State of New Jersey
Office of the Ombudsman For Individuals with Intellectual
or Developmental Disabilities and Their Families
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Philip D. Murphy
Governor

Sheila Y. Oliver
Lt. Governor

Paul S. Aronsohn
Ombudsman

July 8, 2020

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 the 2019 calendar year. Due to the COVID-19 pandemic, 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,

P. Sa

Paul S. Aronsohn
Ombudsman

Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families
Annual Report for 2019

Submitted July 8, 2020

Paul S. Aronsohn
Ombudsman

This report is dedicated to the individuals and families with whom we have had the opportunity to work – extraordinary people living extraordinary lives who inspire us in profoundly important ways.

This report is also dedicated to my sister, Patti, who passed from this earth 3 years ago at the age of 54. Patti lived her life with disabilities, but also with enormous strength, courage, grace and beauty. I learned so much from Patti as well as our mother, Margot, who was her loving caregiver.

Preface

A draft of this report was submitted for internal review in February 2020. The original intent was to submit the final report and release it to the public on March 11 – the same date on which this annual report was submitted and released last year.

Due to the outbreak and spread of the coronavirus, however, the report's review, submission and release were delayed.

Clearly, there are many lessons to be learned – good, bad and otherwise – from the experience of the pandemic, and much attention will be paid to this over the coming months, if not years. That is true with respect to our national experience as well as our statewide and local experiences. That is also true with respect to our particular experience within New Jersey's disability community.

However, as stipulated in the law creating the Ombudsman office, the focus of this report is on the work done and issues raised during the previous year. **We therefore have not revised this report to address the State's response to the COVID-19 pandemic, but rather, we plan to devote much attention to it in our 2020 report next year.**

In the meantime, our office – working with our colleagues throughout State government and the larger disability community – will strive to ensure that individuals with intellectual or developmental disabilities and their families play a central role in the reviews, discussions and lessons-learned exercises that will take place with respect to the pandemic. We will work to ensure that they have a seat at the table and that – going forward -- their insights and experiences inform our State's emergency management planning, preparedness and response.

Now, more than ever, their voices need to be heard.

P. Sa

Paul S. Aronsohn
Ombudsman
July 8, 2020

2019 Annual Report
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Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families
2019 Annual Report

Introduction

This is my second annual report. Similar to last year, I view it as an opportunity to discuss issues of importance to individuals with intellectual or developmental disabilities and their families. That means not only including my summary and recommendations, per the enabling legislation cited below. It also means giving voice to the wisdom, insights and experiences shared with me by the individuals, families and other stakeholders who comprise New Jersey's large, vibrant and diverse disability community.

Due to its scope and purpose, the Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families ("the Office") is most often contacted by people who don't know where else to turn or who feel that the system is not serving them or their loved one. They may have a question. They may have a concern. They reach out to us, because they want assistance.

Clearly, that is how it should be. That is why the Office exists. But that means our focus is largely on the challenges faced by individuals and families – their frustrations as well as their unmet needs – instead of the many success stories.

That said, I have tried to present information in this report in a balanced way, noting both strengths and weaknesses of the system. There is no intent to finger-point or lay blame. Rather, the objective is 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.

To that end, this report speaks to challenges as well as opportunities. It underscores the need for continuous improvement throughout our system of care -- building on that which is working, while fixing that which is not. And hopefully, it provides a platform for moving the conversation forward and for making meaningful, much-needed changes.

Beyond the addressees on the cover letter, this report has been written for a much larger audience – for anyone even remotely interested in disability issues. That includes officials at all levels of government. That includes advocates, providers, journalists and other community leaders throughout our State. That includes the individuals and families at the center of our work as well as their neighbors, classmates, co-workers and friends.

Simply stated, everyone should know these issues. Everyone should understand these challenges and opportunities. Because everyone either has an intellectual or developmental disability or probably knows someone who does.

Background

The Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families was established by the 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 Christie in January 2018, the Office was made operational when Governor Murphy appointed me a few months later and has been kept busy by our Administration's determination – across departments and agencies -- to move the needle on the full range of issues affecting people with disabilities.

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.

The work of the Office is 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 that end, the work of the Office is guided by the Murphy Administration's effort to make New Jersey a stronger, fairer place for <u>everyone</u> to live, work and raise a family.

Since the Office is relatively new, we have taken great care to develop it in a way that would provide a "value added" to the work of our colleagues throughout N.J.'s system of care and to the lives of the people at the center of it all -- the thousands of individuals with intellectual or developmental disabilities and their families. Sometimes as an advisor. Sometimes as an advocate. Always as a partner and a resource, trying to serve as a conduit for 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 -- I have made it a point to spend most of my time visiting people where they live, learn, work and socialize.

Professionally, this has been a tremendous opportunity. Personally, as someone who also comes from a family with disability, this has been a blessing. Through my work, I 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 2019 Services Provided

Throughout the year, the focus of our efforts was threefold: (1) helping individuals and families access the services and supports they need and deserve, often serving as a troubleshooter; (2) working to improve New Jersey's system of care; and (3) elevating the voices of individuals and families, helping to ensure that they have a seat at the policy-making table and are in a position to inform – if not drive -- policy conversations.

This required a great many one-on-one conversations with individuals and families – conversations that took place through emails, phone calls and in-person meetings. It also required a great deal of work with government officials (State, County and Municipal), advocates and providers.

Through our first 20-plus months of operation, including throughout 2019, I was the only person working in the Office, although the Department of Treasury provided some much-needed administrative support. On February 4, 2020, we hired an Associate Director, Christine Bakter.

Taken together, in 2019, I drove more than 36,000 miles and visited about 170 towns in all 21 counties.

My reason for doing so was threefold:

1. It made it easier for individuals and families to meet with me.

2. It gave me an opportunity to meet with people where they live, learn, work, and socialize – providing me with an important perspective into their individual situations.

3. It gave me an opportunity to meet with the professionals who serve on the frontlines of our system of care – the professionals who staff our schools, day programs, workplaces, group homes and other congregate settings.

Ombudsman Office by the Numbers
(April 2018 – December 2019)

Drove about 60,000 miles
Visited about 220 municipalities
Participated in about 240 events.
Worked with 65 State Legislators/Staff
Worked with several hundred individuals & families

Moreover, I tried to accept every invitation to visit with people and to participate in various meetings and events throughout the entire State, because such occasions provided me with an opportunity to listen and learn, if not also to make a difference in some way. They also often gave me the opportunity to talk about our work as well as the work being done in other offices in other parts of the government.

Accordingly, throughout 2019 --

- I worked with colleagues across the State's Executive and Legislative branches, including in the Departments of Children and Families, Education, Health, Human Services, Justice, Labor, State and Transportation.

- I participated in multiple meetings of the N.J. Council on Developmental Disabilities and spoke regularly with its Executive Director.

- I participated in multiple meetings of the Family Advisory Council as well as meetings of the individual Regional Family Support Planning Councils.

- I participated in multiple meetings of the N.J. Statewide Independent Living Council as well as N.J.’s Centers for Independent Living.

- I participated in several meetings of the Independent Developmental Disabilities Fee for Service Transition Oversight Board, collectively as well as with individual members and legislators.

- I met regularly with Disability Rights New Jersey (DRNJ) and communicated regularly with its Executive Director.

- I attended multiple meetings of the New Jersey Association of County Disability Services and worked closely with several of its members.

- I attended multiple training sessions and presentations organized by The Boggs Center on Developmental Disabilities.

- I attended several school transition events, including the Department of Education’s "Dare to Dream" leadership conferences.

- I participated in about 170 events, including the opening ceremony of the N.J. Special Olympics summer games, the Ms. Wheelchair New Jersey 2020 ceremony, and the Governor’s Conference on Housing and Economic Development.

- I participated in multiple events and meetings in recognition of the 100th anniversary of Vocational Rehabilitation Services in New Jersey.

- I visited 2 out-of-state residential settings that are home to New Jerseyans – Woods Services in Langhorne, PA and Triform Camphill Community in Hudson, NY.

- I participated in family meetings at Trenton Psychiatric Hospital, the Hunterdon Developmental Center in Clinton and Children's Specialized Hospital in Toms River.

- I participated in several discussions with self-advocates, including quarterly meetings with the New American Movement for People with Disabilities and various meetings and events with The New Jersey Self-Advocacy Project.

- I visited several group homes as well as the State’s one privately run intermediate care facility.

- I participated in 2 emergency management training exercises, which included people with disabilities -- one organized by the Port Authority of New York and New Jersey and one organized by N.J. Transit.

- I authored a few opinion pieces, including one "giving thanks" to New Jersey’s disability community.

- I spoke with journalists on a range of topics, including the challenges and opportunities of aging individuals, the need to provide for those with severe challenging behaviors and the work of the Ombudsman office.

- And very importantly, I had about 200 one-on-one meetings with individuals and families – in addition to many group meetings, email exchanges and phone calls.

Observations & Recommendations

In last year's report, I expressed my belief that 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. And now – having met hundreds more families and worked with hundreds more advocates, providers and government officials – I am fully convinced of that fact.

On the one hand, there are many good stories to be told. Students having solid, enriching educational experiences. Adults working in meaningful jobs or participating in dynamic day programs. Individuals – young and old -- living with the right balance of supports and independence.

Behind these good stories are good people – professionals who staff our system of care and whose lives are largely defined by their service to others. Some work in government. Some work in schools, provider agencies and other businesses and organizations throughout our State. As I explained in my last report, collectively as well as individually, these professionals 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.

On the other hand, there are many other stories to be told, too – heartbreaking stories filled with anxiety and frustration as well as anguish and loss. Children denied desperately needed supports; some even effectively shut out of the classroom. Adults confined to substandard living experiences. Families traumatized and seemingly left to fend for themselves.

For them, the system is not working. It's too rigid. It's too uncaring. And no amount of talk about "school budgets" or "waiting lists" or "Medicaid rules" helps to mitigate their challenging situations. No denial – however rationalized -- makes their situation any less devastating.

My email folders are full of messages from individuals and families falling through the cracks, who share experiences with unanswered calls, unexplainable denials and unimaginable hardships. My voicemail is often full of cries for help and expressions of despair. And the conversations I have with individuals and families – often around their kitchen tables – tell the stories of people desperately, urgently seeking a better life for themselves or their loved ones.

Granted, none of this easy. Providing individuals and families with the necessary services and supports is expensive, time consuming and challenging in myriad ways. And after years of systemic changes and resource cuts, the Murphy Administration had to hit the ground running – delivering services and supports, while revisiting old polices and exploring new ideas.

Regardless, we know that it is our duty – as stewards of the State's commitment to New Jerseyans with disabilities – to do everything in our power to "get it right" and to provide these individuals and their families with the services and supports they need and deserve. That's our charge. That's our responsibility.

Without exaggeration, lives are at stake, and it is incumbent on all of us to work together to make the system more accessible and more responsive.

This is a point embraced by many of my colleagues throughout the Murphy Administration, the State Legislature as well as the larger disability community. It is at the center of many of our conversations, and it is the driving force behind much of our work.

But going forward, we need to do more – much more. We need to take these conversations and this work to the next level – stepping up our game in ways that make a meaningful difference in the lives of all New Jerseyans with intellectual or developmental disabilities and their families.

In that spirit, below is a discussion of observations from last year. Some are general. Some are specific. All are rooted in the experiences of the people we serve.

General Observations

In last year's report, I highlighted several systemic observations. Below, I review and add to them.

Need for Simplification

In last year's report, I identified the system's complexity as one of the biggest barriers for many individuals and families trying to access and navigate New Jersey's system of care. I stand by that point. The system is still 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.

To fix this, I suggested a full-scale review of the entire N.J. system of care for individuals with intellectual or developmental disabilities. The idea would be to explore ways to streamline the system to deliver better outcomes for individuals and families, while delivering potential resource savings for all of us.

Starting with a figurative blank piece of paper, those involved in such a review would be driven by three key questions:

- Who are we trying to serve?
- What are we trying to do?
- How best should we organize ourselves to get it all done in an effective, efficient way?

To facilitate this comprehensive review –

- 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' strengths and shortcomings.
- And we should make sure that individuals and families are central to this review process, driving the conversation and informing the decisions.

I realize that such a comprehensive review is a tall order, but I also know that it is this type of zero-based-budgeting that keeps many businesses and organizations successful and sustainable. And if a system-wide review seems currently beyond reach, I would suggest applying this approach to specific issue-areas, such as housing, employment and transportation as well as using it to develop better approaches to those with who are medically fragile/complex and those who have severe challenging behaviors.

Need for a Sense of Urgency

As discussed in last year's report, 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 so when they turn to us for assistance, they often do so with a very real sense of urgency.

Therefore, for us to effectively serve these individuals and families, we need not only to recognize and understand that sense of urgency; we need to share it. We need to be patient, sensitive and responsive – providing answers in a thoughtful, timely fashion. We need to do everything in our power to get to "yes" with their requests for assistance and realize that behind every policy decision and every eligibility determination is at least one human being, whose life will be profoundly affected either in a positive or negative way.

"Unlike most parents, we want to outlive our children."

A father explaining the anxiety felt by parents of adult children with intellectual or developmental disabilities, who worry that no one will care for their child when they're gone.

Granted, I have had the opportunity to work with colleagues who fully "get this" and show up for work each day with a profound sense of mission and determination. You can see it in their eyes. You can hear it in their voices. And you can certainly feel it in their presence and recognize it in their work.

However, we need more of it, and the best, most effective way to make this happen would be to increase direct contact between decision-makers and the people they serve. There is no substitute for "being there." There is no substitute for personal connection.

To this end, as I discuss at the end of this report, all government officials working on these issues should make it a priority to spend meaningful, quality time with individuals and families – not at big events, but in their homes and in their communities. I know everyone is busy, but if we are serious about effectively serving individuals with intellectual or developmental disabilities and their families, there really is no other way.

Need for a Focus on Civil and Human Rights

Nationally as well as locally, there continues to be a great deal of focus on civil and human rights. Usually, the conversations and policies are centered on issues of race, religion, gender and sexual orientation. Rarely, however, do they include people with disabilities.

As I explained in last year's report –

> 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.

In fact, it seems that individuals with intellectual or developmental disabilities are the only people in our country who still face overt, policy-based restrictions with respect to "where" they can live and work. They also face barriers with respect to a whole host of issues related to communication, criminal justice, education, healthcare, marriage, transportation, voting and other important rights that many of us take for granted.

And to make matters worse, the United States remains one of the only governments in the world that has not yet ratified the United Nations Convention on the Rights of Persons with Disabilities.

This is certainly unacceptable. Disability rights are civil rights. They are human rights, too. And while guaranteeing these rights for individuals with intellectual or developmental disabilities may sometimes be challenging, it is always worth the time, effort and cost to do so. Again, as stewards of the State's commitment to New Jerseyans with disabilities, this is our responsibility.

The upcoming 30th anniversary of the Americans with Disabilities Act in July gives us an opportunity to recommit ourselves to the cause of civil and human rights ... for everyone. Let's seize the moment.

Need for More Disability Perspectives

As discussed in last year's report, 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. Sadly, it seems that people with disabilities are too often taken for granted – a point I addressed in an op-ed last summer, noting that none of the more than 20 presidential candidates even mentioned the word "disability" during their first 4 hours of debate.

This needs to change.

To that end, we need more people with disabilities and their family members "in the room" and "sitting at the table." We need them running for local office. We need them working on government staffs. We need them serving on boards and commissions. Going forward, diversity in the workplace must include people with disabilities and their family members.

We also to need more people with disabilities and their family members engaging in political activism, making sure that their voices are loud and heard. We saw the effectiveness of such activism in the effort to save Medicaid funding in 2017 in Washington. We also saw it last year in Trenton where legislation originally drafted to ban plastic products was changed to allow for plastic straws, which are vitally important to many people with physical disabilities who depend on them for nourishment and hydration.

Finally, in my last report, I floated an idea being explored in Washington for an "Office of Disability Policy" which would create a mechanism for reviewing proposed policy and legislation for its impact on people with disabilities. And while that might be an overly ambitious task for us on the State level, I do think it would be very useful – to all concerned – for an organization like the New Jersey Council on Developmental Disabilities to establish a process to review draft legislation and policy, as requested. With its strong representation of people with disabilities and family members, the NJCDD could provide an invaluable service for Administration officials, Legislators and the disability community more generally.

As disability self-advocates proudly and appropriately say, "Nothing about us without us."

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, too, needs to change.

As discussed above, individuals with disabilities are just that – individuals – and like everyone else, they deserve the right to make individual choices. From where they live to where they work to how they spend their respective State-funded budgets, we need to stop assuming that others – however well-intentioned – know better than the individuals and their families themselves.

Yes, it is important to have safeguards in place to protect people against abuse and dangerous situations. Yes, we need to have safeguards in place for budgetary reasons, too. That's true for all public policies, regardless of whether they are for people with or without disabilities. But if we really subscribe to "person-centered" planning, then we need to make sure that the actual person is central to all decisions. That means honoring and celebrating individuality. That means providing choice wherever, whenever possible.

Need for Flexibility, Exceptions Procedures

To that end, we need to adopt a new mindset and possibly, a new set of procedures that recognize the need to occasionally make exceptions to established policies and processes. Again, there is a lot of talk about "person-centered" approaches, but much more needs to be done to operationalize those words.

As noted in my last report, 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. And while I know that some government officials do, in fact, recognize this and have gone out of their way to practice it, I believe we need to establish more formal, more transparent exceptions procedures.

Staffing Anecdote

A young adult with significant disabilities is permitted 130 hours per week of Direct Support Professional (DSP) coverage. That includes 3 full-time employees and someone (when possible) to fill a 10 hour slot. The family requests the ability to pay overtime to its regular staff members <u>only</u> in those instances when one of the DSPs is sick or on vacation. Government officials decline the request, citing a prohibition on overtime pay. As a result, the parent is forced to try to fill those slots with another DSP, possibly with a complete stranger – a near impossible task when someone unexpectedly calls in sick, a frightening task given the very personal nature of the job….

That said, there is some disagreement on this point. It has been suggested that standard policies and processes are necessary and should be universally applied, so everyone is treated the same. No favorites. No exceptions for those who can hire attorneys or are more familiar with the system.

To me, such reasoning misses the point.

Equity is not about giving everyone the same services and supports; it is about ensuring everyone has the same opportunities. For some, that may mean more services. For some, that may mean more supports. In fact, that perspective is already built into our system of care – to some extent – in that person-centered assessments determine the budgets and level of services and supports available to individuals.

Now, we just need to take that to the next level – giving individuals and families more flexibility on how they spend those budgets and how they utilize the services and supports offered.

We must recognize that even people with the same disabilities and who are even at the same tier / budget level will likely have different, unique needs. As the saying goes, "When you've met one person with autism, you've met one person with autism." And that can and should be said about every individual, regardless of disability status. Again, each person is unique. Each situation is different.

Simply stated, saying "no" to someone – just because their request does not fit neatly into a particular policy -- should be the absolute exception to the rule, rather than a seemingly regular default.

To that end, as discussed in my report last year, we should explore the establishment of formal, transparent "exceptions" procedures in each of our departments and divisions – procedures that would give due consideration to requests that fall outside of our official policies or, at a minimum, would flag for review policies and procedures that, rigidly applied, could result in denials of appropriate services and supports.

Such procedures 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 in the human services business, we should do everything humanly possible.

Need for More Emphasis on Health & Wellness

According to the U.S. Centers for Disease Control and Prevention (CDC), individuals with disabilities face higher levels of stress, depression, obesity, diabetes and other serious health conditions. Some of this is related to nutrition. Some of this is related to exercise. And some of this is related to the barriers that prevent individuals with intellectual or developmental disabilities from accessing quality health care.

Regarding nutrition and exercise, we should take some relatively easy, albeit important steps to place more of an emphasis on both health / wellness components by demanding more from our residential and adult day programs. Better food. More physical activity. More overall emphasis on healthy bodies and healthy minds. In fact, the Department of Human Services' (DHS) Division of Developmental Disabilities should consider including "nutrition outcomes" and "exercise outcomes" as mandatory parts of its Individual Service Plans. Moreover, DDD should also allow for more flexible use of the "goods and services" budget, doing anything and everything to encourage fitness center memberships, dance classes, etc. and (once again) to allow for personal trainers, as appropriate.

Regarding access to health care, this is a more challenging issue, due to the seeming scarcity of health care providers (physical, mental, behavioral and dental) willing and able to work with individuals with intellectual or developmental disabilities AND also willing to take Medicaid. But we need to make this a priority. One idea suggested by a parent would be to make it easier to use Medicaid coverage with out-of-state providers, allowing individuals and families to benefit from specialized services in surrounding States – something similar to the benefit offered to State employees, whose "plans are limited to New Jersey, New Castle County in Delaware, and bordering counties of Pennsylvania and New York."

To address these health and wellness imperatives, several organizations throughout the State have already undertaken some innovative and promising approaches, such as --

- A proposal for a Center for Disability Sports, Health and Wellness at Rutgers University – an idea developed by the school's Department of Kinesiology and Health to "promote, research and educate on issues related to individuals with disabilities and inclusion through healthy living, sports, exercise, nutrition and education."

- A N.J. Council on Developmental Disabilities effort to address barriers to quality dental care through the development of a 5-year advocacy plan and the creation of a searchable database of oral health resources.

- And various examples of integrated, coordinated health care -- for adults, for both children and adults and for transitioning children -- which provide treatment options for individuals through a collaborative, accessible team of primary care physicians, nurses and specialists.

Without question, on the most basic level, making health and wellness more of a priority is not just the right thing to do, but the smart thing to do, too. The right thing to do, because everyone deserves to be healthy. The smart thing to do, because better health outcomes will most certainly lead to a better quality of life for individuals and families, while also leading to cost savings related to expensive medical treatments and hospitalizations for poor health.

Need for More Intergovernmental Collaboration

Information is central to our system of care. Yet, accessing good information -- clear, accurate, timely information – is far more difficult than it should be.

As discussed, the system's complexity is one of the biggest barriers to individuals and families getting the services and supports they need and deserve. There are just so many offices and agencies and websites and policies and rules and procedures and paperwork requirements. Often, people don't know where to begin the search for information. Often, they don't even know what questions to ask. "They don't know what they don't know," as one parent explained.

To me, this speaks to a tremendous opportunity for our 21 County governments, which seem uniquely positioned to play a critical role in the flow of information. They are close enough to individuals and families to be more readily accessible and to have an appreciation of region-specific challenges and opportunities. They are resourced enough to maintain relationships with Trenton-based colleagues.

Specifically, as a starting point --

- Each County should have a full-time Director/Coordinator of Disability Services, who can serve as a point person for individuals and families in their jurisdiction as well as for State government officials – a role similar to mine as a troubleshooter for individuals and families in need of resources. (For some County governments, this should not require a change of mission or additional resources. We don't necessarily need new programs. We just need someone to help with the flow of information to and from Trenton – someone who knows "what" to ask for and "whom" to ask.)

- Each County should have a disability website portal dedicated to not only sharing County-specific information, but also links to services and supports provided through State government.

- The N.J. Association of County Disability Services, which meets bimonthly, should create official non-voting positions for representatives of the Departments of Children and Families, Education, Health, Human Services, Labor, Law and Public Safety and Transportation.

Simply stated, with minimal reorganization and realignment, County governments can help take our system of care from good to great by playing an even more meaningful information-sharing role for their residents.

Need for More Transparency

There is a real need for more transparency.

Policies are made. Decisions are taken. Money is spent. Yet, too often, individuals and families are kept in the dark about the details.

Granted, discretion is important, and privacy must absolutely be respected and protected. But there is no reason that individuals and their family members should learn about new policies only after they are made. No reason they should be denied copies of investigation reports concerning them or individuals under their guardianship. And no reason that they should not have access to the details about how their DDD budgets and social security benefits are spent by providers.

We need to shine more of a light on these issues, making it easier for individuals and families to know what's going on and why.

- Engaging them more in the policymaking process would be the smart thing to do, because it would likely result in better, more person-centered policies.

- Sharing investigative reports would be the right thing to do, because individuals and guardians should not have to get a judicial order to learn the details about a potentially dangerous situation involving them or a loved one.

- And it would seem to be both smart and right to make budget information more readily available to individuals and families – information 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 in group homes). Good for the individual or family. Good for the taxpayer.

On a more basic level, every department – at every level of government – should include on its website an organizational chart and detailed contact information – name, position, email and phone – for key frontline personnel. Individuals and families should know "who" is making decisions about them and "how" to directly contact them. Currently, that's not the case.

In sum, in addition to engaging individuals and families more earnestly and more regularly in the policy-making process, I suggest –

- Every individual and/or their guardian should have access to relevant investigation reports from the Department of Children and Families (DCF) and the Department of Human Services (DHS).

- Every individual and/or their guardian should have access to the relevant unannounced visit reports produced under the Stephen Komninos law for day and residential programs.

- Every individual and/or their guardian should have access to DDD's iRecord as well as relevant provider agency notes/logs. (One parent explained how helpful it is that the family's agency provides access to a web portal with detailed notes about the adult child and thus allows the parent to play an informed, constructive role in the care of the child.)

- Every individual and/or their guardian should be given a detailed reason for any denials or any change in services and supports by a government agency or a managed care organization.

- Every individual and/or their guardian should have access to detailed information regarding the expenditure of publicly-funded budgets as well as their personal monies, including their supplemental security income.

- Every individual and/or their guardian should have easy access to contact information for frontline government officials.

One important example of transparency has been an annual "risk indicator" report produced and made available to the public by DHS's Office of Public Integrity & Accountability (OPIA) – a report that gives the public insight into the number of reported "unusual incidents" as well as the number of substantiated investigations into abuse and neglect, among other things. The last report covered up through mid-2018. I understand that DHS has been working on a more user friendly format and that it was in the final stages of review prior to the coronavirus pandemic. I expect that DHS will release the report[s] covering the last two years soonest.

Need for More Innovation

As stated in my report last year, 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 providing "coordinated care" – a practical way to make health care more accessible to those who need it by effectively co-locating practices. (This concept was included as part of Governor Murphy's proposal last year to explore a Medicaid Behavioral Health Home project.)

- 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 exploring a range of residential options – from shared homes to integrated housing to ranches.

- Some are exploring a range of transportation ideas, including a possible "rideshare" platform.

As I reference in my recommendations below, this is the type of "big thinking" that we urgently need. At the State level, we should do everything possible to encourage it.

Need for Better Communication

The need for better, clearer, consistent communication is of paramount importance. The quantity and quality of communication – between those who staff our system of care and those who rely on it – impacts the effectiveness of the system to deliver services and supports. It also impacts the ability of individuals and families to manage their often challenging, busy lives.

To that end, we need to do better. In addition to County governments (above) playing a more central role in the flow of information, we should enhance the way we utilize two key communications platforms – government websites and public meetings -- as discussed in the next section.

Specific Observations

In addition to these general, 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 from the 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.

Adults

The New Jersey Department of Human Services (DHS) is home to the Division of Developmental Disabilities (DDD), which provides services and supports to adults aged 21 and over, as well as a host of other divisions and offices important to individuals with intellectual and developmental disabilities and their families. In fact, there are approximately 25,300 New Jerseyans registered with DDD.

The resources available to adults are significant, both in terms of quantity and quality. An individual's annual DDD budget can range from approximately $20,000 to just under $420,000, depending on the level of need, and can be used for a host of services and supports through the Division's Supports Program and Community Care Program. Additionally, there are employment-related resources available through the N.J. Department of Labor's Division of Vocational Rehabilitation Services as well as housing and transportation resources available in other parts of our government.

So, despite concerns expressed by individuals and families transitioning from the children system into the adult system (see "Transition" below), there is an abundance of resources and opportunities available to them. The problem, however, is that the system is very complex and can be both rigid and unresponsive.

To begin, unlike for students under 21, services and supports for adults are not an entitlement. This therefore requires more work in terms of identifying and obtaining resources – work made more difficult because of the complexity of the system. Again, the biggest barrier for many individuals and families is the myriad programs and policies and procedures and acronyms and offices – much of which seems to change with disruptive frequency.

Adding to these challenges is the seeming rigidity of the system. As discussed, despite a conceptual emphasis on "person-centered" planning, the actual provision of services and supports often seems to be more "system-centered" and determined more by resource considerations than by personal needs. Too often requests for flexibility are denied. Too often individuals and families – looking to the system for understanding, compassion and assistance -- are told "no." Too often they don't even get a clear answer.

Importantly, these concerns regarding complexity, rigidity and responsiveness are not focused on any one particular department or office. They are systemic and seem rooted in a longstanding government culture that is not fully "person-centered."

As outlined throughout the "general observations" section above, there is a lot we can and should do to improve New Jersey's system of care for adults with intellectual or developmental disabilities.

Autism

Not only does N.J. have the highest rate of autism in the country – 1 in 32 children – but according to the latest research out of Rutgers, approximately 25% of these children are not diagnosed early enough to receive the right interventions at the right times. Moreover, this study concluded that "black and Hispanic children are most at risk for missed autism diagnosis."

This seems to suggest the need for universal screening at various ages.

According to Autism New Jersey, it is estimated that there are 131,347 individuals with autism in New Jersey (roughly 1.5 percent of our state's population).

- That includes about 61,347 children and 70,000 adults.
- That includes about 43,782 individuals (children and adults) with an intellectual disability as well as substantial communication impairments – some of whom are unable to speak.
- That includes about 14,594 individuals with severe challenging behaviors.

Moreover, individuals with autism often face a host of additional serious challenges, including --

- Approximately 33% of individuals with autism have epilepsy / seizure disorders.
- Up to 60% of children / teens with autism have Attention Deficit Hyperactivity Disorder (ADHD).
- Up to 40% of children / teens with autism have anxiety disorders.
- In fact, according to Autism Speaks, the average lifespan of someone with autism is much shorter than the general population -- a terrible reality caused by a higher prevalence of both accidental deaths (28%) and medical and behavioral conditions.

These facts and numbers are compelling. The personal stories behind these numbers are even more so. And while people often talk about the impending "crisis" or even "tsunami" when referring to the future demand for services and supports, I think we are already there.

As such, every elected official should learn about autism and make addressing it a policy priority. Every first responder and educator should understand autism and be trained accordingly. And everyone else, to some degree, should know more about this neurobiological disorder that affects many families and all communities.

At the State level, there is much good work being done. The recent enactment of the Applied Behavior Analyst Licensing law is an important development – one that will help ensure that New Jerseyans with autism get proper care. Similarly, all Medicaid-eligible children with autism will soon have access to medically necessary Applied Behavior Analysis (ABA) and other services. And Governor Murphy's proposed initiatives to enhance services and supports for those with intellectual or developmental disabilities and co-occurring mental health conditions should help us to make important advances for those with autism and severe challenging behaviors.

But as we all should acknowledge, much more needs to be done. Now.

Bathrooms

On multiple occasions, individuals have approached me on the very serious topic of bathroom access – something that speaks to both a health imperative and a basic civil and human right.

Specifically, the concerns have focused on the need for better access in public restrooms, in airplanes and at outdoor events.

- For public restrooms, the issue is that people with disabilities should be given priority access – perhaps through better signage -- to specifically-designated restroom stalls. This would help ensure people with disabilities do not have to wait for people without disabilities, who also use these stalls.

- For airplanes, there is a national effort to make lavatories more accessible for people with disabilities. In fact, the U.S. Department of Transportation is currently exploring a new rule to effectuate such a change.

- For outdoor events, there should be better use – if not exclusive use -- of larger, accessible portable lavatories. Everyone would benefit from such universal design.

Budget / Funding

DDD services and supports were previously funded primarily through the use of New Jersey tax dollars. A few years ago, however, the State transitioned over to a Medicaid-based system (see "fee for service" below), so that the services and supports are now paid for using a mix of State and Federal dollars. Practically speaking, that should have allowed DDD to use less N.J. tax dollars and/or increase the overall budget available for individuals with intellectual or developmental disabilities.

Like most changes, this transition has had its own share of strengths and weaknesses, some of which are discussed throughout this report. But one consequence that needs particular attention is the gap that is sometimes created by the reliance on Medicaid funding, because the federal government has its own set of rules, which don't always align with individual and family needs. Here are three examples --

- If an individual stays in a hospital, her Direct Support Professional (DSP) cannot accompany her, because the hospital is supposed to meet the needs of the individual, and Medicaid will not pay for what it considers a duplication of services. This can be problematic for an individual, who may have an important personal relationship with her DSP and is uneasy about being in the care of strangers. This can be problematic for the DSP, who can be out of work – without paycheck – while the individual is in the hospital.

- If an individual exceeds the Medicaid income eligibility threshold – because of social security payments or some other reason – she will not qualify for DDD services.

- Under the "fee for service" system, providers only get paid for services delivered, which certainly makes sense from a taxpayer perspective. However, that means providers don't get paid when an individual is absent or even late, even though they are paying for staff coverage and other administrative expenses. Granted, there has been a 5% "absentee factor" built into residential program rates – meaning residential providers get paid for up to 18 absences per year per individual – and Governor Murphy just proposed a similar measure for day program providers. Yet, even with these helpful "absentee factors", individuals – in some circumstances – may need even more flexibility due to illness, hospitalizations, family visits, vacations, etc., thus forcing providers to either lose money or terminate services for individuals in need.

For these and other such situations, there should exist a bucket of state-only funding available for DDD to help individuals and families who are at risk of falling through such unintended gaps in coverage.

Bureaucracy

As discussed, N.J.'s system of care for individuals with intellectual or developmental disabilities could use some structural reform. The complexity can be overwhelming for those who depend on it as well as those who work in it.

Among the ideas that should be explored is the possibility of a single-point-of-entry for the entire State-based system – something that could reduce the complexity, the paperwork and the costs associated with providing and receiving services and supports.

Just a quick look at the numbers highlights this point.

- The N.J. Department of Health currently has approximately 14,000 children (ages 0 – 2) with developmental delays in its Early Intervention system.
- The N.J. Department of Education has approximately 240,000 children (ages 3-5) and (ages 6-21) with disabilities in its system – a number that includes about 23,000 children with autism and an additional 14,000 with "multiple disabilities."
- The N.J. Department of Children and Families currently has approximately 14,000 children (ages 5-21) with intellectual or developmental disabilities in its Children's System of Care (CSOC).
- The Department of Human Services currently has approximately 25,000 adults (ages 21 and above) with intellectual or developmental disabilities in its Division of Developmental Disabilities (DDD).
- The N.J. Department of Labor has approximately 19,000 individuals (ages 14 and above) with disabilities in its Division of Vocational Rehabilitation Services (DVRS).

Each department has its own set of eligibility forms. Each department has its own requirements for supported documentation. Each department has its own processes and procedures.

Clearly, it would make at least some sense to give these individuals and families the option of registering their information in one, single government database accessible to those departments/agencies charged with providing services and supports. It would make sense for families so they do not need to keep registering and re-registering with the State. It would make sense for government officials so we have a better sense of the population we are serving and could presumably better coordinate the delivery of services and supports.

Again, intellectual and developmental disabilities are lifelong. Once identified – which is often early in childhood – it might help everyone involved to have that individual's information in one central location, updated as needed.

To its credit, in 2019, DDD rolled-out a "short application for eligibility" for those individuals already registered with the Children's System of Care, representing an important step forward in this regard.

Care Management Organizations

As noted below (see "Case Management"), Care Management Organizations (CMO) play a critical role for families seeking to access services and supports for their children ages 5-21. Yet, there seem to be persistent concerns associated with this approach to case management for which the State pays these agencies $775 per month per child.

Among the most frequent complaints –

- **Unresponsiveness**: Agency staff not returning phone calls/emails or following through on requests.
- **Inexperience**: Agency staff, new to their jobs, not knowing what resources are available or how to work with the respective government agencies. (Some parents have complained about having to "train" their Care Managers, who are sometimes exceedingly inexperienced.)
- **Turnover**: Agency staff leaving their positions after a short time – something that is particularly upsetting for individuals whose disability includes a difficulty navigating change.
- **Lack of Choice**: There are only 15 CMOs in New Jersey, and families must (with few exceptions) utilize the agency assigned to their particular county.

Also, as discussed below (see "Children"), many parents feel that their CMO does not understand their child's disability and is therefore not appropriately serving them or the rest of the family.

This needs to change. Although I recognize that there are many really good, really dedicated care managers serving families throughout the State, the overall CMO role is too important for there to be so many problems associated with it.

Case Management

In recent years, case management has been effectively outsourced to private agencies. For children, the Department of Children & Families (DCF) utilizes region-based Care Management Organizations (CMO). For adults, the Department of Human Services (DHS) utilizes Support Coordination Agencies (SCA). The role of these private agencies is to work closely with individuals and families to help make sure they get the services and supports they need and deserve.

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

This is a dynamic that can only diminish our understanding of people's situations and (as a consequence) our ability to develop and deliver "person-centered" policies. Without question, it's easier for an official to deny a service and say "no" when it can be done through a third-party.

We need to find a way around this. As discussed above, we should be creating and nurturing more opportunities for people to have direct contact with government officials, not less. Perhaps DCF and DHS can explore a more hybrid approach -- one which utilizes the CMOs and Support Coordinators, while guaranteeing and facilitating direct access to decision-makers by individuals and family members, if/when requested.

Census

The Murphy Administration – along with local partners throughout the State – is undertaking a concerted effort to ensure all New Jerseyans are counted in this year's census, and based on conversations with the Secretary of State's office, there is a clear determination to ensure that individuals with intellectual or developmental disabilities and their families are central to that process.

Children

For children (ages 3 to 21) with intellectual or developmental disabilities, local school districts usually play a lead role in the provision of supports and services – a role 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 needs of the student and the availability of public resources.

Additionally, since 2013, the Department of Children and Families (DCF) has been responsible for providing other services and supports to children with intellectual or developmental disabilities. Through its Children's System of Care (CSOC), DCF provides a range of essential services, including in-home supports, group home placement, respite and summer camp.

Despite best efforts, however, I often hear complaints from parents concerning everything from the quality of their children's education to the need for more residence-based supports.

With respect to education, parents and local school administrators are frequently at odds over how best to serve the students – in or out of district. These differences often lead to legal battles or even just the threat of them – a terrible dynamic that places a financial and emotional burden on already overburdened families.

Clearly, there has to be a better way. Local school administrators 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. Families should also avail themselves of N.J.'s Special Education Ombudsman, who serves as a resource to provide information and support, as well as non-governmental organizations, such as the SPAN Parent Advocacy Network.

Regardless, 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. No parent should ever feel intimidated. No child should ever be deprived of a quality education.

With respect to residence-based supports, parents and DCF are regularly at odds regarding the resources available to children, particularly those with autism spectrum disorder and co-occurring severe challenging behaviors. Parents frequently plead for intensive in-home supports or alternatively – and very reluctantly -- out-of-home residential placements. DCF, however, frequently declines such requests, due to a lack of resources. (See "Housing Options")

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

To their credit, DCF officials have not only acknowledged this “cultural” predisposition, noting the Department’s traditional focus on emotional and behavioral health, but have begun to remedy this situation through the recent creation of the position of Family Liaison for Youth with Intellectual and Developmental Disabilities – a position that should help ensure that families have a seat at the CSOC policymaking table. Already, the Family Liaison has begun a comprehensive review of the infamous PerformCare application, which has been—in itself –a barrier to children and families accessing needed services and supports.

Family Anecdote

For a child’s family, State government policy currently allows 60 hours of in-home respite per every 90 days – effectively 20 hours per month. A parent with two children – one with autism and challenging behaviors -- requested an additional 10 hours of respite per month to meet the basic care needs of everyone in the family, including the other child, who often feels neglected. Government officials declined the request, noting that they have never allowed such an exception before. The family has since been seeking an out-of-home placement for the child with autism – a decision that is devastating for the family and far more expensive than the cost of additional respite….

Incidentally, one of the best resources for parents of special needs children is the Rutgers-based, DCF-funded "Mom2Mom" 24/7 peer support helpline, which provides emotional support as well as referrals and advice.

Communications Disabilities

Many people with intellectual or developmental disabilities have speech / language impairments, including some who do not speak at all. The same is true for many people with other types of disabilities – including those associated with Parkinson's disease and Alzheimer's disease as well as those associated with stroke and a variety of other conditions. And according to the NJ Department of Education, there are more than 50,000 students (ages 3-5) and (ages 6-21) with speech or language impairments.

The Americans with Disabilities Act (ADA) identifies 3 communications disabilities – vision, hearing and speech. Yet, we only have State entities for two of them -- the NJ Commission for the Blind and Visually Impaired (CBVI) and the NJ Division of the Deaf and Hard of Hearing (DDHH). There is no dedicated State office/division/commission to provide services and supports to New Jerseyans with speech disabilities.

We should review this situation. At a minimum, we should ensure that individuals requiring services and supports – including assistive technology -- for all of the 3 communications disabilities are being served appropriately.

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 starting salary in New Jersey is about $12.00 per hour – only $24,960 per year.

Let's put this into perspective:

- At $12.00 per hour – only $24,960 per year – many DSPs are getting paid just above the State's new minimum wage level. In other words, although they have a very demanding set of responsibilities, they are getting paid at almost the same rate as a child working in a retail store.
- At $12.00 per hour – only $24,960 per year – many DSPs are getting paid so little that they fall under the federal poverty level for a family of four.
- At $12.00 per hour – only $24,960 per year – many DSPs are getting paid so little that they are eligible for food stamps in New Jersey for a family of two.
- At $12.00 per hour – only $24,960 per year – many DSPs are getting paid so little that they are eligible for Medicaid in New Jersey for a family of four.

Moreover, due to low salaries and lack of benefits, there is an estimated 44% turnover rate annually – a dynamic that has budgetary implications as well as human implications, particularly for individuals whose disability makes coping with change especially difficult.

To help address this situation, the last two State budgets – passed by the Legislature and signed into law by Governor Murphy – included increases to DSP wages, and Governor Murphy has proposed an additional increase for calendar year 2021.

But to attract and sustain a DSP workforce, we need to increase and index salaries, guarantee benefits and require ongoing educational and training requirements. Yes, that would require additional funding, but the higher price tag would likely be mitigated, in part, by savings from DSPs no longer needing food stamps, Medicaid and other government assistance. It would also be mitigated, in part, by savings related to less turnover and to having a better trained workforce.

Simply stated, if we are serious about providing individuals with intellectual or developmental disabilities with the supports they need and deserve, then we need to take the long view and do a better job treating Direct Support Professionals like professionals. That means living wages. That means benefits. That means continuous training.

There is no other way.

Employment

N.J. is an "Employment First" State, which means we view "competitive employment in the general workforce as the first and preferred post education outcome for people with any type of disability." The New Jersey Department of Labor and Workforce Development (DOL) provides important supports to help make that a reality – a mission embodied by the Department's professionals in Trenton as well as those based around the State.

Yet, despite best efforts, too many New Jerseyans with intellectual or developmental disabilities are either unemployed or underemployed. Notwithstanding their skills and talent, they face a host of challenges, most notably:

- Cultural barriers often prevent employers from recruiting people with disabilities or providing workplaces accessible to them.

- Systemic complexities often prevent jobseekers from accessing – or even knowing about -- resources available through State and County government.

- And transportation limitations often prevent them from getting and keeping their jobs.

As a result, at the end of 2018 (the last year that comparable numbers are available), the unemployment rate was 12.5% among New Jerseyans with disabilities, compared to the State's overall unemployment rate of 4.0% (Nationally, unemployment rates were 7.9% and 3.9%, respectively.)

Importantly, as part of the effort to raise the State's minimum wage last year, the Governor and Legislature included a provision in the new law that provides up to $10 million in tax credits to businesses that employ people with disabilities. The measure seeks to provide relief to businesses and protect individuals' jobs.

Importantly, too, another bill was introduced in the State legislature in 2019 and then adopted and signed into law by Governor Murphy earlier this year to establish a Task Force for Maximizing Employment for People with Disabilities, which will study the issue and make recommendations.

One notable success story has been has been Project Search – a U.S.-based program designed to give young adults practical workplace experience and set them on a career path. In New Jersey, there are now 9 Project Search sites serving students and/or adults. To date, many of the costs associated with Project Search have been covered by local school districts and the Department of Labor. With the recent expansion of the program to include adults over the age of 21, there may be a need for the Department of Human Services to also play a supportive role.

Fee-For-Service

Over the past several years, the Division of Developmental Disabilities (DDD) has been transitioning to a Medicaid-based fee-for-service (FFS) model. This transition – which was undertaken to increase our system of care's resources, efficiency and effectiveness -- has resulted in 3 significant changes:

(1) All DDD services now require Medicaid eligibility;
(2) The federal government now shares the cost of providing DDD services and supports; and
(3) Providers only get paid for services delivered and according to rates set by the State.

Not surprisingly, the 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.

To assist DDD's transition to the Medicaid FFS model, the State Legislature adopted legislation in May 2017 to establish an independent board to monitor, evaluate and make recommendations about the transition. In December 2018, Governor Murphy appointed members to that Board, which met throughout 2019 and issued its first report in September 2019.

I have been encouraged by the work of the board – the Independent Developmental Disability Fee-for-Service Transition Oversight Board – because its membership is strong and its mandate is substantial:

> The "board shall evaluate and report on the status and effects of the transition…" and "shall primarily focus on its effects on access to care, continuity of care, and quality of care … and may also independently evaluate providers' costs, revenues, revenue shortfalls, and other needs including technical assistance, training, and business infrastructure needs that are affected by the transition, and how these factors affect providers' ability to serve their clients.

To me, the Board provides us with a unique and important opportunity – to reinforce that which is working, to course-correct that which is not. To those ends, my hope is that this process will result in a rate structure that is current, indexed and best meets the needs of individuals and families as well as providers. My hope also is that particular attention be given to the rates regarding Direct Support Professionals, Self-Directed Employees, Goods and Services, Support Coordinators, Day Programs and Transportation.

Government Websites

Websites can be great communications tools. I say "can" because as we all know, that is not always the case. Too often, information is outdated and wrong. Too often, the sites are not user-friendly and hard to navigate. Too often, the information we need just seems nowhere to be found.

Such is the case with many government websites on many levels of government, and this is a real missed opportunity – for those who work in government and for those who depend on it. There would be so many fewer calls and emails to government offices if timely, relevant information was easily accessible through websites.

There has been an effort underway throughout the Murphy Administration to improve our online presence, but we need to redouble our efforts – for everyone's sake. And among the things we should all be doing is making available on our websites (1) department organizational charts, and (2) contact information for key frontline personnel.

As noted in last year's report, I have begun to develop a one-stop website for individuals with intellectual or developmental disabilities and their families. Unfortunately, the project was put on hold, due to a limited number of hours in a day, but with the doubling of our Office's staff (from one to two), this is a priority for 2020.

Guardianship

As previously discussed, issues related to guardianship are among the most consequential, and decisions regarding it should therefore never be taken lightly or without full information about its implications as well as about 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.

We also need to make restoring capacity a more readily available option when appropriate. On a few occasions in 2019, I was approached by individuals, who wanted their guardianship revoked. Yet, as I learned, doing so can be even more expensive and even more cumbersome, if not seemingly impossible.

I have begun exploring this issue with some of the legal organizations that work on disability issues. My hope is that we can find our way forward on this.

Housing Options

Housing is one of the most challenging, most consequential issues. For parents of young children, the decision to place their child in an out-of-home residence is unbearably painful and is considered only after exhausting any and all in-home resources. Conversely, for parents of adult children, there is a sense of urgency, because they realize their responsibility to prepare for the day when they are not around to care for their daughters and sons.

In all situations, the difficulty of the decision is compounded by the uncertainty regarding the availability of a safe, secure and appropriate residential setting. And until recently, the options were very limited.

Fortunately, there seems to be a sea change in thinking about residential opportunities – one that is increasingly innovative and open-minded. In the past, the discussions seemed to focus on either large institutional settings or small group homes. There was very little in-between. Now, the discussion is broadening to include a range of options – from a variety of independent apartment settings to shared homes to even the possibility of campuses, farmsteads and additional small private intermediate care facilities. Hopefully, too, the discussion will again embrace innovative approaches – like "shared living" or "community care residences" utilizing host families – that have been tried with success on a limited basis in the past.

Driven by self-advocates and parents – and supported by new guidance from the federal Centers for Medicare and Medicaid -- this new housing conversation has found an increasingly receptive audience in the Murphy Administration and throughout the State Legislature. Officials increasingly recognize that one size does not fit all and that people with disabilities – like everyone else – deserve choice.

However, we need to act fast. The housing shortage is real and causing a great deal of hardship, particularly with respect to those children who urgently need a good, safe out-of-home placement. In fact, the number of residential options for children has actually declined over the past year – from 388 to 363 available beds – and the average wait time (prior to the coronavirus pandemic) for a crisis / stabilization placement is now 55 days.

According to DCF, that decline – and the potential for further reductions – owes itself to a rate structure that incentivizes providers to invest their funding in adult residences, rather than youth residences which are, by definition, relatively short term. To help address this situation, it has been suggested that the State allow and incentivize residential providers to make available housing options that permit children to age in place without having to move once they reach the age of 21, which is current policy. I think this idea has merit and should be explored.

Regardless, there now seems to be general agreement that we need to grow the number, location and type of residences available – for children as well as adults – and that is a very important step forward. In this context, the recent announcement by the Housing Mortgage and Finance Administration of a new $50 million Special Needs Housing Subsidy Loan Program is very encouraging.

Housing Subsidies

The Supportive Housing Connection – available to all adults enrolled in DDD -- is a great program that helps make community living a reality for many adults with intellectual or developmental disabilities. However, the published rent standards -- on which it is based – can make it very difficult to find rental residences in certain parts of the state. Similarly, there is a general prohibition against using the voucher in a home owned by a family member.

While both limitations are based on federal policy, State officials – who are using State funding – have more flexibility and could exercise their discretion more broadly. An ability to utilize more reasonable rent standards and / or to use the vouchers in a family member's home would be beneficial in 3 important ways:

- It would increase the pool of available residences, thus helping to address the housing shortage;
- It would help ensure that individuals have opportunities to live in safe, community-based settings;
- It would help keep families together and make it more possible for them to provide support for their loved ones.

In fact, this last consideration could help defray costs and demands on the system, by drawing on an individual's natural, family support system.

Individuals with Severe Challenging Behaviors

In my report last year, I spoke at length about severe challenging behaviors – about their widespread prevalence and about our seeming lack of capacity to provide for individuals and families. In fact, of all of the things I have learned since becoming the State's Ombudsman, nothing has been more eye opening and more worrying.

Through my work, I have met many individuals – children as well as adults – who are self-injurious, aggressive towards others and/or destructive of property. I have visited their homes. I have seen the holes in walls made by the pounding of fists and heads. I have met the parents with scarred faces and bruised arms. And I have heard the stories and seen the videos of young adults being taken by police officers either to jail or to an emergency room, where they remain for days or weeks before being discharged with a new mix of psychotropic medicines and a new set of experiences to haunt them.

Through my work, I have also learned about our State's shortage of effective treatment options, stabilization services and staffing needed to allow many of these individuals to live safely in their homes, to learn safely in their schools, to work safely in their jobs and to participate safely in their day programs. And I have learned that, as a result of these shortages, many of these individuals and their families are unable to live safe, fulfilling lives in their communities.

In the "autism" section above, I addressed this issue somewhat, noting that an estimated 14,594 New Jerseyans with autism have severe challenging behaviors and noting that Governor Murphy included some funding in last year's budget to jumpstart efforts to address this issue.

But here, again, we need to do more.

As first steps, I would recommend two sets of reading for everyone:

- Autism NJ's 2019 Severe Challenging Behavior Policy Recommendations:
- The N.J. Dual Diagnosis 2008 Task Force Report

As next steps, we should support the Department of Human Services' (DHS) efforts to move forward the proposals in the Governor's 2020 budget and build on those efforts, using the Autism NJ and Dual Diagnosis Task Force recommendations to guide us.

In that context, we should explore new, better ways for addressing severe challenging behaviors – ways that do not result in individuals being pulled from their homes by law enforcement and left in emergency rooms. That means taking a more holistic, longer-term view – one that places a premium on early intervention and treatment. That means exploring better approaches to crisis stabilization – approaches that could include a better use of mobile response to provide services in the home and increased use of step-down services and supports.

Medically Fragile / Complex Individuals

Throughout the year, I worked with several families with individuals with intellectual or developmental disabilities, who are also "medically fragile/complex" – meaning that they require some level of nursing care. Some expressed concerns about housing and in-home supports. Some expressed concerns about day programs. All expressed concerns about the safety and well-being of their family members.

To put this in perspective, according to DDD –

- There are about 24,000 adults in the DDD community-based system, including more than 800 who are medically fragile/complex.
- Additionally, there are about 1,300 adults living in 6 "intermediate care facilities" -- including the 5 state-run developmental centers – many of whom are medically fragile/complex.
- And there are an estimated 600-700 people who are medically fragile/complex in nursing homes, many of whom are under the age of 60 years old.

For those living or wanting to live in the community –

- There is an enormous need for private duty nurses (PDN), which are in dangerously short supply (see "Private Duty Nursing" below).
- There is a need for more and better transportation options, including vehicles that can accommodate those who use wheelchairs.
- There is a need for safe, dynamic, accessible day programs that have the flexibility (discussed under "Budget" above) to allow for more absences due to illnesses, doctors' appointments, etc.
- There is a need for additional "medical" group homes – which have the capacity to provide nursing/medical support – as well as additional development of small, privately-run intermediate care facilities.

For those living in nursing homes, there is clearly an imperative to find them a more appropriate living environment – one that can provide them with the right level of care, supports, community engagement and independence.

Further, we need to explore the possibility of adding PDNs as a service/support available to all qualified individuals enrolled in DDD. Currently, those in the division's "Supports Program" can – if qualified – benefit from the services of PDNs; those in the "Community Care Program," however, cannot. The reason for this discrepancy is unclear. Regardless, I have met families who require both the significant individual DSP supports that are provided by the Community Care Program as well as the vital nursing supports that are not. This should be fixed.

N.J. Comprehensive Assessment Tool

Without question, filling out the N.J. Comprehensive Assessment Tool (NJCAT) is one of the most consequential moments in the DDD onboarding process, because the division uses it to determine an individual's level of need for services and supports which, in turn, determines the budget made available to that individual.

In my report last year, I noted that many families had expressed concerns about the NJCAT with respect to both process and substance.

Regarding process, the concerns have been essentially twofold: (1) that there was not enough guidance for families filling out the questionnaire; and (2) that there may be something wrong with the way the results are evaluated. Regarding substance, the main concerns have been that the NJCAT does not accurately capture an individual's level of need. The questions are too "black and white," despite the fact that disability often presents itself in shades of gray.

DDD officials have understood the need to reform the NJCAT, and in 2019, significantly changed the process. Now, DDD representatives go to the individual and/or family and actually administer the questionnaire. Unfortunately, however, DDD has not yet made changes to address the substantive concerns.

Throughout 2019, I had the opportunity to be with families during several NJCAT assessments and reassessments. I was generally very impressed with the process – with the professionalism of DDD staff as well as the sensitivity they showed to the individuals and families. Some people have criticized the new process, stating that it is a "conflict of interest" for DDD to play such a hands-on role administering the NJCAT. I disagree. I also feel that it is helpful to the families to have someone administer the questionnaire and that this new process provides a good opportunity for DDD staff to actually meet the individuals and families involved, adding an importantly personal component to this process. And very importantly, DDD allows for family members, Support Coordinators and others to participate in the process.

At this point, I suggest only two more small, albeit important changes to the process: (1) The individual and family should have a chance to visually review their answers before the DDD representative hits the "send" button on the computer, and (2) they should also be given a copy of the submission either in hard copy or electronically. This would help guarantee accuracy.

On the other hand, the substance of the NJCAT is still problematic. The questions are too cut and dry, and they do not often capture or reflect an individual's level of need, particularly for those with severe challenging behaviors or medical fragility/complexity. To its credit, DDD recognizes this and has reportedly undertaken a review over the past year – a review that will hopefully involve individuals and families, who have firsthand experience with the questionnaire. However, in the meantime -- having recognized that the NJCAT is flawed -- the division should not be relying on it or at least should be giving it less weight in decisions regarding individual budget levels.

Additionally, there are two other issues for consideration:

- I think that DDD should revisit another aspect of its approach to assessing eligibility. As I understand it, when NJCAT results raise questions about eligibility, DDD sends a psychologist to visit with the individual to do an in-person assessment. That is a very good idea, unless the individual's level of need relates to physical or medical challenges.

- I think that DDD should revisit its policy of conducting NJCAT reassessments every five years. Since these are lifelong disabilities, few (if any) people's level of need will decrease over time. If anything, just the opposite. So, in an effort to save resources – DDD's as well as families' – reassessments should be considered only when there is a functional need change identified by the individual, family, Support Coordinator or provider agency.

Personal Care Assistance

Personal Care Assistant (PCA) services are designed to help people living in the community with activities of daily living (ADL) as well as some household duties. They are Medicaid funded and available to those determined to be medically eligible.

The State's 5 managed care organizations (MCO) do the assessments and (for those who are eligible) determine the number of hours per day / week the person can have PCA services.

Once deemed eligible, an individual can choose to get PCA services through an agency or through self-direction through what is known as the Personal Preference Program (PPP).

PPP is an increasingly popular program that provides much needed supports for individuals, because it allows parents and spouses to get paid for working for their loved one. In fact, enrollment has dramatically increased from almost 9,000 participants in 2018 to almost 17,000 in 2020.

That said, in 2019, I was contacted by several families concerned and frustrated with their PCA services:

- Some were upset about MCO decisions to reduce or eliminate the PCA hours allotted to them, often feeling that the decisions were arbitrary, unexpected and without explanation.

- Some were upset about Personal Care Assistants failing to show up when scheduled or needed.

With respect to decisions to reduce or eliminate designated hours, some have attributed the apparent uptick in such decisions to "new" eligibility requirements. However, according to the State's Medicaid leadership, there have not been any changes to PCA/PPP eligibility requirements in recent years. The only change is that management of the program went from DHS's Division of Disability Services (DDS) to the Division of Medical Assistance & Health Services (DMAHS) in 2018. In other words, while it has always been Medicaid funded, it is now Medicaid managed, too.

Regardless, for those concerned about reductions or eliminations of their hours/budget, they can (1) request an internal appeal through the MCO, and (2) then, if necessary, request a fair hearing. They can also contact DHS's Office of Quality Assurance (609-588-7379).

With respect to PCA attendance, later this year, the State will be introducing Electronic Visit Verification (EVV), which is supposed to enhance the effectiveness of these and other community-based Medicaid services, because it will give us more accurate data about PCA, PDN and DSP coverage, etc. That said, some have expressed concerns about the way it will be implemented, particularly in light of the need for flexibility in individual and family situations.

Nonetheless, the inability to depend on PCA services – whether due to seemingly rash eligibility decisions or unreliable attendance -- creates real and serious hardships for individuals and families. As such, the role of MCOs seems like an area that could benefit from a thorough review, if not also more oversight.

Private Duty Nursing

As noted (see "Medically Fragile/Complex Individuals"), there is a great unmet need for private duty nurses among individuals with intellectual or developmental disabilities. In some cases, the challenge is transportation (the lack thereof) to some of the hard-to-reach parts of our State. In all cases, the challenge is the rate by which PDNs are paid.

Medicaid rates for PDNs have remained flat for over a decade. Moreover, current law provides a ceiling for reimbursement rates, giving the State's 5 private managed care organizations a great deal of discretion. Legislation introduced, but not enacted, in 2019 would guarantee increases in such rates by raising the rates and eliminating this discretion for PDNs in the Fee-for-Service (FFS) system.

Private Duty Nursing Anecdote

For years, a young adult had been receiving 84 hours per week of PDN support. Without warning, the MCO notified the family that they can still get the 84 hours per week, but no more than 12 hours per day, pointing to a state policy that had existed for years, but had not been enforced with this family. The parent explained that the family needs the flexibility, because "some days are worse than others" and the parent has her/his own health challenges. The MCO and government officials not only declined; the family was told that it was not even allowed to appeal the decision….

If reintroduced, consideration should be given to extending the provisions of the legislation to PDNs in the managed care system, including those in the Managed Long Term Services and Supports (MLTSS) program. Consideration should also be given to rewriting the State regulation that currently permits no more than 16 hours per day of PDN support. A truly "person-centered" system would allow individuals and families more hours and more flexibility in using them, as needed.

Regardless, we need to figure this out. The choices available to individuals and families who require nursing support are too limited, particularly for those who want their loved ones – children as well as adults – to live at home or independently. This is undoubtedly the reason why we need many of the 283 beds available in the State's 4 pediatric long-term care facilities and why an estimated 600-700 adults with intellectual or developmental disabilities live in nursing homes.

Public Meetings

Public meetings hosted by government officials present important opportunities for individuals and families, particularly (as discussed) as it seems increasingly difficult to have any direct one-on-one communications with these officials. However, I have noticed a disturbing tendency to hold such meetings at inconvenient times and in inconvenient locations.

Often the meetings are held during traditional work hours (9am to 5pm) in the Trenton area. No evening options. No weekend options. No regional options (outside of the Trenton area).

Needless to say, this is not the best way to make sure that individuals with disabilities or their families are able to participate in the meetings.

We need to be more sensitive to people's work schedules, geographical and transportation challenges and family obligations. There should never be just one meeting in one location at one time. And we should include remote access – video or call-in capacity – with the right accommodations for every meeting, realizing that there are often physical challenges that prevent in-person participation.

Done right, public meetings can and should be important communications tools for all involved.

Public Safety

There are many efforts underway throughout New Jersey to enhance the safety and security of people with disabilities. At all levels of government, community leaders have been developing and implementing a variety of targeted public safety measures. Some involve emergency management. Some involve identification cards. Some involve training for first responders.

Public Meeting Anecdote

One government agency, which works exclusively for people with disabilities, held its two annual public forums in 2019. The first forum was at noon in the Trenton area in a conference room, which was divided evenly between the agency's 15 staffers sitting comfortably around a u-shaped table on one side of the room and dozens of members of the public – some in wheelchairs – crowded together on the other side. The second forum was at 6pm in downtown Newark. Stuck in rush hour traffic, many of us didn't make it to this meeting….

Last year, I was able to participate in several important initiatives, including:

- The N.J. Office of Emergency Management's County Access & Functional Needs meetings.
- The N.J. Council on Developmental Disabilities' statewide initiative to improve school safety.
- A N.J. Transit emergency response drill in Bergen County.
- A Port Authority of NY and NJ emergency response exercise at Newark International Airport.
- An Ocean County College conference on emergency planning for people with disabilities.
- The Arc of New Jersey's Partners in Justice Task Force.

Moreover, I have been able to participate in a special needs working group established last year by the N.J. Attorney General's Office. The group, which includes County Prosecutors and the State Police, is exploring ways to better serve the disability community on a whole range of public safety issues.

Going forward, we need to continue all of this good work and build on it. The safety and security of people with intellectual or developmental disabilities is often at greater risk.

Self Direction

For years, DDD has promoted some form of "self-direction" – an approach to providing services and supports that gives adults and families more independence and control as well as the possibility of stretching their DDD budget farther.

As noted in my report last year, many families had expressed concerns about a decision taken in 2017 to make Public Partnerships, LLC (PPL) the sole fiscal intermediary for those involved in self-direction. Some of their concerns were focused on the vendor itself. Some of their concerns were focused more generally on this new approach to self-direction, which had some limitations (e.g. no health benefits for self-directed employees and the requirement that the individuals would now have to be the employer-of-record with new legal and management responsibilities).

In 2019, positive changes occurred on both fronts.

- Although some families still experience problems with respect to customer service and late or inaccurate payments, PPL has definitely improved its processes and overall responsiveness and even recently put out a useful new employer handbook.

- DDD now offers families 2 self-direction options: (1) the Vendor Fiscal/Employer Agent model, and (2) the Agency with Choice model. The former model continues using PPL as the fiscal intermediary. The latter model uses Easter Seals, which entails an additional fee, but makes the agency the employer of record and provides benefits to the employees. (DDD provides a useful comparison of the models on its website.)

Despite these improvements, some families continue to express frustration with different aspects of self-direction, most notably –

- The seemingly arbitrary ("reasonable and customary") cap on hourly rates for self-directed employees, which is much lower than the cap on agency rates;
- The difficulty of hiring and retaining qualified DSPs, due to relatively low pay and administrative challenges, including the late and inaccurate payments discussed above; and
- The relatively new budget restrictions that compel individuals to pay for "life necessities" – such as utilities and telephone service – that were previously covered by the DDD budget.

Also, it is still not clear why the Personal Preference Program (PPP) allows parents, guardians and spouses to be hired as employees, but DDD does not allow them under "self-direction." Both are Medicaid-funded. Both can use the same fiscal intermediary. This should change.

Stephen Komninos Law

The Department of Human Services (DHS) deserves a great deal of credit for its seemingly smooth, effective implementation of the landmark Stephen Komninos Law, which 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, drug testing of direct care staff and strict notification requirements to parents/guardians and DHS.

That said, one concern that families continued to bring to my attention relates to the provision in the law that requires provider agencies to facilitate communication with and between families/guardians through the exchange of contact information for those involved in both day and residential programs. The purpose of this provision is to keep families/guardians engaged and knowledgeable about the experiences of their loved ones. The concern is that this provision does not seem to be widely implemented.

Another concern relates to the process for conducting unannounced visits. Specifically, it has been suggested that guardians should be made aware of such visits – after the fact – and should be included somehow in the interview process. I agree and also feel that individuals/families/guardians should have access to the final reports of those visits.

And lastly, another more general concern – identified in last year's report – is that this law only applies to adult (aged 21 and over) residential and day programs. The reason for this limitation is still not clear, and so we should explore the expansion of this law to children's group homes and programs.

Support Coordinating Agencies

As noted, (see "Case Management"), Support Coordinating Agencies (SCA) play a critical role for individuals and families seeking to access services and supports for adults ages 21 and above. Yet, I often hear complaints – similar to those expressed about CMOs – regarding a lack of responsiveness, experience and consistency, due to seemingly high staff turnover. In fact, some have questioned whether this large profit-based case management model – currently involving about 180 private agencies -- could ever work as effectively as needed. As one family member put it, "That penguin will never fly."

To be sure, I have had the opportunity to work with some excellent Support Coordinators – diligent, experienced, professional and deeply committed to their clients. I have also heard many families praise the service received, one referring to her son's Support Coordinator as a "godsend."

Further, it has been suggested that the problems outlined above may be a result, in part, of the rate at which Support Coordinators are paid as well as the responsibilities expected of them – concerns that they are underpaid and overworked. This is something that is being reviewed by DDD as well as the Independent Developmental Disability Fee for Service Transition Oversight Board. (Currently, the support coordinating rate is $239.81 per month – a rate that was developed several years ago before the position required a college degree and as discussed above, a rate that is much lower than that paid to Care Management Organizations in the children's system.)

Regardless, due to the importance of Support Coordinators, any problems – such as those outlined above – can have a devastating effect on the ability of an individual or family to get the services and supports they need and deserve. We need to figure this out.

Transitions

In my last report, I highlighted one challenge common to every individual with an intellectual or developmental disability and their families – the transition from childhood to adulthood. Known as the proverbial "cliff" – the point at which there seems to be a sudden drop in services and supports – this transition can be overwhelming for many families and negatively impactful on the individuals. For whatever reason, 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.

This needs to change. The transition from childhood to adulthood is a critical period in an individual's life due to the number and complexity of consequential decisions that must be made, including those related to:

- Adult Services and Supports
- Driving / State Identification
- Employment
- Health / Dental Care
- Higher Education
- Housing
- Legal Status (guardianship, power of attorney, etc.)
- Medicaid (needed for most adult services and supports)
- Social Security
- Transportation

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 for families – one that would ensure that all families, regardless of school district, have access to the same important, timely information about their child's transition into adulthood.

Moreover, DDD should consider allowing individuals to begin utilizing Support Coordinators at age 18, thus easing the transition into the adult system. This would likely go a long way toward eliminating the cliff, because it would help make the transition more understandable and more manageable for all young adults. Families would have a partner to help them with all of the transition-related issues, thus helping to ensure their children are placed on a safe, productive path.

Transitions Anecdote

The parents had their first transition meeting with school officials in late January – one month before their child turned 21 years old in February and 5 months before their child graduated in June. The focus of the conversation was on employment opportunities, and it was therefore good that someone from DVRS was present. The school officials noted the child's need to transition into the adult system of care and suggested inviting a DDD official to the next meeting, which would not be until right before graduation….giving the family no real chance to prepare for this enormous transition….

DDD should also consider relaxing its age-related policy more generally, allowing individuals to enter the adult system at age 18, rather than 21. Currently, there are minimal services and supports available to individuals who do not want to stay in the secondary school system until age 21 – individuals who are ready for employment or want to pursue higher education at age 18. Allowing this early entry into the DDD system would clearly have resource implications, but the cost would be mitigated by federal Medicaid dollars and could also possibly be mitigated by the use of local school funding until the individual turns 21 years old.

Taken together, there is a real need and a real opportunity to make a big difference in people's lives by bridging the gap between childhood and adulthood.

Transportation

The importance of transportation to people with intellectual or developmental disabilities – many of whom do not drive themselves -- cannot be overstated. For them, the shortage of accessible and affordable transportation options makes their involvement in the community – particularly through employment or day programs -- difficult, if not impossible. For them, planning even basic trips to doctors and grocery stores can often be an ordeal.

Plain and simple, we can talk all day about the importance of community integration and competitive employment, but if people do not have realistic transportation options, none of that means anything.

Granted, transportation is a tough nut to crack. Although physically, New Jersey is a relatively small state, transportation is a challenge for many, if not most, of us. Getting from here to there often seems more difficult than it should be. But again, for individuals with intellectual or developmental disability, it's not just difficult; it's often seemingly impossible.

Fortunately, most everybody seems to understand all of that, and there have been important efforts undertaken – in and out of government – to try to address the situation, such as –

- **New Jersey Travel Independence Program**: NJTIP is a Rutgers-based program designed to teach travel skills, including how to use our public transit systems, to people with disabilities and older adults.

- **Access Link**: N.J. Transit's paratransit program for people with disabilities who are unable to use the public bus system, Access Link, has been working in recent years to improve services – including with respect to wait times, payment methods and communications. That said, there should be a review of its policy of tracking N.J. Transit public bus routes, giving rides only to people who are within ¾ mile of those routes.

- **Community Transportation**: County-based paratransit systems are funded with a mix of taxpayer dollars and play an important role in the lives of some residents with disabilities. However, here, too, a review of current practices – including the refusal to provide inter-county transportation – should be undertaken.

- **Arc Mercer**: The Arc Mercer chapter established the "Arc Trans" transportation program for people with disabilities, using a fleet of 65 vans and buses.

- **Kessler Foundation**: The Kessler Foundation -- which is known to many for its work to promote competitive, integrated employment -- devoted its 2019 Annual Grantee Symposium to the topic of **"**Accessible Transportation in the Era of New Mobility" and followed it up with the launch of a "brainstorming" initiative that includes some of the State's key disability transportation leaders.

- **New Jersey Legislature**: There have been significant discussions underway in the State Legislature, including a 2019 hearing of the Assembly's Committee on Transportation and Independent Authorities and a recent hearing of the Senate Select Committee on New Jersey Transit.

Moreover, as part of the Murphy Administration's overall effort to fix N.J. Transit, there is a commitment to ensure that people with disabilities are central to the discussions and planning. In fact, I have had multiple conversations with agency officials, who are proactively seeking to engage people with disabilities in a meaningful way.

Nonetheless, we need to do more. We need to bring these efforts together in a meaningful, results-based way, and we need to add to them.

Among the ideas I have heard over the past year –

- "Transportation Concierge" – a proposed one-stop webpage dedicated to disability transportation that includes an easy-to-use comprehensive listing of and access to public and private options.

- "Transportation Disproportion Factor" – a proposed higher DDD budget and rate for those individuals who live in more remote areas of the State, recognizing that a person may live only 2 miles from her job, but it may take 10 miles of travel (each way) for a transportation provider to pick up and drop off the individual.

- "Wheelchair Rate" – a proposed higher DDD budget and rate for those who require wheelchair accessible transportation, which factors in the need for additional time and larger vehicle size.

- DDD Transportation Providers – a proposed approach that would allow companies, such as Uber and Lyft, to become Medicaid providers and thus able to take direct payment from DDD clients.

Again, there are a lot of promising conversations happening all throughout our State. We need to now harness all of the good ideas and good intentions into a more concerted effort – one that should probably have a region-by-region perspective, due to the unique challenges and opportunities that exist in different parts of the State. And in so doing, we need to keep in mind that when it comes to transportation, there is no single problem and no single answer.

Transportation Anecdote

Following years of a great school experience, a young adult with significant physical disabilities began participating in a day program. In 2017, due to the transition into the fee-for-service system, the day program provider informed the family that it would no longer provide transportation. In fact, the provider adopted a seemingly arbitrary catchment area of 10 miles, which effectively and immediately eliminated transportation for this individual as well as others in this remote part of the State. As a consequence, this individual now sits at home 2 weekdays per week and one of the parents is only able to work part-time….

Lastly, on the topic of school transportation, I think we need to seriously explore the possibility of mandating the use of camera technology on school buses, particularly those driving students with disabilities out of district. We have cameras on Access Link buses. We have cameras on some of the County-based community transportation buses. It is long past time to include them on buses that our children use.

WorkAbility

The Department of Human Services (DHS) has a great program that allows people with intellectual or developmental disabilities to work, make money, but not lose vital services and supports. Called NJ WorkAbility, the program allows individuals to earn up to about $65,000 without jeopardizing Medicaid eligibility.

However, the annual salary income limit seems artificially low. If we embrace the need to provide supports for people, we should not put a limit on their earning potential, which also puts a limit on their taxpaying potential. Also, there should be an allowance for folks in the workability program to also accept SSDI payments without disqualifying them from DDD services and supports. And lastly, it is not clear why there is an age limit of 65 years old for this program. We should be doing everything possible to support people who want to continue working.

Recommendations

As noted, this report is by no means an exhaustive list of issues facing New Jersey's disability community. Rather, it is a discussion of issues brought to my attention over the past year through my work with and for individuals with intellectual or developmental disabilities and their families.

Clearly, though, the challenges and opportunities are many and varied. Some are systemic and require longer-term approaches. Some are specific and could be addressed with relatively quick fixes.

Clearly, too, none of this is easy. Many of the challenges are complex. Many of the opportunities have resource implications. And many of the people working on these issues – in and out of government – are already laboring long hours, trying to balance a demanding set of responsibilities.

That said, as we all know, we have a responsibility to get it right.

To that end, in addition to specific suggestions noted throughout the report, here are a few general recommendations that can help us to develop a more "person-centered" system – one that places an even greater premium on individuality and choice, one that is even more responsive to the people we serve.

1. I recommend that we strengthen our approach for engaging individuals and families, doing everything possible to ensure that their voices are heard and their needs are met, including:

    - Giving individuals and families more direct, regular access to decision-makers, particularly on issues the directly affect them.

    - Visiting with individuals and families where they live, learn, work and socialize – making it a part of our job descriptions to spend meaningful time in their communities, really trying to get to know and understand their challenges and their opportunities.

    - Hiring more people with disabilities and their family members in government offices and appointing more of them to boards and committees that cover the full range of public policy areas, not just those that are disability-related.

    - Facilitating small group discussions with senior Administration officials, individuals and families – similar to meetings hosted by the Governor's front office late last year, including one hosted by First Lady Tammy Murphy.

    - Making an extra effort to reach more individuals and families, including those who may not have the time or wherewithal to attend government or parent group meetings, by better utilizing communication technologies and by engaging further into the diversity of our disability community, making sure all voices – across all cultures – are heard.

2. I recommend that we ensure that at least one Administration official – representing the views and interests of the disability community – be involved in the development of all major policy proposals, not just disability-related policy proposals.

3. I recommend that we organize ourselves across State government in an interdepartmental group -- breaking down silos -- to address cross-cutting issues, such as aging, transitions, employment and transportation.

Having spent nearly 2 years traveling the State, meeting with people and working with colleagues on a host of disability issues, I can honestly say that we – here in New Jersey – are at a moment. Sure, the challenges are great, but the opportunities are definitely greater. And with a consensus emerging among elected officials – of both political parties and at all levels of government – that more needs to be done, we have a strong wind at our backs.

Looking forward, we need to seize this moment. We need to build on the spirit of collaboration and open-mindedness on disability issues now prevalent throughout Trenton and beyond. And we need to "think big" and take the long view, recognizing the need for bold new approaches to everything from housing to transportation to employment to healthcare delivery to public safety.

There's too much at stake to do anything less.

Acknowledgements

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- Many of my colleagues across the Murphy Administration, particularly in the Governor's front office and in the Departments of Children & Families, Education, Human Services and Treasury with whom I worked on a regular – sometimes daily – basis. In this context, I need to give special thanks to the leadership and staff of the Division of Developmental Disabilities, whose teamwork makes my job easier and whose commitment makes many people's lives better.

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- And most importantly, 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.