underserved. In fact, for many individuals and families, it seems to be the biggest barrier to services and supports.

Although much of this complexity stems from federal law and regulation, there is no question -- we need to do better. We need to simplify the system as much as we can at the State, County and Municipal levels -- making it more user-friendly and more accessible.

To that end, if possible, we should undertake a comprehensive, zero-based budgeting type review of the State's system of services and supports for people with intellectual or developmental disabilities. Starting with a figurative blank piece of paper, we should explore ways to streamline the system – making it more efficient and more effective. In so doing --

- We should think aspirationally and strategically about “what” a gold standard system of care would look like, placing a premium on common sense and customer service.
- We should include in the review all levels of New Jersey government – State, County and Municipal – underscoring the need for alignment.
- We should look across the country at other systems of care, identifying opportunities to learn from others' successes and mistakes.
- We should explore the possibility of a single-point-of-entry for the entire system – something that could reduce the complexity, the paperwork and the costs associated with providing and receiving services and supports.
- And we should make sure that individuals and families are central to this review process.

In the meantime, there are many steps that could and should be taken to simplify our communications and streamline our processes. For my part, I have begun developing a one-stop website for individuals with intellectual or developmental disabilities and their families – an easy-to-use online portal of timely and useful information on the full range of relevant issues, including housing, transportation, education, employment and emergency preparedness.

**Need for a Sense of Urgency:** Families with disability are often overwhelmed. Like other families, they need to contend with a full range of daily pressures and challenges, but unlike others, they also have to worry about and care for at least one family member – child or adult – with a disability. The toll taken on these families is often physical, emotional and financial. For many of them, the challenges are 24/7. For many of them, there are no weekends or vacations or visits to restaurants. And it is this reality that must guide and drive the efforts of every single person working on disability issues.

- That means being as responsive as possible -- making every effort to provide solutions, answer questions and return calls / emails in a timely manner.
- That means being sensitive to the stressful position families are in when they feel the need to advocate for their loved ones, while fearing retribution for doing so.
- Essentially, that means recognizing and sharing the families' sense of urgency – each day, every day.

The best way to do all of this is to ensure that government officials stay close to the individuals and families we serve. The existing forums for receiving individual/family input – such as the [Family Support Organizations](#) and the [Regional Family Support Planning Councils](#) – are very good, but they are not good enough. And while many government officials try to maintain a personal connection, the demands of their jobs too often keep them behind desks and in meetings.

We should therefore find more ways for government officials – at all levels – to see, hear and feel the challenges faced by individuals and families by visiting them in their homes, schools, hospitals and workplaces. We should also be more responsive to individuals and families – not making them wait for decisions or for policy reviews, recognizing that time is a most precious commodity for them.

**Need for More Disability Perspectives:** New Jersey is home to tens of thousands of individuals with intellectual or developmental disabilities. They live in every community. They are a part of practically every family. Yet, despite best intentions, it seems that elected officials rarely talk about them, and government policies rarely consider them. Even in an age when practically everyone’s rights are being asserted and every group’s priorities are being advanced, there often remains a deafening silence in official circles when it comes to people with intellectual or developmental disabilities and their families – an inadvertent, albeit consequential reality that often leads to conversations and decisions void of any real consideration of their rights, priorities, challenges and opportunities. That’s true in Washington. That’s true in Trenton. And that’s true in communities throughout our State. Among other things, this explains the recent discussion about banning plastic straws in public restaurants and cafes – a seemingly well-meaning environmental proposal that would inadvertently discriminate against those with physical disabilities who depend on plastic straws for nourishment or hydration.

To remedy this, we need to make people with intellectual or developmental disabilities and their families more of a priority in everything we do -- from our policy initiatives to our communications, from our hiring practices to our choice of venues for public presentations. That means bringing them into the conversation more frequently and more earnestly. That means fully considering their perspectives.

One idea that is being explored in Washington – and could be explored here in New Jersey – is the establishment of an [“Office of Disability Policy”](#) which would create a mechanism for reviewing every proposed federal policy and piece of legislation for its impact on people with disabilities and their families. Another idea would be to make more of a concerted effort to hire people with disabilities and family members, who would bring their important perspective to their government offices -- strengthening the work environment and informing all policy decisions by having a real “seat at the table”.

Regardless of what we do, we not only need to seek out and listen to more individuals and families; we also need to make sure that the perspectives sought represent the diversity of New Jersey’s disability community. From self-advocates to families with severe behavior disorders to those who do not generally have the time or wherewithal to attend government or parent group meetings – every voice must be heard.

**Need for More Choice:** It is important to remember that people with disabilities – like all other people – have their own needs, preferences, likes and dislikes. That’s true with respect to housing, employment and all other issues. Yet, too often, the services and supports provided incorrectly assume that “one size fits all”. This is particularly evident with respect to the well-intentioned, but sometimes misguided push toward “integration” into the larger community – something which is generally an important goal, but it may not be the choice of all people in all situations at all times. Yes, individuals with intellectual or developmental disabilities should have every opportunity to live, work and play alongside individuals without disabilities. But yes, too, they should also have every opportunity not to do so. Again, everyone deserves choice.

To this end, we need to make the system truly “person-centered” by building more flexibility into the system. More housing options. More employment options. And more opportunities for individuals and families to tailor service plans/budgets to best meet their needs.

**Need for Exceptions Procedures:** Similarly, we need to get away from the business of saying “no” to individuals and families in need of services and supports. Clear policies are good and important, but in the world of human services, they should serve as guidelines, rather than as final decisions. Each person is unique. Each situation is different. We need to understand that, embrace that and work that into our approach to individuals and families in need. Again, saying “no” to someone should be the absolute exception to the rule, rather than a seemingly easy default.

To that end, we should explore the establishment of formal, transparent “exceptions” procedures in each of our departments and divisions – procedures that would be activated as needed and that would give due consideration to requests that fall outside of our official policies. They should be time-sensitive. They should be “person-centered”. They should be designed to get to “yes” whenever possible and reasonable. We need to move away from a “system-centered” approach, whereby the imperatives of the system – budgets, current policies, past practices, fear of precedents, etc. – drive decision-making, and instead, we need to focus more on the imperatives of individuals and their families – their needs and their rights.

Granted, we can’t do everything for everyone, but we should do everything humanly possible.

**Need for More Intergovernmental Collaboration:** Too many individuals and families do not get the services and supports they need, because they do not know “what” is available or “how” to access it. (As one parent put it, “They don’t know what they don’t know.”) For some, the complexity of the system is the problem. For some, the overwhelming demands of daily life leave them neither the time nor the capacity to effectively seek out needed resources.

Regardless, one way to address this knowledge and service gap would be to strengthen the relationship between officials at various levels of government – State, County and Municipal -- through greater collaboration and better alignment of missions and resources. This would inevitably lead to a system that is clearer, more consistent and more accessible to the people who need it.

To this end, County disability offices seem uniquely positioned to play a central role. They not only serve as a “point of entry” into the system for many individuals and families; they also serve as a “go to” place for Municipal officials. As such, County disability offices could be an invaluable partner for State officials in our efforts to make information more readily available and to connect us more effectively with the people we serve.

In Bergen County, for example, an initiative to establish “access for all” committees in each of the municipalities has helped bridge the knowledge and service gap by creating meaningful linkages between the two levels of government – linkages that help make County and State resources more available to the individuals and families who need them. By developing and leveraging such platforms, we could establish lines of communication across the State that are direct, interactive and results-oriented.

**Need for More Transparency:** Many families speak of the need for greater transparency in various aspects of the system. With respect to government, the focus is often on the need for more transparency regarding policy-making, service/support denials and investigations of abuse and neglect. With respect to providers, the focus is often on the need for more transparency regarding the expenditure of “[Individual Budgets](#)” -- the spending of public money -- as well as the expenditure of “[Individual Contributions](#)” -- the spending of personal money, which is used to cover the costs of living expenses, such as food and utilities.



We should explore ways to increase transparency across the board, particularly in the areas identified above: policies, denials, investigations, the expenditure of public funds and the expenditure of personal funds. Doing so would certainly lead to better policies and better accountability.

**Need for More Innovation:** Throughout the larger disability community, providers and advocates are pursuing innovative approaches to serving those with intellectual or developmental disabilities and their families. Some are using cameras in group homes and vehicles to enhance the safety and security of residents, while providing protections for staff members. Some are exploring the use of “telemedicine” – a potentially easy-to-use, cost effective way to bring medical expertise to residential settings in a timely manner. Some are providing “coordinated care” – a practical way to make health care more accessible to those who need it by effectively co-locating practices. (One organization is even promoting “[medical-legal partnerships](#)” which embed attorneys into coordinated care discussions of health and social needs.) These are just a few examples of the important, promising work being done by people and organizations throughout our State.

We should embrace and support such innovation. Through new policies and new pilot programs, we should take our service to those with disabilities to the next level by thinking outside-the-box and by supporting those who are already doing so. Our system of care – like any system anywhere – can always benefit from new thinking and new approaches. To that end, we should better utilize cameras, explore telemedicine and support coordinated care models. And we should seek other such innovative opportunities to improve the lives of the individuals and families we serve.

**Need for Better Communication:** Cutting across these observations is the need for better communications.

- Regarding simplification, we need to communicate with more clarity and more consistency.
- Regarding a sense of urgency, we need to do a better job answering calls and emails as well as engaging in more direct, personal contact with the people we serve.
- Regarding a disability perspective, we need to take greater care with respect to both the substance and the process of our communications – what we say and how we say it – and create more opportunities for more voices to be heard.
- Regarding choice, we need to use multiple platforms for communicating, recognizing that people get their information in different forms and in different languages.
- Regarding intergovernmental collaboration, we need to facilitate better information sharing between different levels of government, which would inevitably lead to better information flow to individuals and families.
- Regarding transparency, we need to increase the quantity and quality of our communications – making sure that individuals, families and the public more generally have real insight into the development and execution of government policies and practices.
- Regarding innovation, we need to leverage the latest in communication technology, including telemedicine.

## **Specific Observations**

In addition to these systemic observations, below are several more specific issues that have been brought to our attention. They are listed in alphabetical order.

Important Note: The absence of an issue / situation from my list below does not – in any way – speak to its relative importance or its possible need for attention. The list below represents many of the issues/situations repeatedly brought to my attention over the past year.

**Aging:** Generally speaking, people with intellectual or developmental disabilities are living longer – a wonderful, positive development that carries with it both opportunities as well as challenges. Among the latter is the need to think differently about the services and supports available to them and their families. That includes residential options with bedrooms on the first floor. That includes access to medical care that is more readily available and attuned to the early onset of everything from dementia to vision and hearing loss. And that includes a host of other accommodations, including day programs that are tailored to the needs and preferences of older individuals.

This is increasingly a topic of conversation in government offices as well as in the non-profit and provider communities. In fact, last year, one organization hosted an important [two-day conference](#) about “aging in place” for those with intellectual or developmental disabilities. Another has [provided training](#). Going forward, we should encourage such conversations and make sure that this topic is central to the thinking and planning of government -- at all levels -- as well as the provider community. We have both an obligation and an opportunity.

**Deaf / Hearing Loss:** It is estimated that [approximately 850,000 New Jerseyans](#) have some form of hearing loss, ranging from those born deaf to those who experience hearing loss later in life. This includes many individuals with intellectual or developmental disabilities as well as many of their caregivers. Yet, it seems that much of our official communications – from website videos and webinars to public meetings featuring government officials – fail to provide proper accommodations.

Going forward, we should work to meet the needs of those who are deaf or have hearing loss through better use of interpreters and appropriate technology. As one advocate explained, “Captioning is for those with hearing loss like a ramp is for those with a wheelchair. It provides access.”

**Department of Children & Families** – Since 2013, the Department of Children and Families (DCF) has been responsible for providing services and supports to children with intellectual or developmental disabilities. Through its [Children's System of Care](#) (CSOC), DCF provides a range of vital services, including in-home supports, group home placement, respite, and summer camp. However, families have often complained that DCF – although completely well-intentioned -- seems to approach their children’s situation through a mental health prism and with a focus on “fixing” behavioral issues, rather than with an appreciation for the life-span nature of the disability. Some DCF officials have acknowledged this, noting the Department’s traditional focus on emotional and behavioral health; others have pointed to the system’s contracted partners – the Case Management Organizations (CMO) and PerformCare – for sometimes taking short-term approaches to families’ long-term situations.

Real or perceived, this apparent “cultural” predisposition should be addressed. It is absolutely essential for everyone involved to understand the very real differences between intellectual or developmental disabilities on the one hand and mental health and behavioral issues on the other. And it is absolutely essential for parents to believe that their children’s welfare is being protected and promoted by people who fully understand the nature of their disabilities.

Recognizing all of this, DCF leadership recently established the Office of Family Voice to connect parents more closely with the Department and has taken additional important steps. Moreover, my almost daily contacts with the Department have demonstrated to me – in very real, very meaningful ways – that CSOC is staffed by professionals who are truly mission-focused and person-centered.

**Department of Human Services:** The [Department of Human Services](#) (DHS) is not only home to the [Division of Developmental Disabilities](#) (DDD) – which provides services and supports to adults aged 21 and over – but also a host of other divisions and offices important to individuals with intellectual and developmental disabilities. More than most departments, DHS is driven by a human imperative to assist people living challenging lives – a responsibility taken very seriously by professionals throughout the organization.

Yet, although many people recognize the enormous demands placed on the Department, many have also criticized it for poor customer service and a lack of transparency. Specifically, they have expressed frustration over unreturned calls / emails, inconsistent responses and denied requests with no justification.

To be sure, this criticism is not new, is not isolated to DHS alone and does not reflect the many people who have had very positive experiences with the Department – experiences that provided them and their families with much needed services and supports. Again, people generally reach out to the Office of the Ombudsman when there is a problem or a concern, not when things are going well.

Nonetheless, the criticism needs to be taken seriously. Perceptions matter. DHS is in the people business and is responsible for working through very personal, very time-sensitive, often very difficult situations. This requires an exceptional level of responsiveness, and it requires an extraordinary amount of trust – real and perceived.

Importantly, the people I have worked with in the Department fully understand this and continuously strive to meet these high standards. Importantly, too, the Department’s leadership recently created the position of “Family Outreach” liaison in DDD to work directly with families.

**Direct Support Professionals:** For many people with disabilities, direct support professionals (DSP) play an indispensable role in their lives – one that is very personal, very physical and generally very demanding. From hygiene to transportation to home management, the support they provide often makes it possible for people with disabilities to lead safe, independent, fulfilling lives. Yet, most DSPs are underpaid, undertrained and underappreciated. In fact, the average salary nationally is about \$10.72 per hour, less than what many people earn doing far less difficult, far less sensitive jobs. This has led to a real [national](#) crisis with nearly 50% of DSPs requiring some type of means-tested government assistance – including Medicaid, food stamps, rental subsidies -- to compensate for low salaries and a near 50% annual turnover rate, which impacts the quality of care provided to those who depend on them.

Going forward, in New Jersey, we need to increase the compensation and training provided to DSPs, while making sure that we hold them to high standards. Last year’s increase in State funding for DSPs was a significant first step, but we need to do more. Some have suggested the need to professionalize the DSP workforce, creating a career path that includes more appropriate compensation packages, training and standards. I have been part of a small cross-sectional group of the disability community that has begun informally exploring this approach. We should encourage this effort as well any other initiative seeking to mitigate the crisis, which will only grow more acute as the need for DSPs continues to increase alongside an aging population.

**Education:** While DCF plays an important role in the lives of many families with children (under age 21), school districts usually play an even more important, more far-reaching role – one that is rooted in the federal [Individuals with Disabilities Education Act](#) (IDEA) as well as corresponding New Jersey law. Many children receive their education and related services “in-district” through their local schools. Others rely on “out-of-district” schools – public or private – in other parts of the State or possibly in another State, depending on the residential needs of the student. Regardless of the situation, it is critical for the family and their local school district to work together – in partnership – for the benefit of the child. Unfortunately, however, that is not always the case, leaving parents and local school administrations too often at odds and too often in court – a reality that places an even greater burden on already over-burdened families.

Clearly, the relationship between local school districts and families should not be contentious. Clearly, too, local school districts should do everything possible to meet their obligations – legal as well as moral – and families should be aware of [their rights](#) and how best to exercise them. Our goal should be to create an environment in which educators and parents are able to focus exclusively on the needs and rights of the students, rather than having to worry about rationing limited resources.

Over the past year, I have had the opportunity to participate in meetings with Department of Education (DOE) leadership and have been really impressed with their commitment to this goal and to thoughtfully and effectively addressing the underlying tensions.

**Employment:** N.J. is an “[Employment First](#)” State that recognizes everyone's ability to work in a competitive, community-based environment, and N.J.'s [Department of Labor and Workforce Development](#) provides important supports to help make that a reality – a mission embodied by the Department's professionals in Trenton as well as those based throughout the State. Yet, too many individuals with intellectual or developmental disabilities are either unemployed or underemployed. Notwithstanding the skills and talent they are able to bring to a job, the challenges they face are real. Cultural barriers often prevent employers from recruiting them or providing workplaces accessible to them. Systemic complexities often prevent them from accessing – or even knowing about -- resources available through State and County government. And transportation challenges often prevent them from getting and keeping their jobs.

Without question, we need to address these cultural, systemic and transportation challenges. Specifically, we need to do more to educate employers about the benefits of hiring people with intellectual or developmental disabilities as well as the ease with which they can make accommodations in their workplaces. We need to simplify the employment-related services and supports provided by government, making them far more understandable and more readily accessible to those who need them. And we need to double-down on our efforts to improve the transportation options available (see Transportation below).

The reason for doing all of this is simple: Making meaningful employment a reality for people with disabilities is not just the right thing to do; it is also the smart thing to do. It's good for the individuals. It's good for the workplaces. It's good for our overall economy.

**Fee-For-Service System:** DHS is still transitioning into the [Medicaid Fee-for-Service](#) (FFS) model, which was adopted a few years ago to increase the system's resources, efficiency and effectiveness. Not surprisingly, however, this transition has posed challenges for many of those who provide services and supports as well as those who depend on them. For some providers, it has meant more work, but less funding. For some individuals and families, it has meant more complication, but less services and less flexibility.

Recognizing that any such major change would inevitably cause complications, the State Legislature adopted [legislation](#) in May 2017 to establish an independent board to monitor, evaluate and make recommendations about the transition. In December, Governor Murphy appointed members to that board, who held their first meeting last month.

This is a very positive development, because the Independent Developmental Disability Fee-for-Service Transition Oversight Board provides the first real opportunity for us to have an informed, public discussion about the impact that the FFS approach is having on the delivery of services and supports. To that end, the Board should (1) make it a priority to engage as many individuals and families in the discussion; and (2) conduct a full financial analysis of all providers, highlighting and explaining the impact on their bottom lines -- good and bad -- as well as on their provision of services. I also suggest that the Board pay particular attention to transportation rates -- the FFS issue most frequently brought to my attention -- as well as the need for a fairer way to determine providers' catchment areas. In this regard, consideration should be given to the additional costs associated with transporting those with severe behaviors or those who require wheelchair accessible vehicles.

**Fiscal Intermediary:** Many families complain about [Public Partnerships, LLC \(PPL\)](#), which was contracted in 2017 to serve as the fiscal intermediary for those seeking to “self-direct” their services. The complaints have focused on poor customer service as well as poor overall performance – all of which have led to a range of bad outcomes, including families spending an inordinate amount of time calling and emailing and submitting and re-submitting paperwork; self-directed employees not getting paid the correct salary or not getting paid on time; and as a result, individuals not always getting the services they need. Several people have also expressed concerns regarding the fact that the current fiscal intermediary arrangement has led to two seemingly unintended consequences: an undue legal liability on families and a loss of benefits (including healthcare coverage) for self-directed employees.

Taken together, many of these complaints and concerns were reflected in a request last summer from [Disability Rights New Jersey](#) for the State Comptroller to investigate the situation.

To be sure, during the second half of the year, there seemed to be a decrease in the number of complaints, but I do not know if that is because the process is working better and/or because families are reporting less often, due to frustration and resignation. Regardless, DHS and PPL are well aware of the complaints and problems and have been working closely for several months to address them.

Going forward, DHS and PPL should continue these efforts and should more regularly and clearly publicly explain the steps that are being taken to improve the product and the process. Perhaps one way to do this would be for PPL to hold monthly webinars for families in which company officials could explain their efforts and answer questions. DHS should also consider a new fiscal intermediary arrangement -- one that offers families more choice and flexibility, and one that addresses the legal liability and benefits concerns.

**Guardianship:** [Guardianship](#) is certainly one of the most important, most consequential issues, and decisions regarding it should never be taken lightly or without full information about its implications as well as other options available to individuals and their families. Although full guardianship is sometimes necessary, families should always explore other options that could allow the individual to remain as independent as possible. From Supported Decision-Making to general Guardianship, there is a full spectrum of possibilities that should be considered. Yet, many families struggle to understand this issue and many struggle with the resources (namely time and money) associated with it.

We need to find a way to make this issue more accessible to individuals with intellectual or developmental disabilities and their families. That means more education about the range of options available. That means making the process less expensive and less cumbersome. Again, this is one of the most important issues affecting people with intellectual or developmental disabilities, and we need to get it right.

**Health Care:** Accessing health care services – physical, mental, behavioral and dental -- is a serious challenge for many individuals with intellectual or developmental disabilities. It seems that too few health professionals are trained to work with them. Too few are willing to put in the extra time it often takes to provide care for them. And too few accept Medicaid or even (with respect to psychiatrists) private insurance.

Clearly, this is neither right nor sustainable. Everyone needs and deserves access to quality health care.

Fortunately, there are important efforts underway to promote such access, including the “coordinated care” approach previously referenced. But we also need more fundamental, systemic approaches that go to the heart of the problem by changing both expectations and responsibilities. To this end, one idea worth exploring would be to ensure that all health professionals – present and future – receive training with respect to individuals with intellectual or developmental disabilities, perhaps making it part of their curriculum in New Jersey medical and dental schools.

**Housing:** For all parents, the decision to place their child in an out-of-home residence is painfully difficult. Parents of young children do so with only the greatest reluctance and only after exhausting any and all in-home resources. Conversely, parents of adult children do so with a sense of urgency, knowing that – among other things – they must do everything possible to prepare for the day when they are not around to provide for their loved ones. In all situations, the pain of the decision is compounded by the uncertainty about the availability of a safe, secure and appropriate residential setting.

Recognizing this, DHS and DCF have both begun taking steps to increase the availability of housing for individuals with intellectual or developmental disabilities. In so doing, they should place their emphasis on growing the number, location and type of residential possibilities. Here, again, efforts should be driven by the fact that one size does not fit all – that we need not just more group homes but also more campus, farmstead and apartment community options – as well as by the fact that greater geographical diversity will make it more possible for families to live closer together.

**MLTSS:** NJ's [Managed Long Term Services and Supports](#) (MLTSS) is a Medicaid funded program that provides comprehensive services and supports through 5 managed care organizations. Although many people associate the program with seniors who need a “nursing home level of care”, the program is also available to children who require skilled nursing and/or a life supporting/sustaining medical device. I have had limited experience with MLTSS, but it is clear that this program – and most importantly, the people who depend on it – suffer from a lack of skilled nurses. In fact, I have repeatedly heard from parents who are doing everything possible to care for their children at home, but whose challenge is made more difficult by a seemingly constant turnover in nurses as well as actual gaps in the hours of coverage provided.

Somehow, we need to fix this problem. If we are serious about providing parents with the resources needed to keep their children at home, we need to take steps to ensure that skilled nurses are available to them.

**NJCAT:** Many families complain about the [N.J. Comprehensive Assessment Tool \(NJCAT\)](#) used by DDD to help determine an individual's level of need for supports and services which, in turn, determines the DDD budget assigned to an individual. Some have claimed that the NJCAT is biased. Some of have suggested that the questions asked and the choices offered are too limited, thus preventing an accurate picture from being drawn. And many have complained that determinations made from it are subjective, depending on “who” fills out the questionnaire and “who” evaluates its results.

Taken together, it is clear that the NJCAT (substance as well as process) needs to be fixed – a point fully recognized by DDD officials, who initiated a review last year.

Going forward, my hope is that the review includes individuals and family members who can inform this initiative and that DDD tells the public soonest about its estimated timeline for offering a new NJCAT and any changes to the process regarding assessments and reassessments. My hope, too, is that among the outcomes of the review would be a more standardized process – one that makes it possible (if not advisable) for DDD to be directly involved in the administration of the NJCAT with all individuals and families.

**Severe Behavior Disorders:** Many NJ families include someone with a severe behavior disorder -- someone with a dual-diagnosis of an intellectual or developmental disability as well as a co-occurring mental health illness. Some are self-injurious. Some are aggressive to others. Many, if not all, suffer from a dearth of services and supports, because generally speaking, New Jersey lacks the capacity to properly provide for them. In fact, too often we hear stories of people with a severe behavior disorders unable to find a school or day program capable of serving them. And too often we hear stories of them having a behavioral crisis and ending up in situations – or rather, real life vicious cycles -- that only aggravate their condition: the police are called; an ambulance takes the person to an emergency room; the doctors are unable to treat the person, who remains in the emergency department for anywhere between 3 hours and 3 weeks before being discharged on a mix of psychotropic medicines.

We need to build capacity – crisis response, stabilization, hospitals, schools, day programs and personal assistants – that can effectively provide services and supports to those with severe behavior disorders. To that end, we should revisit the 2008 report of the [Department of Human Services Dual-Diagnosis Task Force](#), taking a fresh look at its recommendations. We should also give consideration to a recent proposal for a system of care for adults with several behavior disorders – a proposal based on the [Kennedy Krieger Institute's Neurobehavioral Unit](#) in Maryland and which includes a full spectrum of services and supports, including a mobile response capability and a behavioral step-down home.

Granted, this would be a huge undertaking, but with the [nation's highest autism rate](#) – 1 in 34 children -- and with many of them suffering with severe behaviors, we need to think big and be willing to make the necessary investments of time and money. In this context, Governor Murphy's FY2020 proposal for new funding to address this issue is a very welcome, very significant step forward.

That said, this is not just about taking the long view; it's also about dealing with a crisis that currently exists. To that end, we should also pursue specific measures to immediately mitigate the situations faced by people and families with severe behaviors. One parent suggested that all hospital emergency departments should include a "quiet" room that would provide a relatively calm space for those with behavioral challenges awaiting medical care. Another idea floated – and apparently already being pursued by DDD – is to use some of the excess capacity and resources in the Developmental Centers to provide temporary, short-term stabilization for those having a severe behavioral crisis.

**Stephen Komninos Law:** In October 2017, the [Stephen Komninos law](#) was enacted. In May 2018, it went into effect. The landmark law established policies and procedures for protecting those with intellectual or developmental disabilities. Specifically, it put in place several important measures for helping to prevent abuse and neglect in residential and day programs – measures such as unannounced DHS site visits to such programs, drug testing of direct care staff and strict notification requirements to parents/guardians as well as to DHS.

Implementation of this law requires a great deal of resources -- namely time, personnel and money – and by all indications, it is off to a strong start. DHS and the provider community have done a really good job thus far. However, it is not clear why this law only applies to adult (aged 21 and over) residential and community programs, and so we should explore the expansion of this law to children's group homes and programs.

**Support Coordinators:** Support Coordinators play an absolutely vital role in New Jersey's system of care. They serve as a lifeline to the community for adults with intellectual or developmental disabilities and their families – helping to develop the Individual Service Plan, locating the appropriate service providers and serving as an overall resource for information and assistance. They also serve as the primary intermediary between individuals / families and DHS. Unfortunately, however, too many of them are underpaid, undertrained, but overworked.

My hope is that the Independent Developmental Disability Fee-for-Service Transition Oversight Board will include a review of Support Coordination compensation and that DHS will revisit the responsibilities and training associated with this critical component of the system.

**Transitions:** Too many families face the proverbial "cliff" as their children transition from childhood to adulthood. Up to age 21, children with intellectual or developmental disabilities receive most of their services and supports in the form of an entitlement. From that point forward, however, nothing is guaranteed, and adults need to seek and qualify for their services and supports. Yet, for whatever reason, too many families are not aware of the steps that need to be taken to prepare their children for the challenges and opportunities that lay ahead. We need to fix this. We need to make the transition from childhood to adulthood as seamless as possible.

Serious conversations within the Administration have already begun on this important issue – conversations that will hopefully lead to a more standardized process that makes the transition seamless for every special needs student in every school district. Going forward, we should formalize these conversations and make sure that all of the right people – including families – are at the table. And among the possible outcomes, consideration should be given to the development of an easy-to-use, one-stop website repository for timely transition information for families.

**Transportation:** From a quality of life perspective, transportation poses one of the greatest challenges and greatest opportunities. For individuals with intellectual or developmental disabilities, the shortage of accessible and affordable transportation makes their involvement in the community – through employment or day programs -- difficult, if not impossible. In fact, the challenge often has a devastating emotional, physical and financial impact on them and their families.

To be sure, there are valuable resources available to people with disabilities – most notably, NJ Transit’s [Access Link](#), county-provided [Community Transportation](#) services and [NJTIP@Rutgers](#) – but despite best efforts, they clearly are not enough. Not even close.

From my experience, the people running our transportation organizations seem fully committed to the people they serve. They “get it” and work hard to fulfill their important missions. But New Jersey is a very challenging transportation State, and we need to think big and think differently. We need to convene regional conversations that bring together the best transportation minds to work through the challenges and the opportunities – conversations that would also benefit from a zero-based, blank paper approach.

Everything should be on the table.

## **Recommendations**

Without question, none of this easy. Intellectual and developmental disabilities pose very real, very complex challenges for individuals and their families as well as for those of us who seek to provide them with services and supports.

Clearly, from a government perspective, one of the biggest challenges we face is that there are so many issues to address, but so few hours in the day and so few available dollars in the budget. Each of the observations – general as well as specific – speaks to an issue that is important to many individuals and families. And some of the observations have resource implications, thus making it impossible to do all that needs to be done in the short-term.

This makes it necessary to prioritize. This makes it necessary to be realistic about what we can achieve and when we can achieve it.

To that end, I have three recommendations:

1. The Administration should establish an interdepartmental group to review the observations and develop a plan of action. Under the auspices of the Governor’s office, the group should prioritize the steps to be taken to improve the system of care, differentiating between immediate and longer-term opportunities. The group should balance the Administration’s firm commitment to make necessary changes with very real budget imperatives, recognizing that some observations could require additional funding, some could be budget-neutral and some – such as, “the need for simplification” – could actually lead to budget savings.



2. The Administration should convene regular meetings of key Administration officials to address cross-cutting issues – those that require collaboration between and within Departments. This would include some of the issues contained in my general observations as well as those contained in more specific observations, such as with respect to “aging” and “transitions”.
3. The Administration should develop new ways for engaging individuals and families. Again, the existing forums are good, but not good enough. We need to reach more individuals and families, tapping further into the diversity of our disability community. And we need to give them a more permanent, more meaningful seat at the table.

### **Acknowledgements**

Throughout the year, the work of our office benefitted from the partnership and leadership of so many people throughout N.J.’s disability community, including --

- Many of my colleagues across the Murphy Administration, particularly in the Governor’s front office and in the Departments of Children & Families, Human Services and Treasury with whom I worked on a regular – sometimes daily – basis.
- Members of the State Legislature and their staffs, particularly in the offices of Senator Sweeney, Senator Kean, Senator Bateman, Senator Lagana, Senator Pennacchio, Senator Vitale as well as Assembly Speaker Coughlin, Assemblywoman Downey and Assemblywoman Vainieri Huttie.
- Many organizations and providers across the state, particularly the N.J. Council on Developmental Disabilities, Disability Rights New Jersey, the Arc of New Jersey, the N.J. Association of Community Providers, the Alliance for the Betterment of Citizens with Disabilities and Autism N.J.
- And individuals and families from communities across our State with whom I had the opportunity to work – extraordinary people living extraordinary lives who inspire us in profoundly important ways.