



State of New Jersey

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

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April 12, 2021

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

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

Pursuant to P.L. 2017, c.269 (c.30:1AA-9.1-9.3), I am submitting the attached annual report to you concerning the work done by our office during the 2020 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,

A handwritten signature in blue ink that reads "P. S. Aronsohn".

Paul S. Aronsohn
Ombudsman

**Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families
Annual Report for 2020**

Submitted April 12, 2021

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 the many New Jerseyans who lost their lives over the past year as well as to their families, friends and communities.

Preface

Since the outbreak of the coronavirus, we have been living through an extraordinary moment in human history – one that has challenged all of us in ways never before imagined. Our physical health. Our mental health. Our emotional health. Our economic health. In unprecedented fashion, all aspects of our lives have been under siege by the COVID-19 pandemic.

Indeed, there really are no words that can adequately describe this moment. From the loss of family and friends to the loss of jobs and businesses to the loss of so many other things important to us – including our overall peace of mind --- the coronavirus has and continues to take a damaging toll on each and every one of us in ways we don't even fully understand yet.

And for many individuals with intellectual or developmental disabilities and their families, the impact has been especially difficult, especially challenging. That's because --

- Many of these individuals have been particularly vulnerable due to underlying health conditions and medical complexities.
- Many have challenging behaviors, which can be triggered by changes in routines and the loss of much-needed therapies.
- Many have been unable to practice social distancing, because they depend on the physical assistance of others – in group homes and intermediate care facilities as well as in their own private homes.
- Many have been unable to wear personal protective equipment, namely face masks, due to respiratory conditions or sensitivity to touch and texture or physical limitations, which prevents them from always using a mask.
- Many have communication disabilities, which pose a whole range of additional challenges – from those who need to lip-read, but are prevented from doing so because others are using standard face masks to those who need someone to accompany them and speak for them during hospital and rehabilitation stays.
- And many are students for whom remote learning just doesn't work and for whom the absence of in-person teaching and in-person therapy can be particularly damaging.

Moreover, the pandemic has exposed and deepened the fault lines in our State's system of care for people with disabilities. Vulnerabilities have been thrown into sharper relief. Weaknesses have been exacerbated.

It is against this backdrop that our office continued our work with individuals and families throughout 2020 – work that sought to help ensure they had access to the supports and services that they needed and deserved. And it is against this background that we have written this report.



Paul S. Aronsohn
Ombudsman
April 12, 2021

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Introduction

This is our third annual report.

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

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

Due to its scope and purpose, our office is most often contacted by people seeking assistance. Sometimes they need advice or direction. Sometimes they need an advocate. Often they are in crisis and in need of immediate relief.

Our focus therefore is most often on the many challenges faced by individuals and families – their frustrations as well as their unmet needs – rather than on the many success stories.

That said, we have tried to present information in this report in a balanced way, noting both strengths and weaknesses of the system. **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.

Throughout the report, I speak of the "system of care" for people with disabilities. By "system" I am referring generally to all of the people, policies and procedures in place for people with disabilities throughout New Jersey. That includes all levels of government, the provider community and beyond. That helps keep the focus on the net effect of all of the components in place for individuals with intellectual or developmental disabilities and their families.

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

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 supports and services 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 our 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 our office is guided by the Murphy Administration’s effort to make New Jersey a stronger, fairer place for everyone 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 advisors. Sometimes as advocates. Always as partners and resources, trying to serve as conduits 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 -- we have spent as much time as possible working one-on-one with individuals and families and, whenever possible, visiting them where they live, learn, work and socialize.

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

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

This is that report.

Summary of 2020 Services Provided

For all of us, the year 2020 was largely defined by our response – individually and collectively -- to the COVID-19 pandemic. In our office, that meant a slightly different approach to a much more demanding set of challenges.

With respect to approach, prior to the pandemic, we had made it a point to bring our office to the people we serve – visiting them in their homes, their schools, their places of employment, their communities. This gave us a uniquely personal and valuable perspective on the challenges faced by individuals and their families. We could see, hear and feel their life experiences, which, in turn, better equipped us to help them.

As noted in our [2019 annual report](#), this meant driving about 60,000 miles and visiting about 220 towns during our first 20 months of operation. Most importantly, it meant meeting one-on-one with hundreds of individuals and families.

Since the State shutdown last March, we have had to adjust this approach, while doing everything possible to maintain our personal connection to the people we serve. As such, we spent most of our time – often 7 days a week – talking by phone, communicating by email and meeting by video with individuals and families across the State.

And throughout much of the year, particularly in the early months of the pandemic, we made it a point to share – in real time -- the input we received from them with our colleagues throughout State government. We did this to inform the policy-making process. We did this to help ensure that the voices of individuals and families were heard during this unprecedented period of rapid decision-making.

With respect to challenges, the pandemic has only increased the need for supports and services, causing further strain to the already strained system of care for people with disabilities. Indeed, many in New Jersey's disability community have been disproportionately impacted by the pandemic – a point discussed in the "Preface" above and in the "COVID-19" section below.

Moreover, many of the pre-pandemic challenges faced by the community remain unresolved. In part, this is due to the State's focus on the public health emergency over the past year. As with so much else in our lives, attention to non-pandemic issues has largely been deferred.

Fortunately, in February 2020, our office doubled in size when Christine Bakter joined as our Associate Director. Like me, Christine brought with her an important mix of personal and professional experience with disability. As such, she was able to hit the ground running just as the pandemic was beginning to wreak havoc on our State and on the people we serve.

Together, we tried to accept every invitation to talk with people and to participate in various virtual meetings and events. Together, we tried to help as many people as possible.

Accordingly, throughout 2020 –

- We worked with colleagues across the State's Executive and Legislative branches, including in the Departments of Children and Families, Corrections, Education, Health, Human Services, Justice, Labor, State and Transportation as well as the Motor Vehicle Commission.
- We participated in multiple meetings of the [N.J. Council on Developmental Disabilities](#) (NJCDD) and worked closely with its Executive Director.

- We participated in multiple meetings of the [Regional Family Support Planning Councils](#).
- We participated in multiple meetings of the N.J. [Statewide Independent Living Council](#) as well as N.J.'s [Centers for Independent Living](#) and worked closely with several of their leaders.
- We met regularly with [Disability Rights New Jersey \(DRNJ\)](#) and worked closely with its Executive Director.
- We met regularly (often weekly) with NJCDD, DRNJ and [The Boggs Center on Developmental Disabilities](#) to compare notes and to organize public forums on pandemic-related topics.
- We met several times with the leadership of [Autism New Jersey](#).
- We participated in several meetings of the [Arc of New Jersey](#), including its Partners in Justice Task Force, and worked closely with the leadership of some of the organization's [local chapters](#).
- We attended multiple meetings of the [New Jersey Association of County Disability Services](#) and worked closely with several of its members.
- We participated in several State [legislative hearings](#).
- We actively supported the launch of the [New Jersey State Legislative Disability Caucus](#) – an initiative spearheaded by the NJCDD.
- We 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](#).
- We helped conceive and stand-up the [N.J. COVID-19 Disability Action Committee](#) – a diverse group of disability advocates – and participated in many of its meetings.
- We attended or participated in over 150 events, including some of the important programs organized by the Bergen County Special Services School District [CAPE Center](#), the [Passaic County Parents of Adults with Disabilities](#) and the [Alliance Center for Independence](#).
- We continued to formalize our office operations and strategic priorities by starting to build databases to help track the thousands of emails and phone calls received as well as an [official website](#), which will grow into a one-stop site of resources for individuals with intellectual or developmental disabilities and their families.
- I authored [a few opinion pieces](#), including one calling on the presidential candidates to prioritize people with disabilities.
- I participated alongside the New Jersey Attorney General [in a video](#) in recognition of Disability Employment Awareness month.
- I participated in a training session conducted by [New Jersey Travel Independence Program \(NJ TIP\)](#) for an individual learning how to ride New Jersey Transit trains.

- I spoke with journalists on a [range of topics](#), including the proposed expansion of our office to involve all people with disabilities.
- And very importantly, we had more than 1,000 one-on-one meetings and phone calls with individuals and families – in addition to many group meetings and email exchanges.

Through it all, we worked to ensure that individuals and families received the supports and services that they need and deserve.

- For some, that meant merely providing them with the names and contact information for specific government officials or advocacy organizations.
- For some, that meant speaking with them on a regular basis – answering questions, advising on a full range of issues and/or helping to develop and deliver communications to key decision-makers.
- And for some, that meant actually joining them in meetings with government officials, providers and advocates – sometimes as their silent partner/adviser, sometimes as their advocate.

Observations and Recommendations

In my first two annual reports, I asserted that New Jersey's system of care is a tale of two systems - one good, one not good enough. Having now served as the State's Ombudsman for about 3 years, I am restating that conclusion with even more certainty.

On the one hand, the system definitely has its strengths. Most notably, there are so many good, well-intentioned people working within the system – people who have dedicated themselves to serving others. Some work in government. Some work as Direct Support Professionals, Self-Directed Employees, Personal Care Assistants, Educators, health care workers, providers, advocates and in a whole host of other positions. They make it possible for so many New Jerseyans with disabilities to live safe, fulfilling lives.

Additionally, significant funding for programs, supports and services is often available at all levels of government – State, County and Municipal. That's true for children as well as adults.

Yet, on the other hand, the system definitely has its shortcomings, too.

Almost daily, our office is contacted by those who are falling through the cracks. Despite federal and state mandates, their child's education is less than "appropriate." Despite promises and official commitments, their ability to access much needed supports and services is lacking. Many are left to struggle on their own without any real help coming from government. Many literally call us in tears.

For some, the need is immediate and a matter of basic health and safety. For some, the need relates to housing, transportation, education, employment or some other quality of life determinant. And for still others, the need is longer-term and a matter of doing everything possible to make sure that vital supports and services remain in place for them or their loved one. This is particularly true for those parents who contact us, worrying about the future and asking "who will take care of my child when I'm gone."

Moreover, as discussed below, I have a haunting feeling that many adults who need supports and services are effectively being shut out of the system. Cultural barriers. Language barriers. Socio-economic barriers. For a host of reasons, I believe many adults with disabilities are "aging out" of the children's system of school-based entitlements and effectively falling off the figurative "cliff," never actually making it into the adult system.

In my first two reports, I catalogued and discussed many of the issues brought to our attention by New Jerseyans with intellectual or developmental disabilities and their families. Some of the issues were systemic, such as the complexity of our system of care and the need to place more emphasis on the civil and human rights of people with disabilities. Some of the issues were specific to certain groups of people or to certain challenges faced by individuals and families.

For this third annual report, we are trying something a little different: We have focused on a few key themes which demand attention:

- Our System's Approach to the COVID-19 Pandemic
- Our System's Approach to Families
- Our System's Approach to Basic Needs
- Our System's Approach to the Disability Community

Within that framework, the report speaks to many of the topics and concerns repeatedly brought to our attention over the past year by individuals and family members.

This is not to suggest that the previous years' long list of issues is no longer relevant. Quite the contrary. The issues discussed in prior years' reports remain as significant, if not more so, to many New Jerseyans with intellectual or developmental disabilities and their families – a fact reinforced daily through emails and phone calls to our office. Again, that is due, in part, to the pandemic and the State's need to focus its resources – namely, time, people and money -- on our response to it.

As such, we encourage everyone – particularly those in public office -- to read [those reports](#) and take note of the issues discussed, understanding that they remain front and center in the lives of tens of thousands of our fellow residents.

Issues Addressed in Last Year's 2019 Annual Report

[\(Click to see report\)](#)

General Observations

Need for Simplification * Need for a Sense of Urgency * Need for a Focus on Civil and Human Rights * Need for More Disability Perspectives * Need for More Choice * Need for Flexibility, Exceptions Procedures * Need for More Emphasis on Health & Wellness * Need for More Intergovernmental Collaboration * Need for More Transparency * Need for More Innovation * Need for Better Communication

Specific Observations

Adults * Autism * Bathrooms * Budget / Funding * Bureaucracy * Care Management Organizations * Case Management * Census * Children * Communications Disabilities * Direct Support Professionals * Employment * Fee-For-Service * Government Websites * Guardianship * Housing Options * Housing Subsidies * Individuals with Severe Challenging Behaviors * Medically Fragile / Complex Individuals * N.J Comprehensive Assessment Tool (NJCAT) * Personal Care Assistance * Private Duty Nurses * Public Meetings * Public Safety * Self Direction * Stephen Komminos Law * Support Coordination Agencies * Transitions * Transportation * WorkAbility

Importantly, most of the recommendations offered throughout this year's report would cost little, if any, money to implement; yet, they could go a long way to enhance the value of the system to the thousands of individuals and families who depend on it.

Our System's Approach to the COVID-19 Pandemic

With respect to New Jersey's response to the pandemic, there really are no words that can sufficiently recognize the extraordinary work done by so many people - in government, in health care settings, in communities throughout the state.

Personally, I am in awe of and grateful to many of our colleagues in the Murphy Administration and throughout all levels of New Jersey government. I am also in awe of and grateful to many of our colleagues in the provider community, particularly those serving on the frontlines, such as Direct Support Professionals, Self-Directed Employees, Personal Care Assistants, Nurses, Doctors and Educators. Without exaggeration, their efforts saved lives and kept people safe and healthy.

In the context of our office's work, I am particularly grateful to our colleagues at the N.J. Department of Health (DOH). Throughout the pandemic, we have worked closely with the Commissioner and her leadership team, and they have been exceptionally responsive and accessible to us. Whether we raised a question, made a suggestion or requested their intervention on behalf of an individual or family, the DOH leadership team has always been available and helpful.

That said, as noted above, the pandemic exposed the fault lines in New Jersey's system of care for individuals with intellectual or developmental disabilities.

Here are some observations about our response to the pandemic as it relates to the disability community, noting some of the things that worked and some of the areas that present opportunities for improvement going forward:

- **Communications**

The importance of accurate, timely and consistent information is absolutely vital during a crisis. In that context, the Governor's daily briefings were exceptional. It was so critical and so useful to have him, the Health Commissioner, the State Police Superintendent and others speak publicly on a daily/regular basis and to take questions from the press.

With respect to the disability community in particular, the communications were good, but could have been better.

Credit should be given to the N.J. Department of Human Services' regular meetings of the [N.J. Group for Access and Integration Needs in Emergencies and Disasters](#) (NJ GAINED) as well as the N.J. Office of Emergency Management's [Access and Functional Needs](#) (AFN) office. Both have been useful venues for State agency representatives and community partners to share timely information for the disability community.

Credit should also be given to the N.J. Department of Human Services' Division of Developmental Disabilities (DDD), whose weekly/biweekly webinars have been opportunities to exchange information with the public. We are not aware of another State division that has provided such a regular forum for the disability community.

That said, the approach and platform used by DDD has not allowed for a meaningful give and take with participants. It has not allowed participants to know all of the questions asked; nor has it made available a "chat" function available in many video platforms. As such, we have often heard of people's questions left unanswered.

More generally, we have heard complaints about unreturned calls and emails and just an all-around frustration with the “radio silence” many have often perceived with respect to disability-specific information, particularly concerning the availability of personal protective equipment (PPE), the status of State education policies for children and the status of State-licensed day programs for adults.

“We've been attending the online webinars Unfortunately, every time we asked about the DDD website translated to Spanish, (DDD) didn't reply.”

-- Parent, April 2020

Again, during a crisis, people’s need for accurate, timely and consistent information is at a premium.

Policies

Throughout the year, new policies had to be developed, revised and updated in real time. The pace of decision-making was often intense. And the need for information to make those decisions was constant.

As such, we did our best to inform that decision-making process by sharing with our colleagues throughout the Administration the input we were receiving from individuals and families. In fact, from mid-March through early-September, we compiled and shared with them a daily rolling list of issues, concerns, questions and ideas received through phone calls, emails and video meetings. Again, we did that to inform the policy-making process and to help ensure that the voices of individuals and families were heard and considered.

We also worked closely with our colleagues in the advocacy community, most notably the New Jersey Council on Developmental Disabilities (NJCDD) and Disability Rights New Jersey (DRNJ), to make sure Administration officials were getting public feedback as soon as possible.

Three significant memoranda, issued early and later revised, by the N.J. Department of Health – concerning visitation in [hospitals](#) and [long-term care facilities](#) as well as the [allocation](#) of critical resources – demonstrated that our Administration colleagues were responsive to the input received from individuals, families and advocates. That said, as intimated below, other policy decisions taken by State officials throughout the year did not always reflect the input received and shared.

Schools

One of the most daunting challenges faced by communities last year was educating our more than [1.4 million](#) school-age children during a statewide public health emergency. With little warning or preparation, big changes had to be made: Schools closed. Living rooms became classrooms. Parents became part-time teachers. In many communities, educators and families came together and found their way forward, rising to the unprecedented challenges quickly and effectively. Indeed, their ability to adapt to remote learning was nothing less than extraordinary.

Almost immediately, however, it became clear that this approach was having mixed results. Some families lacked the technology needed to participate in this new online reality. Some families were stretched beyond their limits as working parents tried to balance the increasing demands on their time, attention and energy. And some families, particularly within the disability community, discovered that virtual learning and virtual therapy just does not work for their children.

Indeed, many students with special needs have not only lost a year of school; many have reportedly regressed. Over the past year, parents have told us the most heartbreaking stories about children falling behind in essential skills (academic as well as basic life skills), while engaging increasingly in self-injurious and other dangerous behaviors.

As such, we heard from many parents seeking relief. Many wanted in-person [Extended School Year \(ESY\)](#) programs last summer and wanted their school buildings to reopen last fall – only to be largely disappointed and left feeling that their children’s needs were being disregarded. Now, many want the option of “making up” the school year that their child effectively lost – something that is being considered in Trenton.

Adult Residential Programs

Similar to the situation with schools, many of those providing supports and services to adults with intellectual or developmental disabilities also had to make big changes on short notice. This was particularly true for those adult residential provider agencies who (collectively) are responsible for the care and well-being of nearly 10,000 New Jerseyans. This was also true for the N.J. Department of Human Services (DHS) team that oversees and works alongside them.

Overall, they did a tremendous job under trying circumstances. New policies. New procedures. New financial arrangements. So many changes needed to be implemented – quickly – to make sure that the adult residents in State-licensed group homes and apartments were kept safe and healthy. And again, special recognition must be given to the frontline staff, namely the Direct Support Professionals, who regularly risked their own health and that of their families by providing hands-on assistance to the residents under their care.

That said, throughout the year, it became increasingly clear that there is a real need to revisit the State’s relationship with residential provider agencies. Simply stated, the agencies seem to have too much discretion, and the State – through DHS – should exercise more authority over their respective policies and practices. And while I fully appreciate attempts to balance strict infection controls with the adverse impacts of social isolation, State officials should – going forward – play a more forceful role to guarantee the basic civil and human rights of the individuals under its care.

Indeed, we heard story after heartbreaking story of residents having little, if any, meaningful contact with family members. No real visitation permitted. No real means to connect through technology. No sense of urgency with respect to the residents’ emotional well-being.

As such, we often heard family members voice concerns that their loved ones were being treated like second-class citizens – that seemingly “draconian” policies might be protecting their physical health, while doing real damage to their mental, emotional and behavioral health.

“What is the governor doing to help special needs students? Four months into the pandemic and no school for our most vulnerable population. Our students are experiencing severe regression and a lack of learning. Many of our children will suffer from severe behaviors going back to school as their world will again shift dramatically. It will take months to get them back on track when school begins. What is the governor going to do for them? Will he extend a district’s responsibility to educate our children passed age 21 to make up for the lost time?”

Parents are doing their best but we are not a replacement for the teachers that have specialized training. We cannot provide that level of teaching.”

-- Parent, July 2020

A compelling example was the recent [DHS policy](#) forcing a 14-day quarantine on individuals living in State-licensed homes – including in individual apartments – who merely visit with their families, regardless of their virus status. It was a policy far more stringent than the Center for Disease Control’s (CDC) [quarantine guidelines](#). And it was a policy that effectively forced many adult residents to be kept indoors and alone, while most other New Jerseyans had been free to work, visit family/friends, shop, eat at restaurants, etc. without any need to quarantine. (NOTE: This policy had been maintained until [March 15, 2021](#), despite the fact that many residents had been vaccinated.)

Another example was the DHS policy last summer that required agency providers to permit family visitation with loved ones living in State-licensed residences. When it was discovered that one such agency was not allowing family visits inside or outside one of its group homes – and thereby compelling at least one parent to literally sit in the public street outside the residence -- the response from the Department was that “Within the policy, we do require the implementation of outdoor visits. However, they do not have to take place on [the] property.”

To be sure, I know none of this has been easy, and I know that congregate settings pose especially serious challenges related to the spread of the coronavirus. But going forward, I also know that we need to do better. We need to do a better job striking the delicate balance between physical health and mental/emotional health.

Simply stated, we need to do a better job protecting and advancing the fundamental rights of the people we serve.

Adult Day Programs

State-licensed day programs for adults with intellectual or developmental disabilities were effectively closed throughout most of the year. The N.J. Department of Human Services (DHS) took steps, however, to provide programming for its clients and to maintain a level of financial support for the provider agencies to keep them from going out of business. Among other things, the introduction of virtual programming was a welcome and important development for both reasons.

Moreover, last May, DHS established a 10-person working group to develop guidelines for reopening the day programs. The group reportedly met a handful of times and produced guidance, which was circulated in early September and which resulted in the temporary reopening of some day programs for several weeks in the fall. [Note: My request to be a member of this working group was declined.]

Nonetheless, many families questioned the need to keep day program sites closed throughout most of the year, particularly since the State [reopened childcare centers](#) on June 15 and many schools were reopened in the fall. Questions were also raised about DHS’s refusal to allow individuals to use their assigned budgets to purchase technology, namely tablets and laptops, to engage in virtual programming. As a result, many individuals reportedly have had to use smartphones for their virtual programming, while others have only been able to call into the programs using basic cell phones.

Clearly, the closure of State-licensed day programs has had significant impact on the individuals involved. We have heard many troubling stories about the limitations of virtual programming as well as the devastating effects of social isolation and changes in routine. Moreover, similar to the situation with closed schools, the closure of State-licensed day programs has had a terrible impact on many families, too – families who try anxiously to keep their adult children engaged and safe, families who must sacrifice their jobs to stay home with their adult children.

[Note: Just prior to the release of this report, DHS announced [new guidelines](#) for reopening day programs by the end of March 2021. These guidelines, however, have thus far precluded the reopening of most day programs throughout the State – a fact that has led many families to contact us to express their outrage, their concerns and their fear for the potential negative impact on their adult children and their families.]

“My reason for contacting your office has to do with the fact that there is still no soft or firm opening dates for any of the community based programming.... I’ll be frank – camps, schools, daycares are all open. There is a stunning lack of priority or concern about DDD families. Our folks are forgotten and the communication is poor again. We just feel that we aren’t a priority. “

-- Parent, June 2020

• **Centers for Independent Living**

One of the best kept secrets in New Jersey is the work done by the regionally-based [centers for independent living \(CIL\)](#). Serving in a variety of capacities -- providing resources, services and advocacy – the CILs often play a critical role in the lives of thousands of New Jerseyans with disabilities.

Over the past year, their work – and their value – was taken to a new level as they were on the ground helping people with food, personal protective equipment (PPE) and appointments for vaccinations. And they have done all of this with a limited mix of federal and State funding – something that should be reviewed, particularly in light of the seeming disparity in monies received from the federal government during the pandemic.

• **Direct Support Professionals / Self-Directed Employees**

Adults with intellectual or developmental disabilities often rely on DSPs or SDEs – professionals who provide them with the supports and assistance they need to live, work or socialize safely and independently. And during the pandemic, these professionals – along with Private Duty Nurses and Personal Care Assistants – have been among the disability community’s frontline heroes.

Recognizing their indispensable role and their intensified pandemic-related workload, the N.J. Department of Human Services (DHS) decided early on to increase temporarily the salaries paid to those DSPs working "[in provider managed settings](#)" by \$3 per hour. Unfortunately, however, a similar increase in salary was not given to DSPs or SDEs working in other settings. The reason for this bifurcated approach is unclear.

• **Technology**

Like others, adults with intellectual or developmental disabilities have had a greater need to use technology for communication purposes over the past year. Many have needed it to participate in State-licensed day programming. Many have needed it to stay connected with family and friends. This has been particularly true with respect to those sheltering in place in State-licensed residences and physically cut-off from their loved ones.

However, the N.J. Department of Human Services (DHS) did not allow individuals to use their State-provided budgets to purchase such technology. Nor was there any effort – like the [Governor's initiative](#) to address the digital divide for students – to make technology and internet access available to adults with disabilities.

"We are asking that the NJ government acknowledge the mental anguish and permanent damage that this lockdown is doing to NJ families. It's literally tearing families apart...."

We are asking that you advocate on behalf of NJ families with disabled adults and push the DDD to permit parents to see their children in a more meaningful way."

-- Parent, July 2020

Fortunately, the New Jersey Council on Developmental Disabilities (NJCDD) and the Arc of New Jersey stepped forward later in the year to make a limited number of reimbursement grants available to individuals and families in need – up to \$250 for handheld devices, up to \$500 for computers.

Going forward, DHS should revisit its policy. Moreover, we need to draw from our pandemic experience and make better use of technology. In addition to the uses noted above – staying connected to family/friends and participating in day programs – we have also gained a new appreciation for the role technology can play in facilitating meetings, remote learning and telemedicine. Granted, technology is no substitute for “being there” and should not be viewed in that way. Rather, it should be considered a supplement – one that can help make life more accessible for all of us.

• **Personal Protective Equipment**

Throughout much of the year, personal protective equipment (PPE) was in high demand. That was true practically everywhere.

Using federal coronavirus relief funding, State agencies provided limited PPE resources to individuals with disabilities and their staff. That included provision of face coverings and gloves to participants in the State's [Personal Assistance Service Program \(PASP\)](#), which provides supports to many individuals with physical disabilities. However, we heard from several parents of adults with intellectual or developmental disabilities who noted that the State [only provided relief/reimbursements](#) to State-licensed provider agencies, leaving out many families, including those who “self-direct” their supports and services.

• **Vaccines**

At the end of the year, two vaccines received [Emergency Use Authorization \(EUA\)](#) from the U.S. Food and Drug Administration and were made available in New Jersey. The N.J. Department of Health – working in conjunction with the N.J. Department of Human Services – sought to [prioritize many people](#) in the disability community. Most notably, State officials adopted a very broad definition of “health care worker” that allowed many people who care for a person with a disability – paid or unpaid – to be vaccinated early in the process. They also placed a priority on residents and staff of State-licensed settings, including the Developmental Centers and group homes. And early in the new year, the Health Commissioner [sent a note](#) to all vaccination sites that, among other things, highlighted the need to make accommodations for people with disabilities.

However, we have heard from many individuals and family members, who were concerned and upset that – unlike in some other states, such as [Missouri](#) and [Ohio](#) – New Jersey did not initially establish a priority category for all individuals with intellectual or developmental disabilities. And with respect to people with disabilities more generally, some had wanted the State to prioritize those who are unable to wear a face mask or practice social distancing, because of their reliance on the physical assistance of others.

Instead, per guidance from the U.S. Centers for Disease Control and Prevention (CDC), on January 14, the State prioritized people with Down syndrome and other conditions that put them at "[increased risk](#)," which included some individuals with disabilities. Two months later, on March 15, New Jerseyans with neurological conditions (including autism spectrum disorder) were added to the eligibility list, and on April 5, all individuals with intellectual or developmental disabilities became eligible to receive the vaccine.

[Note: Just prior to releasing this report, we had an opportunity to visit all 6 vaccine megasites in New Jersey. The primary purpose of our visits was to review accommodations being made for people with disabilities. Generally speaking, we were very impressed with and grateful for the preparations made and the sensitivity and thoughtfulness of site staff to accommodate people with special needs and their families.]

"I'm sure you have heard this from other families, but the lockdown from Coronavirus has been devastating for those on the autism spectrum and their families. Day programs were abruptly suspended, likewise the fitness center programs. Many young adults with autism need a lot of physical activity every day; if they don't get it, they engage in self-injurious behavior, meltdowns, tantrums, etc. Boredom can even be a seizure trigger.

My son's forehead looks like raw hamburger because he is hitting himself so much out of frustration and boredom. That may do more damage to him than COVID-19 could

I know Governor Murphy is doing all he can to protect the lives of New Jerseyans. But life with a cooped-up autistic person can be so stressful, that we might prefer to take our chances against the virus".

-- Parent, August 2020

Our System's Approach to Families

Without question, families are often central to the lives and overall wellbeing of individuals with intellectual or developmental disabilities. The early onset and lifelong nature of the disabilities involve families in profoundly important ways. This is particularly true with respect to parents and siblings, who often play critical roles in the lives of their loved ones, such as that of caregiver, advocate or guardian. And as a general rule, no one knows or cares more about an individual than their mother, father, sister and brother. Absolutely no one.

Yet, we have often heard from families who feel that they have been treated in disrespectful and dismissive ways by government officials, by provider agency staff and representatives and even by disability advocates. Their views disregarded. Their motives challenged. And there is often a seemingly disapproving undertone to conversations about the role of family members in the lives of individuals with intellectual or developmental disabilities.

For me, this has been one of the most disturbing revelations since starting this office 3 years ago.

We see it in email exchanges. We hear it in conversations. And we feel it in the stories shared with us – stories of parents being told “what is best” for their child, stories of parents being made to feel responsible for their child's disability.

Sometimes the contempt seems obvious – evidenced by strained conversations and rudely worded emails. Sometimes it is subtle – heard and felt just beneath the surface. But believe me, it is often there, and it is always painful and always wrong.

As a result, we often hear anger in family members' voices – anger born of fear and frustration. They fear for their loved ones. They are frustrated with their treatment. And we often hear and feel the anger boil over in ways that tell us in no uncertain terms that these families do not feel heard.

Granted, sometimes the anger may seem unjustified or misplaced. But in all cases, it should be understood.

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

On a more basic level, part of the problem is that families are not always valued in their roles as caregivers, advocates, guardians or even as potential partners by government officials or provider agency staff and representatives – partners who, at a minimum, should have an equal seat at the decision-making table.

Regardless of the reason, this needs to change. Policies and processes should be put in place to give individuals and their families more agency and more consideration. This would be good and fair for them and for the system as a whole.

In fact, for everyone's benefit, we should facilitate more regular contact between families, government officials and providers, so that everyone's perspective and expectations can be better understood. We should enhance transparency regarding policies and practices, because, in part, a lack of transparency breeds distrust and sows discord. And we should level the playing field, because everyone should be treated with respect and equity.

To that end, as a start, here are some suggestions for empowering families in ways that would certainly benefit their loved ones as well as our system of care more generally – suggestions that could be included in a larger “Disability Family Bill of Rights” –

The Need to Strengthen Family Access to Decision Makers

- All individuals or their families/guardians should have direct access to senior officials in relevant State government departments, including the N.J. Department of Children and Families and the N.J. Department of Human Services. They should not always have to work through outsourced case management companies, namely care management organizations (children) and support coordinating agencies (adults).
- All State-licensed provider agencies – residential as well as day program, children as well as adult – should establish and maintain family advisory boards that meet regularly with agency leadership. Similarly, all State-licensed provider agencies which have a Board of Directors or Trustees should include some of their family members on the Board.

The Need to Strengthen Family Access to Information

- All individuals or their families/guardians should have ready access to read the information in their [iRecord file](#) – the electronic health record system utilized by the N.J. Department of Human Services and State-funded support coordinating agencies.
- All individuals or their families/guardians should have ready access to obtain relevant investigative reports produced by the N.J. Department of Children and Families, N.J. Department of Human Services, or any State-licensed provider agency.
- All individuals or their families/guardians should have ready access to review detailed information regarding the use of their personal and publicly-funded budgets, making clear exactly how their monies are being spent by State-licensed provider agencies.
- All State-licensed provider agencies should share contact information among individuals or family/guardians involved in their programs – something that has been a legal requirement for adult provider agencies since the 2018 enactment of [The Stephen Komninos Law](#).
- All State-licensed provider agencies should inform individuals or their families/guardians of any significant staff changes and prolonged staff absences from residential or day programs.
- All non-profit State-licensed provider agencies should make their [Internal Revenue Service \(IRS\) Form 990](#) – which provides the organization’s financial details -- readily available on their websites.
- The online databases offered by the [N.J. Department of Children and Families \(DCF\)](#) and the [N.J. Department of Human Services \(DHS\)](#) should be made more user-friendly and should be expanded to provide more useful information about the supports, services and amenities (including video monitoring technology) available.

The Need to Level the Playing Field

- All official meetings should be balanced in terms of participation. Unless by choice, a family member should never be alone in meetings with school officials, State-licensed providers or State government officials. Family members should be officially and consistently encouraged to invite other family members, friends, advocates, physicians, etc. to participate alongside them.
- The N.J. Department of Children and Families (DCF) and the [N.J. Department of Human Services \(DHS\)](#) should update, improve and provide individuals and families with detailed lists of their rights -- similar to what the N.J. Department of Education provides through its "[Parental Rights in Special Education](#)" brochure – and include the provisions outlined in this section.
- Families/guardians should always be welcome in congregate settings. They should never have to beg and plead for opportunities to visit with their loved ones. The N.J. Department of Children and Families and the N.J. Department of Human Services should establish and enforce policy to that effect.
- All "self-directing" families – those who hire and manage their own staff to care for their adult loved ones – should have the same rights, responsibilities and flexibility as State-licensed provider agencies providing a similar function, particularly with respect to rates of compensation and ability to hire relatives.

Beyond all of this, what is needed most is a change in mindset and approach – one that recognizes the rights, responsibilities and perspectives of families, one that respects their important role as caregivers, advocates, guardians and potential partners.

To that end, I urge my colleagues – in and out of government – to try earnestly to put yourself in families' shoes and see the situation from their perspective.

- Try to understand what it means to have a child or sibling with special needs.
- Try to understand that for many families, caring (and worrying) for a special needs child or sibling is a full-time – 24/7 – lifelong reality.
- Try to imagine being shut out of the conversation about "what's best" for your child or sibling.
- Try to imagine being admonished and reduced to tears when advocating for your child or sibling.

Again, none of this is easy. Providing supports and services to individuals with intellectual or developmental disabilities and their families is often challenging, and many of the people who work in our system of care -- government officials, providers and frontline staff – are professional, compassionate and completely well-intentioned.

But there is no question -- we need to do better by families. We need to treat them as valued partners. We need to treat them with respect. And to that end, in addition to the recommendations outlined above, we need to foster more meaningful collaboration among all stakeholders, including with families – a point discussed at length later in this report.

Our System's Approach to Basic Needs

Many people who work within the disability community talk about aspirations – about individuals attaining goals, realizing dreams, living fulfilling lives. That is both good and important. In fact, we need to do more of that. All people – regardless of disability status -- deserve to live, learn and work to their fullest potential, and we should always strive for the very best for ourselves and for each other.

That said, many individuals and families are unable to focus on such aspirations, because their attention, by necessity, is on meeting basic needs. Staying safe. Staying healthy. Staying alive. In fact, in our office, most of our conversations with individuals and families are about these basic needs.

- Parents desperately seeking behavioral and medical supports as well as critical therapies for their children; many left with no real choice except to place their child in an out-of-home residence – unquestionably, one of the most devastating decisions a parent could ever feel compelled to make.
- Adults and family members urgently seeking Private Duty Nurses, Direct Support Professionals and Personal Care Assistants to provide critical home and community-based supports, including help with [activities of daily living](#).
- Families seeking relief and protection for their children (minor as well as adult) living in sub-standard group homes, supervised apartments or other congregate settings; many the victim of abuse and neglect.
- Families seeking help during times of behavioral crisis.

Sadly, I do not believe that such situations are outliers. Although many New Jerseyans with intellectual or developmental disabilities have the supports and services they need and deserve, many do not. In fact, many are really struggling.

We therefore need to strengthen our approach to meeting people's basic needs.

The Need to Provide Fundamental Supports

With respect to those who have significant needs – medical, physical, behavioral or otherwise – we must make sure that they have the right mix of fundamental supports to live safe, healthy lives. As we continue to learn, without such supports, many individuals inappropriately end up in hospitals, nursing homes or some other less-than-optimal congregate settings. Or conversely, they end up staying at home, while posing a dangerous risk to themselves and their families (including often young siblings and ageing parents).

For children, we urgently need to make in-home supports more readily available – for their health and safety as well as for their family members. That means more specialists, including Private Duty Nurses (PDN) and Behavior Analysts, who will oversee and provide the child's treatment – something that would likely require an increase in both our Medicaid rates for [PDNs](#) as well as for Applied Behavior Analysis (ABA) therapy (See box below). That also means more respite hours for families, who need both time and space to take care of their own basic needs.

Medicaid Rates for Applied Behavior Analysis Therapy for Children (up to 21)

(15 minute intervals)

	New Jersey	Pennsylvania	Maryland
Direct ABA Therapy By a Technician	\$11.20	\$12.73	\$13.75

And for those children with severe challenging behaviors – which endanger them and their families -- we also urgently need more and better out-of-home residential options, so that we can end the practice of placing families in crisis on multi-year waiting lists for treatment beds. Currently, there are only 311 out-of-home residential placements (beds) for these children, including 27 in out-of-state settings. We desperately need more and better in-state beds, but until we have enough, families should be given – when necessary – more out-of-state options. We must be willing and able to help families when they need it most.

For adults, we urgently need more Private Duty Nurses and more Direct Support Professionals. That means we must increase their respective rates of compensation. The [Medicaid rate](#) for PDNs has not really changed in over a decade, and Direct Support Professionals often make just above [the minimum wage](#). Yet, both are very demanding professions and absolutely vital for the health and well-being of people with disabilities.

And here, too, we urgently need more State-licensed residential options for adults with significant medical or behavioral needs. Specifically, the State needs additional privately-run intermediate care facilities, medical group homes and residential settings – including campuses -- that can provide those with severe challenging behaviors the safety, treatment and community they need and deserve.

The Need to Improve Crisis Response

Due to the unmet need for fundamental supports, we often hear stories of individuals -- children as well as adults -- having a behavioral crisis and ending up in situations that only aggravate their condition. Often, the police are called; an ambulance takes the person to an emergency room; the doctors are unable to effectively treat the person, who remains in the emergency department for anywhere between 3 hours and 3 weeks before being discharged on a mix of psychotropic medicines.

Notwithstanding the use of vital, often scarce local resources – including first responders, hospital staff, and hospital rooms – the individual’s acute clinical needs are not addressed. The experience is traumatic. The new mix of medicines often detrimental. And without the right follow-up interventions, this vicious cycle inevitably continues and inevitably does more damage to the individual and the family.

In my 2019 report, I spoke of the need to take a more holistic approach to those with severe challenging behaviors – one that places a premium on early intervention and treatment and that takes a better approach to stabilization. This year, at a minimum, I am urging that we at least develop meaningful crisis response protocols.

To that end, I suggest that officials from various State government departments – Children & Families, Health, and Human Services -- work together to develop new, better, more effective processes and procedures for addressing a behavioral crisis. The Attorney General’s office has already taken an important step in that direction with [the December issuance](#) of a “directive establishing countywide working groups to address mental health and special needs populations...” This might be the right forum to move this issue forward.

Regardless, we must not only increase access to behavioral treatment to prevent and minimize the likelihood of such crisis situations, but when they do occur, we must find ways to increase the use of behavior analysts, while reducing the need for police intervention and acute care hospital stays. We also must ensure safe, appropriate “emergency beds” or other “step down” supports and services. And we must do all of this now – today.

The Need to Prevent Abuse and Neglect

With respect to those individuals – children as well as adults – living in congregate settings, we must strengthen oversight of and training for State-licensed residential providers. People may disagree about the prevalence of abuse or neglect, but there is absolutely no denying it exists. The New Jersey State Assembly Human Services Committee held two hearings late last year that made that painfully clear. [Please see [October 22 Hearing Video](#) and [December 10 Hearing Video](#).]

Granted, this in no way suggests that all State-licensed residential providers require more oversight and training, but until we end the abuse and neglect, we need to be more vigilant and more resolute in our approach, instituting a “zero-tolerance” policy that has real teeth and gets real results.

In recent years, important steps have been taken to ensure the health and well-being of individuals with disabilities living in State-licensed residences. Perhaps most notable were the enactment of [Danielle's Law](#) and [The Stephen Komninos Law](#). And most recently, there has been increased focus on the use of video monitoring technology.

Regardless of how people feel about any of these or other specific measures, there should be no question – more needs to be done to prevent the abuse and neglect of people with disabilities.

In this context, we should take a broad view of the concept of “abuse and neglect” – one that considers all aspects of life in State-licensed residences. After all, despite the 1999 Supreme Court ["Olmstead"](#) decision, some such residences are neither “appropriate” nor indicative of the individual’s choice – two concepts central to Supreme Court Justice Ruth Bader Ginsburg’s [majority opinion](#) in that landmark case. In fact, some such residences – including some group homes -- are seemingly run like cold, impersonal institutions that are effectively segregated from the community and provide only the bare minimum in terms of living conditions.

In my mind, such environments can be, in themselves, a form of abuse and neglect.

- **Community Life**

Notwithstanding their physical location in neighborhoods throughout New Jersey, some State-licensed group homes and supervised apartments do not provide individuals an integrated community experience. Many residents have little, if any, opportunity to walk into town or go to a local restaurant or visit a public park. Many remain effectively isolated

and sedentary. We must enforce standards to ensure a meaningful sense of community is enjoyed by all individuals – children as well as adults – living in all State-licensed residential settings.

- **Physical Environment**

Some residences are clean, attractive and well-designed to meet the needs of their residents. Others are dirty and in disrepair. Here, too, there must be standards enforced that raise the bar with respect to the physical conditions in which individuals with intellectual or developmental disabilities live.

- **Food**

We hear from families concerned about the quality of food available to their loved ones in State-licensed residences. Too much fast food. Too little nutrition. And too little attention paid to the individual preferences of the residents. This is completely unacceptable. Meaningful standards must be established and enforced to address this, too.

- **Health/Safety**

We often hear from families about the quality of medical attention given (or not given) to their loved ones. Mistakes made regarding the administration of medicines. Changes made – without authorization – to a person’s treatment regimen. And seeming deficiencies with respect to understanding the “fatal five” causes of preventable death for people with intellectual or developmental disabilities – aspiration, bowel obstruction, dehydration, seizures and infection/sepsis. Again, standards must be developed and implemented to prevent these very serious threats to people under our care. Fortunately, the [Family Advisory Council](#) last year established a health and safety committee, which will be making recommendations to the N.J. Department of Human Services.

- **Visitation**

Some State-licensed residential providers have very family-friendly visitation policies. Others do not. In fact, even before the onset of the statewide public health emergency, we often heard from families, who expressed concern about restrictive provider agency policies that kept them from spending quality time with their loved ones – in person or even just by phone or video. This is cruel and unfair to the families. This is cruel, unfair and unhealthy for the individuals.

Again, it is really wonderful and important that we think in aspirational terms, but we must – absolutely must – place increased emphasis on getting the basics right. More fundamental supports and services for people with significant needs. Better treatment and response protocols for people with severe challenging behaviors. And an end to the abuse and neglect.

At a minimum, we should be doing everything possible to ensure that New Jerseyans with disabilities are safe and healthy.

Our System’s Approach to the Disability Community

As noted, there is much to praise about New Jersey’s system of care for individuals with intellectual or developmental disabilities. Most notably, we have good people working within the system and significant resources to support it. And as I mentioned in my 2019 annual report, we also have a very supportive group of elected officials – in Trenton and throughout the State – who want to do the right thing with respect to people with disabilities.

That said, as outlined in this report and discussed elsewhere, there is certainly room for improvement.

In my previous [annual reports](#), I spoke to some structural opportunities to make the system more user-friendly, more person-centered and more effective. Among my suggestions were the following:

- Simplify the system.
- Focus on civil and human rights.
- Ensure individual choice.
- Enhance transparency.
- Hire and appoint more people with lived disability experience.

I certainly stand by each of those observations, and again, strongly encourage everyone to revisit our discussion of them. But this year, I want to carry that conversation further by focusing on three additional structural changes that could help make our system of care more accessible, more integrated and more collaborative.

The Need to Ensure a More Accessible System

Our system of care is ostensibly available to anyone with an intellectual or developmental disability. Beginning with our State’s [Early Intervention](#) services, our system is designed to provide vital supports and services to eligible individuals throughout their lifespan. Treatments. Therapies. Personal assistants. Education. Employment. Housing. Transportation. Recognizing the lifelong nature of intellectual and developmental disabilities, there is a full spectrum of resources available to individuals and families.

However, I fear that many people who need these supports and services do not, in fact, have access to them. For whatever reason – cultural barriers, language barriers or socio-economic barriers – I have a haunting feeling that many New Jerseyans with intellectual or developmental disabilities have been effectively shut out of our system of care.

More specifically, I cannot help but think that many young adults – particularly those living in underserved communities – are “aging out” of the children’s system of entitlements and effectively falling off the figurative “cliff.” As children, they get at least some supports and services through their schools, because it is mandatory. As adults, however, many of them fall through the cracks, because it is not mandatory and no one is there to advise, guide and advocate for them.

Granted, my concerns are based primarily on anecdotal evidence, including the fact that my office is rarely contacted by individuals or families living in our State’s cities, but it seems supported by the numbers, too.

New Jerseyans with Intellectual or Developmental Disabilities

Program	Age	Number Enrolled
Early Intervention System N.J. Department of Health	Up to 3 years old	14,000 (2020 approximate)
Special Education N.J. Department of Education	Ages 3 - 21	245,000
Children’s System of Care (CSOC) N.J. Department of Children & Families	Ages 3 – 21	13,760
Division of Developmental Disabilities (DDD) N.J. Department of Human Services	Ages 21 +	26,000

According to the statistics provided by relevant State government offices (see chart), there is a seemingly large discrepancy between those children accessing supports and services from the N.J. Department of Children and Families and from their local school districts. And there seems to be a significant drop-off between the number individuals with intellectual or developmental disabilities in the school system (under 21) and those in the adult system (above 21).

This is concerning.

Granted, not every student in special education has a lifelong, developmental disability. Granted, too, that some of those students with developmental disabilities may decide that they do not need the supports or services available in the adult system. However, the overall numbers seem to suggest that there are large differences between and among children and adults benefitting from government-provided supports and services. The question is “why?”

- Are children/families having trouble accessing supports and services from the N.J. Department of Children and Families? If so, why?
- Are adults/families having trouble accessing supports and services from the N.J. Department of Human Services’ Division of Developmental Disabilities? If so, why?
- Are there geographic or socioeconomic reasons for the difference in number of individuals accessing services through the local school districts, the N.J. Department of Children and Families and the N.J. Department of Human Services?
- Do we need to do more to reach people of different cultures and languages?

The anecdotal evidence and numbers suggest that the answer to each of these questions is “yes” – that many New Jerseyans have been effectively shut out of parts of the system. Regardless, it is clear we need to make a concerted effort to reach individuals in underrepresented communities and make sure that they, too, have access to the supports and services they need and deserve.

To that end, I recommended in my 2019 annual report that we make State-funded Support Coordinators (case managers) available to every 18 – 21 year old with special needs. This would likely go a long way toward eliminating the cliff, because it would help make the transition into the adult system more accessible, more understandable and more manageable for all young adults. Families would have a partner to help them with all of the transition-related issues – adult services, employment, education, transportation, healthcare, legal status, housing, etc. -- thus helping to ensure their children are placed on a safe, productive path into adulthood.

I also recommend that the relevant State departments – Children & Families, Education and Human Services – follow the lead of the N.J. Council on Developmental Disabilities (NJCDD), which has developed an ad hoc committee to explore how best to reach and serve currently underrepresented communities.

Regardless, we need to make it a priority to proactively make our supports and services more readily available to all individuals with intellectual or developmental disabilities and their families. It is not good enough just to offer them. We need to make them truly accessible.

As underscored in my 2019 annual report, “Equity is not about giving everyone the same services and supports; it is about ensuring everyone has the same opportunities.”

The Need to Develop a More Integrated System

Disabilities vary, and individuals with disabilities vary even more. Not only is autism different than cerebral palsy, but as the saying goes, “When you’ve met one person with autism, you’ve met one person with autism.” The same certainly holds true with respect to meeting one person with cerebral palsy or any other condition. Every disability is unique. Every individual is unique.

As such, we often talk and organize ourselves around disability types and categories such as, developmental, physical and mental. You hear it often in conversations. You see it often in practice. But while doing so certainly makes sense in some circumstances, there are downsides to such categorizations as well. They have the tendency to obscure the similarities among people with different disabilities – in terms of needs, challenges, opportunities, etc. They often prevent us from best leveraging resources and lessons learned. And at times, they even create an “us v. them” dynamic within the disability community.

We therefore should consider taking a more holistic approach to disabilities – one that approaches the issue under one big umbrella, while maintaining a necessary focus on specific disabilities and categories. This would allow us to capitalize on the similarities, synergies and overlapping interests among people with disabilities, while paying proper attention to the distinctiveness and unique challenges of each. And this would inevitably lead to a more diverse mix of government officials, self-advocates and family members engaging – together – in policy discussions and policy making, thus inevitably leading to a better, more integrated system of care.

Case in point is the current structure of the N.J. Department of Human Services (DHS). On one side of the department, reporting to one Deputy Commissioner, is the Division of Developmental Disabilities (DDD). On the other side, reporting to the other Deputy Commissioner, are the Commission for the Blind and Visually Impaired, the Division of Deaf and Hard of Hearing and the Division of Disability Services. And then there is the Division of Mental Health and Addiction Services, which reports directly to the Commissioner.

Now, this might make sense from a management perspective, but it seems to create arbitrary dividing lines and workflows that – at least on some level – must serve to undermine a more all-inclusive approach to New Jersey’s large disability community. At a minimum, it might make more sense to have all of the disability-related offices report up through the same Deputy Commissioner.

Regardless, recognizing the need for a more holistic approach, there have been efforts undertaken to create more integrated platforms to represent and serve the full diversity of New Jersey’s overall disability community. The formation last year of the [N.J. COVID-19 Disability Action Committee](#) is one example. The effort to expand the scope of my office to include all people with disabilities is another.

By approaching policy and organizational discussions from a more inclusive, more integrated perspective – one that appreciates similarities as well as differences -- I firmly believe that we will be better positioned to serve all people with disabilities, many of whom do not fit neatly into any one particular category.

Similarly, to the extent possible, I recommend that the disability community coordinate its advocacy efforts by seeking solutions that address common problems. Although disability-specific advocacy is extremely important and often necessary, there is power in numbers and diversity, and when the community speaks with one voice, it can be especially powerful, influential and successful.

The Need to Foster a More Collaborative System

Throughout New Jersey, the maze of offices and programs for people with disabilities is large and confusing. As noted in my report last year, “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.”

This complexity is one of the greatest barriers to people receiving the supports and services they need and deserve. It not only makes the system difficult to navigate; it also makes it highly inefficient, thereby wasting much-needed resources.

And to make matters worse, there is a tendency for people to operate in silos – narrowly focused on their own limited set of needs, interests and responsibilities with little, if any, attention paid to others’ perspectives.

In other words, New Jersey’s system of care for people with disabilities not only has too many moving pieces, but those pieces often do not work well together. There is often a disconnect between work being done on the State level, the County level and even within departments on both levels. There is also often a disconnect between government officials, provider agency representatives and individuals/families – a disconnect that results in miscommunication, misunderstanding and missed opportunities.

We must break down the silos and place a premium on more and better collaboration.

To that end, I offer up a few recommendations:

1. Break Down Silos Between State Government Departments

There should be an interagency working group that meets regularly to address cross-cutting disability issues and coordinate approaches – an idea put forward in my first two [annual reports](#). In addition to its formal meetings, this working group would inevitably result in closer, more meaningful working relationships between officials in different departments.

2. Break Down Silos Between State and County Governments

As discussed in last year’s report, each of the 21 County governments has an office that is responsible for disability issues. Yet, each County’s approach varies, and many have little, if any, working relationship with their counterparts throughout State government, thus preventing them from leveraging all of the programs, supports and services offered in Trenton.

To address this, we should establish regular opportunities for officials at both levels of government to share ideas and coordinate efforts. One way to do this would be to create formal seats on the [New Jersey Association of County Disability Services](#) for officials from various State offices, including the Department of Children and Families, the Department of Community Services, the Department of Education, the Department of Human Services, the Department of Justice, the Department of Labor and the Department of Transportation.

3. Break Down Silos Between Government Officials, Providers and Individuals/Families

We should create more opportunities for government officials, providers and individuals/families to get to know each other -- opportunities that would allow them to speak candidly, thoughtfully and frequently about our common purpose in providing safe, fulfilling life experiences for those with intellectual or developmental disabilities. Perhaps the N.J. Department of Children and Families and the N.J. Department of Human Services could host annual “conventions” and more regular events – in person as well as virtual – that bring everyone together in a meaningful way. Perhaps the provider agency membership organizations – such [the New Jersey Association for Community Providers](#) (NJACP) or [the Alliance for the Betterment of Citizens with Disabilities](#) (ABCD) – could do so as well. Or as suggested by one provider agency representative, perhaps our office could serve as convener and bring people together for informal, thoughtful conversations.

Regardless, we need to build bridges among all stakeholders, putting an end to the “us v. them” mindset that often seems to prevent meaningful, much-needed collaboration.

4. Undertake Internal Reviews

We should revisit the way our State government is organized to address disability issues. Along the lines of my discussion of a “more integrated system” above, reviews should be undertaken within departments or perhaps in the context of the interdepartmental working group discussed above. They should look at everything from the division of labor/responsibility within each department to the ways in which various offices collaborate. They should also look at the

responsibilities in each department and determine whether there is a need to revisit any of them. For example --

- Should the N.J. Department of Children and Families give responsibility for children with disabilities back to the N.J. Department of Human Services?
- Should the N.J. Department of Education play a more robust, more comprehensive role in transitioning children into the adult system?
- Should the N.J. Department of Human Services have more programs for people with physical disabilities?
- Should the N.J. Department of Labor have an office responsible for disability transportation?
- Should, as one colleague suggested, each State government department have a disability policy point person?

Such reviews should be informed, in part, by lessons learned from other States.

5. Place More Emphasis on Mental Health

Over the years, New Jersey State government has placed an emphasis on providing “trauma informed care” – the practice of addressing the link between traumatic experiences and a person’s “basic sense of self, trust in others, physical, social, emotional, or spiritual well-being.” This has been true in the N.J. Department of Human Services’ [Division of Mental Health and Addiction Services](#) and most recently, in the context of the N.J. Department of Children and Families’ work to address [Adverse Childhood Experiences \(ACE\)](#).

Going forward, we need to extend this practice of trauma informed care to people with disabilities (children as well as adults), making it a centerpiece of our approach to them and their families (parents as well as siblings). We should take a “whole of government” approach, ensuring that all of us who work with individuals with disabilities and families are trained on how best to apply the [guiding principles](#) of trauma informed care.

As the COVID-19 pandemic has highlighted, we need to be more aware of and more sensitive to the emotional toll disability can have on a child, an adult, their siblings and their parents. When working with individuals with intellectual or developmental disabilities and their families, we need to better understand the trauma they may have experienced and the trauma they may still be enduring. We also need to develop approaches and policies that do not inflict further trauma upon them.

On the most basic level, our ability to best serve individuals with intellectual or developmental disabilities and their families depends on our ability and willingness to understand them.

Conclusion

Again, New Jersey’s system of care for individuals with intellectual or developmental disabilities and their families has both strengths and weaknesses. Good people. Significant resources. But also gaping holes that need to be fixed.

Granted, none of this is easy – for those who work in the system and certainly for those who rely on it. Providing supports and services for people with disabilities is often time-consuming, expensive and emotionally demanding. Relying on others for basic supports and services is often frustrating, worrying and even frightening.

That said, the system is critically important, and it is incumbent on all of us – particularly those of us who work in government in the field of human services – to get it right.

This report is full of observations and recommendations. Some big. Some relatively small. But all of them are being offered with an appreciation for the realities that often constrain the system as well as the possibilities that can and should strengthen it.

To that end, I will close with an appeal.

Let’s make this work. Let’s redouble our efforts and recommit ourselves to building and sustaining a system of care of, by and for the people it is designed to serve.

- That means engaging people with disabilities and their families in all decisions, paying real homage to the community’s clarion call, “Nothing about us, without us.”
- That means hiring and appointing more people with disabilities and their family members to key government positions, including cabinet-level offices.
- That means keeping the focus on what is best for the people at the center of it all: the thousands of New Jerseyans and their families who depend on it.

In 2017, while running for Governor, then candidate Phil Murphy promised to “make sure that people with disabilities have a seat at our policy-making table,” underscoring that “improving the lives of people with disabilities is a top priority.” And since its start, the Murphy Administration has been working to bring that promise and commitment to life.

It hasn’t always been perfect, and it hasn’t always been smooth. But there is no question, we are moving the ball forward. Working with our colleagues in the State Legislature – in both political parties and both houses – and our partners across the State, we have made progress on a range of issues and have made a difference in the lives of many of the people we serve.

“... even as we continue to confront the pandemic’s challenges, we cannot – and we will not – allow our state to sit still. We won’t allow New Jersey to be pulled backward. This is the time to look ahead.”

-- Governor Phil Murphy, February 2021

Let’s keep the momentum going. Let’s keep striving for a more perfect system – one that finds its way through the pandemic, embraces families, meets people’s basic needs and serves the entire disability community in a more accessible, integrated and collaborative way.

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