APPENDIX

Testimony Human Services Committee

My name is Javier Robles I am currently the chair of the Covid-19 Disability Action Committee. I am also the Director of the Rutgers Center for Disability Sports, Health and Wellness as well as the Vice President of the Latino Action Network and the creator and moderator for the Facebook group People with Disabilities Help Each Other Survive the Coronavirus. This group has close to 700 members at this point.

Today, we stand at a crossroad of what has been and what could be. The systemic failures which people with disabilities and people of color have been confronted are unprecedented and overwhelming. By the state own estimates about half the people that died in the state of New Jersey, died in nursing homes. 6438 residence and 133 staff members. There were 557 long-term care facilities that self-reported outbreaks! Many of these individuals were people with disabilities, some psychiatric, developmental or physical.

These facilities as well as our own state facilities were woefully underprepared for what many knew was coming. As the CDC and the World Health Organization have stated it was not a matter of if it would happen but when it would happen. The state of New Jersey, it's departments and those that it contracts with were unprepared. Plain and simple. The Covid – 19 Disability Action Committee is in the process of preparing our own report, by people with disabilities, their family members, advocates etc. we have been meeting for almost 2 months to identify what went wrong, who was affected, and what we can do to fix these problems in the future. We anticipate a final report by this Fall.

We are looking at short and long-term fixes. Some of these fixes and issues include the following:

1. During the height of the pandemic people with disabilities, their caretakers, and family members were unable to secure PPE. When some of these individuals reached out to government agencies, including some right in human services they were told that they would have to purchase their own PPE. Although, they were members of existing programs in those departments.

2. People with Disabilities lost direct support professionals and had no options to replace them. Many family members and/or friends were forced to step in to ensure the survival of people with disabilities in their own homes. There was no plan before hand as to what visiting homemakers, personal care assistance programs, or other programs at human service should do.
This is unacceptable! Thousands of people depend on the professionals in these departments to ensure their safety and well-being. Our report will provide recommendations for this.

3. Food security. We need all existing programs that provide food assistance or funding for such programs to have a plan for ensuring that people with disabilities can have access to safe affordable food during a crisis or pandemic. This did not happen. Many including myself, were

unable to find any type of access to food or food delivery. We were forced to ask other family members to put themselves at risk by going out and shopping. We need more accountable corporations maybe on the contract with your department, the Department of Health and maybe the governor's office to ensure that all people in the state of New Jersey are able to receive food in times of crisis. This is especially troubling for people on specific diets such as diabetics, individuals with immune system issues or other dietary requirements.

4. Individuals with disabilities and their families across all departments should be able to make health decisions which affect themselves and loved ones on their own. The fact that many of our state citizens died unable to see or talk to their family members is unacceptable. Moreover, the fact that without input from people with disabilities, their family members, and/or advocates our state adopted The Pittsburgh Tests which is a scale to evaluate who received lifesaving equipment and who does not is a slap in the face to our democratic values.

It is illegal under the Americans with disabilities act, section 504 of the rehabilitation act, and the law against discrimination of New Jersey. It is not easy to trust a system which does not incorporate the views and values of people with disabilities as well as, on committees and lawmaking bodies in the state. No adult with a disability, whether it is intellectual, developmental or physical should be asked to give up their rights, and many did without family members present. This is especially troubling as it relates to individuals with developmental and intellectual disabilities. It shows, that the fight for equality in this country is far from over. This is something we also saw in nursing homes. Family members unable to speak to or see their loved ones before they passed away.

No hospital member, or committee should force a DNR order on a person who is disabled or elderly without a trial or a fair hearing. All hospitals should instead ought to perform CPR or other lifesaving measures unless the individual with disability or family member has expressly written and consented to a DNR. This is extremely troubling. The lives of individuals with disabilities matter to someone. They should matter to this body and they should matter to our state government. We must come up with a policy that takes into account the worth of people with disabilities and the elderly. This cannot be done without the input of people with disabilities, their family members and the elderly.

5. This pandemic affected many people with disabilities, but it was especially troublesome for those who had to see doctors, dentists, and mental health professionals. Many people with disabilities who receive dialysis or other life-sustaining treatments were highly vulnerable with no alternatives in place. Many had to either forgo treatment or risk getting infected with coronavirus and received treatment. Many people including myself waited before my doctor was able to provide telehealth. However, the state of New Jersey was not set up nor does it appear that they were in contract with many health providers for telehealth services. The inability to leave your home during the pandemic was also destabilizing and stressing for individuals with mental health conditions who see a therapist on a regular basis. The fact that many could not reach their therapist or doctors and had no telehealth service available to them, exacerbated a problem that needn't have happened. The state of New Jersey must do a

better job at ensuring that telehealth is an option for all regardless of where you live, how much money you make, or what your disability or race is.

5. People with disabilities of color were overwhelmingly affected. Better job at outreach - language.

6. During this pandemic so many people on the frontline died in order to take care of others. We should honor their memory by ensuring that people on the front line, doctors, nurses, visiting homemakers, personal care assistance, and parents who take care of their children with disabilities have adequate services and pay available to them. Some individuals with disabilities saw their workers become infected with coronavirus and move from home to home with the possibility of infecting others. Why?

The answer is simple some of the lowest paid workers in the state happen to be homemakers and personal care assistance. These individuals have worked for years for a single or multiple people with disabilities and their families. By working for multiple families, the individuals are able to make more money. It is unconscionable, that our state does not pay them more money for the work that many will not do. In fact, many of these individuals could make a lot more money, $15-$16 an hour working at Amazon or FedEx, then the $9 to $11 dollars that they make to working as personal care assistance. Moreover, doctors and nurses, PCA that assisted and/or will assist in future pandemics should have hazard pay attached to their salaries.

7. Communication access for people with various disabilities also showed how unprepared we were to deal with issues of communication. From PPE equipment such as facemask that was a barrier to the elderly and those who read lips to sign language access during telehealth appointments state and many of our medical facilities were unable to solve these issues. In many instances, people with disabilities themselves came up with ideas such as facemask or shield with a clear plastic to allow individuals to still be able to communicate and stay safe. Departments should have a communication plan in place with everyone they contract with especially the Department of human services, who contracts with nursing agencies visiting homemakers, personal care assistant services etc. These contractors click clearly spell out what it is that the contract he's are expected to do as it relates to communication and people with disabilities. It is the law that the state of New Jersey and its departments as well as those they contract with do not discriminate against people with communication disabilities.

8. Since, Wade blank a Presbyterian minister who was fired from a nursing home in the 1970s for advocating community living to those people with disabilities there, we have been working on the issue of inclusive housing. As opposed to institutional settings such as nursing homes, psychiatric hospitals, etc. No person with a disability should be forced to go into a nursing home simply because there is no other option. Nursing homes as we have just witness are not the answer to community living. They are not the answer for people with disabilities and I would dare say they are not the answer for our state elderly many who are veterans. This model is broken! It is up to us to fix it. We cannot fix this model by throwing more money at nursing home corporations and those who lobby to get the state's business. We must use whatever

resources are available to renew the call which Wade Blank set out in the early 70s. Inclusive, community housing for people regardless of ability. Moreover, our committee and our Facebook group often discussed the fact that corporations who oversee nursing homes in our state will never learn from those who died in their care as long as government across the United States and in New Jersey issue pardons for their utter lack of preparation.

Many of us are fortunate to be alive. So many of us in the state of New Jersey have underlying health conditions and one in five individuals in the state has a disability. The current pandemic is an opportunity to learn and to fix the systemic issues which affect the independence, life, and opportunities available to people with disabilities and their family in the state of New Jersey. While my testimony has not painted a rosy picture, it should offer this committee and opportunity to see where we can fix things for the long haul. My committee of individuals with disabilities, their family members and advocates will be making various recommendations specific to many departments in New Jersey, the governor's office and the legislature. We understand that some of these things cannot be fixed but through legislation. We also know that some of our recommendations may be met with resistance asked the question that is always asked will be asked. How do we pay for this? That is a fair question. However, that is not the question that any policymaker should be asking. The question should be, how do we not pay for this?

Thank you for your time and patience.
Javier Robles

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Testimony In Opposition to A-4239
Assembly Human Services Committee
June 25, 2020

Allows in-person visitation for immediate family members and legal guardians of residents of certain community-based residential programs and group homes during COVID-19 pandemic

Easterseals New Jersey understands the intent of A-4239. Our agency has worked hard to make visitation safe and accessible for family and guardians during the COVID-19 pandemic. That being said, the bill as written, does not offer service agencies and regulators the flexibility and clarity needed to effectively address this matter.

Additionally, the Department of Human Services and other state regulatory agencies recently released a comprehensive set of rules which enable safe and accessible visits, in addition to guidance for establishing screening procedures. We believe that this existing framework is sufficient to achieve the goals set forth in A-4239.

We are heartened to see this issue is being taken seriously by the Committee and the sponsors of this bill. Families and guardians play an essential role in the care of those in our group homes, and our intent is to always include them when safe and feasible. However, the safety of our program participants and staff must come first.

The COVID-19 pandemic has created challenges for visitation that we have never had to deal with in the past. The State correctly suspended all visitation in an effort to minimize exposure to the virus for this already vulnerable population. However, now that New Jersey is slowly reopening, we want to ensure our community is included.

Easterseals New Jersey commends the hard work of the legislature and this Committee for keeping health, safety and inclusion at the forefront of the conversation. We look forward to working with the Chairwoman and members to continue the important discussions about how we ensure the wellbeing of those in our care.

While we cannot support A-4239 today, we believe that there is an opportunity for service agencies, the sponsors, the Committee, and relevant state agencies to work collaboratively to craft a thorough and flexible solution that ensures access to visitation while protecting the safety of our program participants and staff members.

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Easterseals is a national 501(c)3 nonprofit organization that has helped children and adults with disabilities and special needs, live better lives for 100 years. Operating in 21 counties throughout the state, Easterseals New Jersey offers a variety of disability services to help people with various special needs address life's challenges. Annually, Easterseals New Jersey serves over 5,000 individuals at our over 100 sites with direct services, advocacy, and education. We believe everyone, no matter their circumstance or level of ability, deserves the opportunity to increase their independence and achieve their goals.

Brian Fitzgerald, President and CEO
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Easterseals New Jersey Testimony
Assembly Human Services Committee
June 25, 2020

Understanding the impact of COVID-19 on New Jerseyans with disabilities, their caregivers, and the non-profit agencies that serve them

Easterseals New Jersey is grateful for the opportunity to share our perspective on the impacts COVID-19 has had on our agency, our staff and those we serve. Thank you to Chairwoman Downey and the members of the Human Services Committee for scheduling this hearing in order to receive our feedback and listen to our concerns.

COVID-19 has had severe impacts on disability services in New Jersey. The past several months have been an incredibly challenging time for Easterseals New Jersey and the entire human services industry. There have been sector-wide furloughs and layoffs, a massive reduction in revenue, and cutbacks to available services.

Our agency has been working through these monumental challenges while also dealing with the medical impact COVID-19 has had on our tight knit community. These obstacles have unfortunately been foisted upon non-profit service agencies at a time when need for our services has never been higher.

When a crisis occurs, caregivers and Direct Support Professionals (DSPs) are among those hardest hit. As a critical part of the healthcare infrastructure, particularly at community and individual levels, their unique potential for contribution to pandemic preparedness cannot be overstated.

One in four Americans lives with a disability, and many people with disabilities face heightened risks if their DSPs are unable to perform their critically needed services. It is our responsibility to give DSPs and caregivers the necessary counsel and resources in order to protect themselves and those in their care.

According to the New Jersey Division of Developmental Disabilities, more than 30,000 people across New Jersey are employed as DSPs. This group of passionate caregivers has proven to be an essential part of our collective response to this pandemic. We could not be more proud of the amazing work they continue to do.

Easterseals New Jersey provides services to nearly 5,000 New Jerseyans living with intellectual disabilities and mental health challenges. Some of these services are indoor activities that have had to close during the pandemic. These include Day Habilitation, Employment Services, and individual counseling and case management.

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These services have been curtailed in order to ensure the safety and health of our program participants and staff. Unfortunately, this is a sword that cuts both ways. By reducing services, our program participants have lost access to the care they need, and our staff have lost the employment that sustained their livelihoods.

The long-term damage done to some agencies may be irreparable. And for those agencies who can recover from the shutdown, the services we offer may not look the same for some time. Day Habilitation has been particularly hard hit; and this service was already in need of additional support before the COVID-19 pandemic struck.

Additionally, we have had to restructure our Day Habilitation and related transportation programs to be compliant with social distancing and other important COVID-19 related health guidelines. We are making difficult choices about who will have access to services in the coming new human services reality.

Our residential services and supportive housing staff have been working throughout the pandemic. Their efforts have been truly inspiring, but it does take a toll on them. We need to ensure that our essential workers are paid a fair wage and acknowledged for their tremendous efforts during this challenging time.

Easterseals staff from our Employment Services and Day Habilitation programs have been working hard to maintain contact with their program participants through virtual means. While this cannot replace the interactions that program participants are used to, our staff's ability to think outside the box has been inspiring to see.

As New Jersey begins to reopen, it is important that those living with disabilities and mental health challenges are included. We must work together to ensure that the State and service agencies work collaboratively to ensure those we serve have access to care, and also are protected from exposure to COVID-19.

Steps such as ensuring access to PPE, setting clear guidelines, guaranteeing a living wage for DSPs, reimbursement for remote services such as telehealth, and maintaining regular communication between agencies and state regulators will enable a successful reopening of the human services industry in New Jersey.

Easterseals New Jersey stands ready to assist in the reopening in any way we can. We look forward to working with the Legislature, the Department of Human Services, the Department of Labor, and the Governor's Office in partnering on a safe and sustainable reopening of services for New Jerseyans living with disabilities.

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Brian Fitzgerald, President and CEO
Jacob Caplan, Advocacy Manager

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NJACP New Jersey Association of Community Providers
Advancing Quality Services for People with Intellectual and Developmental Disabilities

NJACP Testimony
Assembly Human Services
committee
June 25, 2020
Valerie Sellers, CEO

On behalf of the over 55 agencies the New Jersey Association of Community Providers (NJACP) represents and the thousands of people our members serve with intellectual and developmental disabilities (IDD), thank you for the opportunity to comment on A4239. I am Valerie Sellers, CEO of NJACP

NJACP is empathetic about how difficult it is for families to be separated from their loved ones, it is difficult for anyone, and maybe even more so for people with IDD. However, at the height of the pandemic, this was the policy and recommendation of the Division of Developmental Disabilities (DDD) and the Department of Health (DOH) in an effort to keep the individuals served, the staff who work for them and family members safe and healthy. This is every agency's number one priority. The current policy permits outdoor visits, however, that is after a marked improvement in the number of infections and deaths in New Jersey.

Under most circumstances, it is the Commissioner of Health that will dictate practices during the declaration of a public health emergency; as such, directives such as visitation should originate with the Department of Health in consultation with DHS. It is every agency's goal to protect the health and safety of those they serve. Visits occurring before public health and DDD officials issue an authorization. It is by no means unrealistic that when visits occur in the homes, those entering the home may be COVID-19 positive but asymptomatic. At issue is the possibility families and other visitors can bring the virus into the home. Given the vulnerability of many within the IDD community and potential exposure to staff and their families, the priority must always be the health and safety of those being served, among others.

Complicating and contributing to the risk of visits prior to receiving directives from DOH and DDD is the fact that individuals with IDD may not be able to tolerate masks or recognize the need for social distancing As we all know, these are critical practices as a preventive measure to protect against the transmission of COVID-19. One cannot ignore the fear that the direct support professional workforce has with individuals coming into the home with no knowledge if they are COVID-19 positive. There are individuals who cannot tolerate face coverings or understand preventative measures, putting individuals at greater risk of contracting the virus. Policies and procedures should have the objective of protecting both the clients and the workforce and to mandate desired visits does nothing to minimize the risk of transmission.

Agencies want to do everything possible to keep individuals connected to their families in a safe way. During the pandemic, agencies encourage the use of electronic communication platforms, such as Skype, to maintain close contact with loved ones without potentially bringing infections into the home.

NJACP must oppose this measure and support directives from state public health officials in collaboration with DDD. This is critical for the health and safety of individuals with IDD as well as the staff and their families.

As always, please consider NJACP a resource and do not hesitate to contact me with any questions or for additional information at 609-406-1400.

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Assembly Bill 4138
Assembly Human Services Committee
Tom Baffuto, Executive Director
June 25, 2020

Good Afternoon members of the Assembly Human Services Committee. The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and developmental disabilities and their families. We have 20 affiliated local chapters providing services in all 21 counties in New Jersey. Our mission is to enhance the quality of life of children and adults with intellectual and developmental disabilities (I/DD) and their families through advocacy, empowerment, and education

Thank you chairwoman Downey for the opportunity to provide brief comments today in support of Assembly Bill 4138, which requires the Division of Developmental Disabilities to develop a public emergency response plan for service providers and facilities serving individuals with developmental disabilities (I/DD). We agree with the goal of the legislation, which is to create a blueprint for how to handle a crisis like COVID-19 in the future. Doing so will ensure a statewide outline is available for all community providers and will help maintain the health and well-being of individuals with intellectual and developmental disabilities.

Before I delve into the details of the legislation, I want to take a moment to commend DHS Commissioner Johnson, Deputy Commissioner Adelman and Assistant Commissioner Jonathan Seifried for their excellent leadership and support of people with intellectual and developmental disabilities and the community providers who serve them during this challenging and unprecedented time. This has been a difficult period, with complex and unforeseen obstacles, and we are grateful for the Department's dedication and commitment to those we represent.

We thank Assemblywoman Huttle for her sponsorship on the legislation and we ask her to consider two additions to the legislation that we believe will further strengthen the bill. First, we believe that the in a time of crisis, both the Department of Human Services and community provider agencies should be following the guidelines distributed by federal agencies overseeing the emergency situation. With that in mind, we ask that language be added mandating the public emergency response plan to require, "any guidance published by the US Department of Health, the CDC or other relevant federal agencies involved in remediating the emergency."

Secondly, we believe community provider agencies must be at the table with the State when the public emergency response plan is developed. I am proud to say that many Chapters of The Arc actually implemented practices during the pandemic that the Department of Human Services later mandated for all community provider agencies. This included closing day programs before the state ordered it and prohibiting staff from working in multiple programs or with multiple agencies in order to prevent further spread of the virus. Community provider agencies can offer important insight to the Department about the experiences they had during this difficult time and this will result in a more comprehensive emergency response plan that everyone can support. That is why we ask you to amend the bill to include community provider participation.

Thank you again for the opportunity to voice our support for the legislation.

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Assembly Bill A4239
Assembly Human Services Committee
Tom Baffuto, Executive Director
June 25, 2020

Good Afternoon members of the Assembly Human Services Committee. The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and developmental disabilities and their families. We have 20 affiliated local chapters providing services in all 21 counties in New Jersey. Our mission is to enhance the quality of life of children and adults with intellectual and developmental disabilities (I/DD) and their families through advocacy, empowerment, and education

Thank you chairwoman Downey for the opportunity to provide brief comments today in support of Assembly Bill 4239, which requires community provider agencies who operate group homes to allow in-person visitation between a resident and the resident's immediate family members and legal guardian. I think it's fair to say COVID-19 has put a tremendous strain on our state and much of that is due to the social distancing requirements we all must adhere to in order to prevent further transmission of the virus. And while a necessary step, social distancing has been even harder for the families who's loved ones live in group homes, many of whom do not fully understand why they haven't seen their families for weeks and now months. In lieu of visits, I am proud to say that Chapters of The Arc have worked hard to keep residents connected to loved ones through virtual means and with traditional phone calls.

Many individuals with I/DD also have medical challenges and underlying health issues that make them more susceptible to COVID-19. A NPR story published earlier this month stated people with I/DD who contract COVID-19 die at higher rates than the rest of the population. With this in mind, community provider agencies have limited in-person gatherings. The goal is not to keep residents away from their loved ones, it's to keep people healthy and safe.

However, we understand that these have been a very long three months and we agree that families who have been kept apart from their loved ones should be allowed to visit, so long as they follow the requirements set forth in this legislation such as maintaining social distancing, wearing a face covering and completing a screening for exposure to, or symptoms of COVID-19. In addition to the precautions already in the bill, we urge the sponsor to amend the language to match the *"Guidance for Residential Providers on Visits with Family and Friends,"* which was released last week by the Department of Human Services. The Arc of New Jersey fully supports the Guidance because it does an excellent job outlining the steps both providers and family members need to follow in order to keep everyone safe while COVID remains a threat. We strongly endorse the document which fairly balances the desires of families with the need for precaution.

The primary item missing from the bill, is the requirement stipulated in the guidance that requires visits to take place outdoors. As per the Guidance: "These visits, referred to as Social Distancing Visits, must occur outside of the group home…The Centers for Disease Control and Prevention (CDC) reminds us that indoor spaces are more risky than outdoor spaces for interactions to occur. This is because it might be harder to keep people apart and there is less ventilation."

It is critical that providers balance the need of the individual receiving visitors with the well-being of other residents at the home who may be more medically-fragile or who have underlying health conditions that put them at greater risk of contracting COVID.

In closing, we believe when done with proper safety precautions, group home operators should allow individuals the opportunity to visit with loved ones. We thank Assemblywoman Huttle for sponsoring the legislation and for the chance to speak on it today.

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Assembly Human Services Committee
Impact of COVID-19 on People with Intellectual and Developmental Disabilities
Tom Baffuto, Executive Director
June 25, 2020

Good Afternoon members of the Assembly Human Services Committee. The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and developmental disabilities and their families. We have 20 affiliated local chapters providing services in all 21 counties in New Jersey. Our mission is to enhance the quality of life of children and adults with intellectual and developmental disabilities (I/DD) and their families through advocacy, empowerment, and education

Thank you Chairwoman Downey for convening today's hearing and for focusing on the needs of people with intellectual and developmental disabilities, their families and community provider agencies during this incredibly difficult time. Although we have faced significant challenges, and continue to do so each day, I am incredibly proud of our 20 local county Chapters of The Arc and the Direct Support Professionals who have done everything they could to protect the health and well-being of those they serve. The state, and the disability community is not out of the woods, and the future is marked by incredibly challenges, but I am hopeful that in partnership with state leaders, the system can continue to provide the service people with I/DD and their families depend on.

I want to start by acknowledging the Department of Human Services Commissioner Carole Johnson, the Deputy Commissioner Sarah Adelman and especially Assistant Commissioner Jonathan Seifried who oversees the Division of Developmental Disabilities. The Department has exhibited excellent leadership in a time of crisis and they are dedicated to the well-being of those we serve. To start, Assistant Commissioner Seifried hosted weekly webinars for families and providers to keep communication lines open and to provide updates. It was incredibly helpful to have these sessions each week at the height of the crisis, and we appreciate the Department keeping stakeholders and families apprised of all relevant happenings. The Arc of New Jersey also thanks the Department for their continued support on other critical items including, a 20% enhanced rate for residential providers who have been caring for individuals at home 24 hours a day, seven days a week, since this crisis began more than 100 days ago. We are also grateful for the retainer payments providers have received for day habilitation programs that were mandated closed by the State in mid-March. These payments have helped providers maintain day program staff and pay for other incurred costs while providers are unable to bill Medicaid for services delivered. And we are especially grateful to the Department and the Governor for recognizing the critical role of our Direct Support Professional workforce, who have cared for and assisted residents during this uncertain time, with a temporary $3 per hour wage increase for three months. The funding for these items have helped providers retain staff and facilities so they can focus on the health and safety of those they serve.

Personal Protective Equipment

Direct Support Professionals who care for individuals with I/DD are often responsible for assisting with tasks of daily living. Bathing, toileting, and feeding are all intimate tasks that cannot be accomplished while practicing social distancing. The need for Personal Protective Equipment (PPE) for our DSPs cannot be overstated and while we are grateful that the Department was able to provide some, at a time when even hospitals couldn't obtain enough supplies, community provider agencies were mostly left to fend for themselves when it came to PPE. To date, providers have spent thousands of dollars on PPE to protect both residents and staff without a means of state funded reimbursement. During the height of the health crisis, providers had a very difficult time securing PPE which also made it very difficult to assure the safety of the staff, who are the lynchpin to the support system. As New Jersey moves to re-opening, and individuals start to receive services again outside the home, the need for PPE will only grow. This need, as well as accompanying funding mechanisms, must be addressed in the days ahead so that services can safely resume.

Direct Support Professionals

In the past three months, the Direct Support Professional workforce has proven to the state what The Arc of New Jersey already knew: that these staffers are more than just employees, they are essential to our community and their work should be both elevated and admired. During this crisis, DSPs kept showing up to care for those they serve, even if it meant jeopardizing their own health or the health of their families. And they didn't just perform their normal workload. They kept spirits up during the stay at home order, reassuring individuals, many of whom are medically vulnerable and scared about the contracting the virus. They found ways to keep people engaged, to practice the habilitative skills they were no longer receiving at a day program or at an employment site. DSPs kept people in touch with their families through virtual means and phone calls so that social distancing didn't have to mean isolation. When everyone with an office job was able to complete assignments remotely, safely from home, DSPs continued to venture out each day so those that need them wouldn't be left alone. We cannot thank them enough.

Recommendations and Reopening

While the past three months have presented obstacles we have never seen before, the road ahead is paved with unique challenges that will require both creativity and additional funding in order to be successful. Social distancing requirements and face coverings present distinct challenges for people with I/DD that others may not encounter. Those we represent may not understand why they are being asked to stay six feet apart, while for others, a full day of wearing a face covering will likely prove untenable. We urge the state to keep the provider community at the table as the re-opening process continues. Any moves forward must be done in a planful way. Providers are looking at all new mechanisms for serving people with disabilities. Everything from facility and vehicle modifications, schedule modifications and transportation reconfiguration must be taken into account. We are pleased to be included in the current DDD re-opening committee and we hope to continue this needed dialogue so that all perspectives are taken into consideration before plans are implemented.

Our recommendations are as follows:

As we move toward re-opening, the state must continue the day program retainer payments and the enhanced residential rate until providers are fully operational again. When day program does re-open it will be a slow process. Providers will need to limit the capacity of these programs and this means some individuals will I/DD will still receive the bulk of their service provision at the group home or residential setting. Until day programs can safely serve a full roster of individuals, the enhanced residential rate and day program retainer payments are critical.

In addition, we urge the state to continue the $3 increase for DSP wages. While New Jersey may be making moves to re-open, COVID is still here and DSPs are putting their health on the line every day just by showing up to work. We must continue this increased wage to maintain staff during the weeks and months ahead.

The State must also create a system that allows for quick and easy access to PPE. When the pandemic first hit, available PPE was distributed to hospitals and nursing homes but not to our group homes even though the population we serve can be both medically-fragile and more vulnerable to COVID-19. While the DHS did distribute two small shipments of PPE, it was much later into the crisis. Should the state face another pandemic in the future, or a second wave of COVID, there must be a mechanism for quick and early access to PPE. Protecting individuals and staff served by our system cannot be optional. A stockpile must be created so providers can receive the supplies they need to ensure everyone's safety. In addition, providers must be reimbursed for the thousands of dollars they've spent thus far on protective equipment. Providers have also spent similar sums on needed medical supplies and cleaning supplies.

As the state prepares for a potential second wave of COVID, people with intellectual and developmental disabilities and our DSPs must be prioritized when it comes to testing. While testing is now more readily available, people with I/DD and their staff struggled at the start of the crisis to get the testing they needed to prevent further spread of the virus. We recognize the importance of nursing homes and emergency responders, but our system is equally important and we too serve people with significant medical and health challenges. As we continue to push back on COVID, or should we face another health crisis in the future, this population must be given quick and easy

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access to testing. In addition, "in-home" testing must be made available to individuals with I/DD who cannot go to a testing center. During the height of the crisis, providers had great difficulty waiting in long lines at testing centers with clients who were ill and experiencing possible COVID symptoms.

Finally, we recommend Direct Support Professionals be deemed an essential workforce for any future emergency. Not having this designation added to the difficulties providers faced when trying to staff group homes in the midst of the health crisis. While nursing home workers were deemed essential, our staff were not given the same label and this made it more challenging to support people with I/DD. This needs to be changed going forward.

In closing, The Arc of New Jersey recommends that people with intellectual and developmental disabilities and our staff be given the same prioritization and considerations other vulnerable populations receive. Inclusion of our population moving forward will mean people with I/DD are not left out when it comes to needed resources, supplies and assistance. I thank Chairwoman Downey for prioritizing these issues, and convening today's hearing. And thank you to the Committee members as well for your continued dedication to people with intellectual and developmental disabilities.

June 25, 2020

Dear Chair Downey and members of the Assembly Human Services Committee:

My name is Dr. Toby Davidow and I am an advocate for elder abuse awareness and partner with fellow advocacy organizations such as CEAR (Center for Estate Administration Reform) and Kasem Cares, where we seek guardianship reform and visitation rights between seniors/vulnerable adults and their loved ones, respectively. I am writing in support of NJ A-4239 being considered today, and also urge you to incorporate a vulnerable person abuse awareness recommendation.

Many residents living in community based homes may not always be fully able-bodied or able-minded to care for themselves. They rely on staff and loved ones' visits to assist with everyday tasks, such as eating and socializing. When loved ones' visits go away, especially due to the COVID-19 visitation ban, it takes a toll. For example, international nursing home research has shown that loneliness affected nearly 40% participants in one study (Trybusińska, D., & Saracen, A. (2019)), while another study found that severe loneliness was felt two times more in nursing homes over other group homes, and contributed to early death (Victor, 2012).

Severe loneliness is an important enough reason for visitation rights to be reinstated between seniors/vulnerable adults and their loved ones. However, an equally important, but often overlooked, rationale is the amount of emotional and financial abuse that takes place, when no one is watching. Corrupt guardianship is a silent epidemic wreaking havoc on seniors, vulnerable adults, and their families across the United States, where unscrupulous people control their ward(s) AND profit (Aviv, 2017). The pattern is so similar in hundreds of known cases, the factors have become a battle-cry in advocacy circles: "Isolate. Medicate. Liquidate." This means a corrupt guardian isolates the senior/vulnerable adult from their families, over medicates the person to get them to sign over asset control to the guardian, and then liquidates their estate to gain a profit even while the ward is alive. We are also finding that "defaming legitimate protectors" is another tactic that is often used by manipulative guardians to control money and assets. Whether medicating, defaming, or liquidating, it starts with the isolation of a vulnerable individual. While major news stories about this are emerging out of California, Florida, Michigan, Nevada, and Texas, occurrences in New Jersey are prevalent as well. The stories are eerily similar to my own.

I grew up in Cherry Hill, NJ, where I was an only-child to two very loving parents. For all of my adult life, my mom was a vulnerable adult who had Multiple Sclerosis (25 years) and Dementia (10 years). Yet, my mom was isolated from me, and the rest of the family, for the last three years of her life. Neither her sister, nieces, nephews, friends, nor I knew she was receiving hospice treatment for 3 months or that she even passed away. I learned of her passing from a friend of a neighbor a week after it happened. My mom was not afforded a funeral, was cremated against her original burial wishes, and all her possessions were trashed or sold. She died alone. The cause of this devastation is easily pinpointed to a fraudulent caregiver, who incrementally took control of our household four years prior by isolating my parents from the rest of the family, controlling phone calls and emails, inserting herself on all estate plans, selling off our family heirlooms on EBay, and moving herself and her ill husband into the family home. All the nefarious actions of the caregiver were fully orchestrated and protected by the predatory legal community. Once the caregiver controlled and isolated my parents and their estate, there was no cost effective way to stop them. Law enforcement viewed her actions as "civil" and Adult Protective Services did not see any physical harm being done and dropped the case. Professional guardianship in the US is an abyss fully controlled to serve the legal community at the expense of the vulnerable. If this can happen to me, it can easily happen to anyone in an unmonitored group home, where a resident is already isolated and even confused.

In conclusion, while justified at the height of the first wave of COVID-19 in NJ, completely banning visitation to seniors/vulnerable adults has been an infringement on human rights, welfare, and even legacy. Now that NJ restrictions are being lifted, it is time to allow visitation of loved ones. Please consider two requests:

- Pass NJ A-4239 so that families can connect with their loved ones, as soon as possible
- Reconsider NJ A-3648, the "New Jersey Alienation Prevention and Consensual Response Act" which was introduced to your committee on March 16, 2020.

Thank you for your support and care of our most vulnerable populations. Please feel free to contact me with any questions ([redacted]com).

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State of New Jersey
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PAUL S. ARONSOHN
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Testimony of Paul Aronsohn,
Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families
New Jersey Assembly Committee on Human Services
Thursday, June 25, 2020

Good afternoon, Chairwoman Downey and Members of the Committee.

Thank you for holding today's hearing and for including all of us in this important discussion.

Without question, we are living through an extraordinary moment in human history – one that has challenged all of us – individually and collectively – 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.

- That's true across our country and our world.
- And that's certainly true across New Jersey.

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 an overall piece of mind --- the pandemic 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, the impact has been especially difficult, especially challenging. That's because --

- Many of these individuals are particularly vulnerable due to underlying health conditions and medical complexities.
- Many have severe challenging behaviors, which can be triggered by changes in routines.
- Many aren't able 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 homes.
- Many are 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 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.

In the Ombudsman Office, we know of these challenges through our direct and personal connection to many of these folks. Through daily phone calls and emails, we have been in regular contact with individuals and families – responding to questions, listening to concerns and learning, first hand, about their often very difficult experiences.

And we've been sharing those insights with our colleagues throughout the Murphy Administration in an effort to inform their thinking and to shape their decision-making ... doing our best to make sure that the voices of these individuals and their families are heard in a meaningful way.

And we've had the opportunity to work closely with legislators, advocates and providers from all over the State, including many of those participating in today's hearing.

Going forward, I hope and expect that we will all benefit from lessons learned over the past few months – good, bad and otherwise. I hope and expect that we will engage in honest, thoughtful and open conversations about what worked and what didn't ... acknowledging the unprecedented nature of this experience, while fully recognizing and fully owning our responsibility to get it right.

And going forward, we will do everything possible to make sure that individuals with intellectual or developmental disabilities and their families play a central role in these conversations. Because to get it right, we need to make sure that they have a seat at the table and that their insights and experiences inform our State's emergency management planning, preparedness and response.

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

Thank you.

ACI
ALLIANCE CENTER
for INDEPENDENCE

Carole Tonks, Executive Director

Alliance Center for Independence

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Good Afternoon. Thank you to the committee and Assemblywoman Downy for inviting me to speak.

My name is Carole Tonks, I am the Executive Director of the Alliance Center for Independence, we are one of 11 centers throughout the state and one of 400 centers throughout the country. We serve people with all disabilities and all ages in assisting them in learning the skills to live independently.

Historically, people with disabilities have been left out of planning and left behind during disasters...Because of this, our office has been involved in disaster planning since Hurricane Irene.

I am also the parent of a 36-year-old autistic son. My son Jason attends a day program and lives at home with my husband and I. Jason requires full care in dressing, toileting, eating and all of his daily needs. He does not have verbal speech, he has social anxiety, as well as behavioral and sensory issues. As not to paint only a bleak picture of my son... he is also kind, compassionate and has a great sense of humor.

My son has been home since the end of February, he had health issues when he was younger making him immune compromised. Life has been challenging for us. His behaviors have increased, he demands constant attention and he has regressed. Due to my son's behavior and sensory issues, he will not wear a face covering. I do not know when his day program will reopen and I am not sure that I would feel comfortable sending him back, but I worry about losing his spot in the program. My story is no different than many other families struggling to work and care for their disabled child or adult. We have many questions and not many answers. How will day programs accommodate those with significant disabilities?

Over the past several months our office has made wellness checks to 3500 of our consumers as well as calls to those on the Middlesex County Register Ready list. We heard a lot of stories during those calls and kept a running list of concerns that we heard from people with disabilities and families. I would like to share some of those concerns with you today. I would also like to point out that while this session is focusing on people with intellectual and developmental disabilities, people with ALL disabilities are affected by COVID and I ask that the committee does not lose sight of that.

- **Congregate care** is obviously a large issue affecting individuals not only in nursing homes but group homes, developmental centers and long-term care facilities. We are all aware of the lack of PPE and shortage of staff. Shortage of home health aides etc., puts people with disabilities at risk of being placed in congregate settings such as nursing homes, if they do not have adequate supports.

- **Testing** - Residents and workers in developmental centers have been tested for the virus, group homes have still not been tested. We are unable to receive an answer as to when this will happen.

- We heard from a family who told us of their adult child who lived in a group home tested positive for COVID. She was taken to the hospital, the hospital wanted to release her to a nursing home, where there have been staggering death tolls. A recent study showed that people with developmental disabilities have a 16% higher chance of dying from the virus than the general population.

- **Group home staffing** - We were made aware of agencies running group homes and not assigning the Direct Support Professionals (DSPs) to specific homes. DSPs are not equipped with PPEs or told not to wear them in the home. The only protection is that their temperature is taken upon entering. DSPs should be assigned to specific homes to help contain the spread of the virus. DSPs should be provided with the proper protection for their safety and the safety of those residents living in the homes. This issue needs to be addressed prior to a possible resurgence in the Fall.

· **PPE** - We received a call from an elderly Grandmother caring for 4 children with disabilities, 3 with autism, she would not allow her home health aides into her home because they did not have face coverings. Currently, staff who fulfill caregiving roles across a variety of settings—from nursing homes and long-term care facilities to home and community-based settings—perform many of the same or similar services as frontline hospital staff but without the same protections. This means that many of these workers and those they care for are not given the same level of access to necessary PPE as hospital personnel, leaving them and those they care for vulnerable to infection and cross-contamination.

•**Long Term Care Facilities** - Families/guardians that have a loved one in a long-term care facility were not getting updates on how their loved ones were doing. We have heard of several situations where residents in the facility were testing positive, but family members were never informed.

It was also brought to our attention that families in at least one of the developmental centers had no contact or information on their loved one for over a week. Long term care facilities must do a better job in contacting families/guardians as well as having the technology to allow residents to keep in touch with their loved ones.

· **Resource for Families** – The people working the NJ 211 hotline are very nice and are compassionate. However, there is a need for additional training on providing accurate and complete information that addresses the needs and situations for disabled individuals and their families. Many families calling 211 for assistance were given wrong information, given resources in other states, making families extremely frustrated. Many families were being referred to the centers for independent living for assistance.

· Support Coordinators need to be given the resources to help families during these times. We have had numerous Support Coordinators asking if we knew anything about parental hire (a program which pays families to act as DSPs for their children).

· Technology - Many people with disabilities/families do not have access to tablets, laptops, smart phones, etc. Many do not have internet service and are unable to access imperative information. For those without the technology to keep them connected to their peers and online events, we are seeing a great increase in social isolation for family members and those with disabilities.

This is especially true among elderly families. Online support groups are a helpful solution to keep people connected, however, there are limited groups for families who have adult children.

These are just a few examples of the challenges facing people with disabilities and their families. I will email a list of concerns that address additional issues. We need to commit to expanding home and community-based services and reduce the number of residents in congregate settings for services within the community.

The disabled community has been saying it for years, Nothing about us Without us! People with disabilities and family members need to be part of the decision-making process and be a part of emergency response planning and preparedness. The policies that are being implemented are not coming because of preparation, but instead they are coming out of reaction.

This July marks 30 years of the American's with Disabilities Act, we are tired of fighting for our civil rights. New Jersey can do better; the welfare and the lives of our most vulnerable citizens are at stake.

I thank you for your time, I am happy to answer any questions and willing to assist in any way.

DATA Collection:

NJ Centers for Independent Living

3/15/2020 – 4/29/2020

Since the "Stay at Home" executive order, Centers for Independent Living have continued standard operations remotely and also engaged individuals with disabilities who may or may not have been part of their existing caseload to ensure they were provided the necessary support during the pandemic.

During this time frame, 11 Centers for Independent Living made <u>15,391</u> contacts (beyond their typical consumer support) and the following topics/services were provided.

- Wellness checks
- Food delivery
- Pantry Services
- Register Ready wellness checks
- PPE delivery
- Personal care product delivery
- Housing/security deposit assistance
- Prescription drug assistance
- Benefits – filing for unemployment/Medicaid/food stamps/stimulus
- CIL – direct consumer financial assistance (food/drugs/housing,etc)
- Advocacy
- Virtual peer support

Issues identified specific to individuals with disabilities during Covid 19 Pandemic

Presented by NJACIL

Personal Care Attendants

- There is concern among people who rely on personal care services and how they will be impacted if their attendant calls out sick or does not show. Do agencies have a backup plan in the event of a shortage?
- How do people with disabilities know that their attendant is not carrying the virus? We are aware of several families refusing to let their attendant come into their home out of fear due to the attendant not having the proper PPE.
- Is there an effort to test personal care attendants and to assure people they are working with are not getting the virus? How can we safeguard the individual (as well as the attendant) from contracting the virus while still getting the assistance they need?
- What is the state doing to ensure people who work as PCAs , HHA and CNAs are provided with the exhausted supply of protective masks, gloves and other personal protective gear. People in these occupations should be given priority, along with doctors, nurses and other medical professionals in the distribution of this gear.
- Latex free masks and gloves must be available and used around people with spina bifida and catheterize. These individuals are highly allergic to latex and could result in a life-threatening situation if they are exposed. People who are allergic to latex need to be cautious with face masks. The Uline mask S-9632 is not made with latex.
- We have heard of agencies running group homes and not assigning the Direct Support Professionals (DSPs) to specific homes. DSPs are not equipped with PPEs or told not to wear them in the home. The only protection is that their temperature is taken upon entering. DSPs should be assigned to specific homes to help contain the spread of the virus. DSPs should be provided with the proper protection for their safety and the safety of those residents living in the homes.

Do Not Resuscitate (DNR)

- No hospital should be encouraging a patient's guardians or family members to sign Do Not Resuscitate forms when elderly patients are admitted with the coronavirus. This situation has been brought to our attention and is an obvious concern to us a disability organization because many people with significant disabilities are just as vulnerable to this practice. Many people with significant intellectual disabilities are their own guardians, and we want to ensure that they realize what DNR means and that they have a right to refuse to sign the DNR.

- It has been brought to our attention that hospitals are encouraging long term care facilities to not bring people to the hospital. Please see statement from one of our consumers:

  "Hi Carole, since we last spoke my sister who is an attorney has 2 cases from 2 different Nursing homes where the facility has been advised by area hospitals not to bring their patients to the hospitals and to manage medical emergencies at the facilities. Confirmed hospitals are JFK in Edison, RWJ Somerset and Princeton Medical Center and "others" which were not specified."

- On March 26th and 27th, the Commissioner of Health stated during the daily briefing that a bioethics advisory committee was being formed in NJ to look into these issues and to provide some guidance to the medical community. ACI responded as this is a critical issue. We suggested that people with disabilities and family members were a part of this committee. We contacted the state and submitted names of individuals who we felt would be instrumental to the committee. On April 2nd, Commissioner Judith Persichilli, said there was no bioethics team and said it was " A professional advisory committee on how to deliver care. " ACI feels regardless if this committee exists or not, the Governor needs to hear from disabled individuals and families members on this issue of utmost importance.
- We appreciate the bulletin that was released by the Office for Civil Rights at the US Department of Health and Human Services which states "Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism," Roger Severino, the office's director, said in a news release. "Persons with disabilities, with limited English skills and older persons should not be put at the end of the line for health care during emergencies." However, there is still a concern that this will not be followed in these very difficult times.

Food Insecurity Issues

- Many people who rely on food delivery from their grocery store have to wait several weeks for their home delivery. Stores are experiencing so many requests for this service that there is a tremendous backlog. There needs to be a system in place to give priority to the elderly and people with disabilities who are unable to get to the store.

- The states Meals on Wheels program is targeted specifically to individuals over the age of 60. NJ does not have a mechanism in place to support individuals with disabilities under the age of 60 that are homebound, living alone and have no support for food. The DDS has advised they will be able to offer a limited supply of meals to individuals with disabilities who meet a very specific criteria. NJ needs to work on this issue to ensure that our residents with disabilities are given the same opportunity for food access as seniors.

- Several stores including Stop & Shop, Target and Dollar General have specific hours dedicated to people who are elderly. Can a directive be given from the state that this be expanded to other stores and include people with disabilities? While we are grateful that more stores are offering special hours, it is mostly marketed to seniors. This has caused confusion among some people with disabilities. ACI have contacted several of these stores and were told it was also for disabled, however, the marketing did not state that.

Resource Hotlines

- There is a long wait for the Department of Health Hotline 1-800-222-1222. Staff have called this number several times and the hold time is at least 20 minutes.

- The people on the NJ 211 line are very nice and are compassionate. However, they seem to need additional training on providing accurate and complete information that addresses the need and situation for disabled individuals. Staff have called the number several times and were given inappropriate numbers to (one to a research organization for doctors in Georgia when asked about where to obtain masks in Middlesex county, NJ). Even after additional lines were added, we are still receiving complaints from our consumers who are unable to get through.

- DAWNcil reports that callers to 211 have been directed to their CIL rather than trying to assist the caller. If 211 is not skilled in answering questions regarding disability services, the network of CIL's is an ideal resource for helping individuals. It is a statewide network and the CIL's understand how the disability service system works and what is available not only on a state and federal level but also on the local level.

- A year-long hotline needs to be set up and run by people with disabilities in the 11 Centers for Independent Living (CIL) throughout the state. CILs are mandated to provide information and referral services, it would not take much to convert what we are already doing.

Long Term Care Facilities/Group Homes

- Families/guardians that have a loved one in a long-term care facility are not getting updates on how their loved ones are doing. We have heard of several situations where residents had either died or were in the hospital testing positive, but family members were never informed that residents in the facility had the virus.

Example: It was brought to our attention that a resident living in an over 55 apartment complex, had tested positive and was in the hospital. The landlords never informed the other tenants. Conversations with families reveal this is also happening in group homes and developmental centers.

- Families/guardians need to be kept aware of the situation at these facilities and given updates on how their loved ones are doing. Going a week without contact is not acceptable. This is also happening in nursing homes.

Hospitalization

- A protocol needs to be in place at hospitals where guardians/parents can stay with their coronavirus-diagnosed son or daughter who may experience anxiety and/or behavioral issues. This can be done on a case by case basis. Many individuals, especially those with autism simply can not be left alone in a hospital. Provisions need to be made for families/guardians so they could stay with their child as well as having PPE to stay safe. This is not exclusive to people with IDD but applies to anyone who has difficulty communicating. There are hospitals in NJ that are allowing families/guardians in with disabled loved ones, we are suggesting a directive from the Governor that all hospitals abide by this. Chicago has put a similar policy in place.

- When a person with developmental disabilities presents with a fever and other symptoms but is unable to confirm additional symptoms how will it be determined to treat them? We are not aggressively treating people who are unable to report symptoms. Early treatment has been found to prevent hospitalization and the need for ventilators.

- ACIs Executive Director has an autistic son who does not have verbal speech, has severe social anxiety and behavioral problems. If hospitalized, he would not understand what was happening, he would not be able to advocate for himself and this anxiety would escalate his behaviors. It is imperative that a family member/guardian be allowed to be with them to provide comfort and to be able to advocate on their behalf.

- People with disabilities have been fighting for decades to live independently in their communities and not in nursing homes. They now fear going to a hospital for fear they will not be given the proper care or they will end up being sent to a nursing home.
- Dialysis - What plan is in place for people who have tested positive for the virus in transporting them to their dialysis treatment? There seems to be much confusion surrounding this issue. What procedure does the state have in place?

Technology

- Many people with disabilities/families do not have access to tablets, laptops, smart phones, etc. Many do not have internet service and are unable to access imperative information. One of our consumers was unable to use the internet once libraries closed. ACI mailed hard copy information and would make weekly calls to check on the consumer.

- Not having access to technology during a quarantine also adds to social isolation. People with disabilities without access to technology are unable to take advantage of many online programs or see their families and friends through programs such as Facetime, Skype or Zoom. ACI has observed an increase of consumers wanting to talk on the phone and requesting check-in calls the longer the pandemic goes on.

Special Education

- Families have shared there has been a significant delay in telehealth services for OT, PT, speech. Will these families be able to access additional services for time lost?

- In regard to transition from early intervention to pre-school programming, families have been told the evaluation process is on hold. So if children have turned 3 during this time, they are left without services once they exit the early intervention system.

- A parent reported that the school district was not as willing to provide assistance to mom in regard to homeschooling her son with autism. After much persistence the school agreed to train mom on how to do ABA and how to work with her son at home. The great news is that her son is now flourishing at home and is even saying some new words. He is happy and his personality is back. He even tried certain food for the first time and enjoyed them! Parents shouldn't have to fight to get their child the help they need. This isn't only a Covid-19 issue but it is being exacerbated by the situation.

- Children with a hearing loss are struggling with telehealth due to their difficulty to access sound. When in the classroom, their teachers and therapists use a FM system. It brings sound to a child's hearing device. Not all school districts are having families borrow their child's FM system while they are home. I am thankful my child's teacher advocated for us to have his FM system, the first three weeks without were very stressful.

- My child has ADHD, he tends to click on the video options during his telehealth. Such as turn off video screen and the mute button. The ability to have that control is very distracting.

- My district can no longer use Zoom, due to an inappropriate image being displayed as a result to a hacking incident. Microsoft Teams only allows 4 people to be viewed at the same time. Peer learning is not occurring and teachers cannot view their whole class. If a child is struggling or needs to ask a question a teacher can't always tell. Children talk over each other as well.

- While trying to work myself, I cannot always sit with my children during their 1:1 therapies. Which are only 20 minutes, the length of each service is shorter but at times I have meetings myself. My one son has a paraprofessional (one on one) during his school day for his attention, hearing loss, toileting problems, and developmental delays. It is impossible to provide him with the extra attention and structure his paraprofessional normally provides while trying to work. Adding her to his telehealth, does add extra motivation but is not the same as her sitting next to him and helping him stay focused.

- Personally, I have my own learning disability. Both my children also have the same reading disability (dyslexia). Trying to help them with their reading is not as effective as a teacher who has been trained in Wilsons. That is a program that has proven highly effective in teaching students with dyslexia to become independent, successful readers.

- My sons receive occupational therapy, at home we do not have the correct writing paper or other tools to help them maintain their skills. Most assignments are being completed via screen, they are not practicing their writing due to how work is also being assigned. We will have to purchase items their OT needs to help visits go smoother and for them to maintain their skills. Personally, my husband is out of work due to COVID-19 and I am able to work, thankfully I can buy them what they need. Many families are not in the position to make extra purchases at this time.

- An educational professional reported – the biggest impact is the abrupt change in learning. It went from a structured environment, to more unstructured since home is more comfortable. Multi-sensory instruction is also not happening, because we don't have those avenues right now. Students do not have the manipulatives that they have in the classroom to help them succeed at home. The reduction in the amount of time the students have access to their teachers in this virtual world, including therapies is significantly less. Plus not to mention the assignments are not in the format they are in the classroom, so that's an additional challenge

Emergency Preparedness:

- In general emergency response was not a coordinated effort. The plan was to have the counties form plans but that did not happen in the way that had been recommended by the State Police.

- Register Ready is a statewide database specifically used to identify vulnerable individuals with functional needs. The databases are held at the local level typically with the local OEM. CIL's do not have access to the local database (although we are asked to identify and enroll individuals). Several CIL's offered their assistance to reach out to these individuals for a wellness check. The response varied by county and so we are not sure individuals in those counties that were not responsive were ever connected with to perform a wellness check.

ABCD

Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

Assembly Human Services Committee
Testimony of Cathy Chin, Executive Director
Respectfully Submitted
June 25, 2020

COVID 19 Impact on the Developmental Disability Community

Good day, Chairperson Downey and members of the Assembly Human Services Committee. My name is Cathy Chin and I am here on behalf of the Alliance for the Betterment of Citizens with Disabilities which represents providers of community services for individuals with complex developmental disabilities at every stage of life and every level of independence Thank you for affording me this opportunity to apprise you of the impact of COVID 19 has had on our community.

Trauma

Individuals with developmental disabilities experience exposure to trauma at a higher rate than non-disabled people. Environmental stressors include social bullying, physical abuse, restraints and seclusion, sexual assault and emotional neglect. Their mental health needs go unrecognized mainly because the disability overshadows the mental health issues which often lead to misdiagnosis and incorrect treatment.

We should anticipate that the mass trauma that is COVID 19 may lead to increased mental health problems for individuals with developmental disabilities whether or not they had PTSD prior to the pandemic and for the staff who work with them every day. A good place to start for both recognition and treatment is to increase the practice and access to Trauma-Informed Care (TIC) which views people through a trauma informed lens.

Family visitation became a very serious issue over the last number of weeks. We are grateful for the efforts of the Commissioners of Human Services and Health, advocates and legislators who worked to remove this painful barrier to people who love and care about each other. While we must remain ever vigilant regarding the health and safety of those living in group homes, we must also consider their well-being.

Front Line Staff

Agencies paid essential workers bonuses, boosted overtime and enhance payments and provided daily meals. The Governor recognized their value and the needs they face and provided a temporary wage increase, extension of emergency childcare access, provision of short-term supports for renters and additional food stamp assistance.

1. Front line staff and managers from residential and day programs worked long hours, sometimes without protective gear, taking enormous risk so that others could stay home.
2. According to DHS reported incidences of abuse and neglect have decreased by 60%. Many believe the reason is because residences were fully staffed with people receiving higher wages and benefits;

3. Essential workers current wage is so low that they cannot save for emergencies through which they will be asked to sustain the rest of the community.
4. They and we will benefit from providing them a living wage.

We ask that the enhanced payment provided by the State remain for the duration of the pandemic.

Provider Additional Expenses Due to the Pandemic

DD providers have worked round the clock to prevent and treat COVID 19 in their licensed residential settings. Spending more on labor, supplies and technology in addition to loss of revenue from decreased occupancy due to hospitalization, death, and return to family home. In preparation for this hearing in a survey conducted by ABCD for the period March-May 2020, 9 of our agencies report a total cost for COVID related expenses to be $7.75 million; 64% for workforce related costs, 16% for cleaning and PPE supplies and 19% for residential vacancies. Many of these providers are applying for federal grants, so we anticipate that some of these amounts will decrease even as the totals increase with the continuation of the pandemic.

We ask that the enhanced residential payment provided by the State remain for the duration of the pandemic.

Throughout this crisis the Division of Developmental Disabilities worked with and for us. We cannot thank them enough.

ALTERNATIVES INC
dignity through independence

Assembly Human Services Committee
June 25, 2020
Testimony By: Carolyn Suero, VP of Admissions and Development, Alternatives, Inc.

Good Afternoon Chairwoman Downey and members of the Assembly Human Services Committee. I am Carolyn Suero, VP of Admissions and Development with Alternatives, Inc. and board member for the New Jersey Association of Community Providers. Alternatives provides a wide array of services for people with intellectual and developmental disabilities. I would like to thank you for the opportunity to submit testimony regarding the impact of the COVID-19 pandemic on some of New Jersey's most vulnerable citizens.

When New Jersey's stay-at-home order was initiated, provider agencies needed to act swiftly to establish procedures, with the safety of individuals with IDD and the Direct Support Professionals (DSPs) who serve them at the forefront. DSPs, who are indeed "essential workers", are responsible for the care of the individuals they serve, often 24 hours a day, 7 days a week. While many of the state's residents were quarantining in their homes, our frontline workers, not unlike those employed in hospitals and skilled nursing facilities, returned home and into their communities, when their shifts were complete, and a new rotation of staff arrived, increasing exposure to all involved. Many DSPs hold multiple jobs due to the low wages afforded them, further increasing potential exposures. Pre-pandemic staff turnover rates were exacerbated by the added challenge of retaining staff during a public health crisis. DSPs, who play a critical role in ensuring that people with IDD live rich, meaningful, <u>and healthy</u> lives, deserve a living wage, not just during this crisis, but into the future as well.

As positive cases increased in New Jersey, providers determined that they would need to secure their own PPE for frontline staff. This was accomplished through many efforts. Provider agencies became creative, by making protective gowns from oversized T-shirts, using coffee filters to enhance the effectiveness of homemade masks, and more - all while upholding their commitment to providing the highest quality of services possible <u>and</u> incurring significant unexpected costs.

In addition to the costs related to PPE, the pandemic has resulted in other financial implications for providers related to the closure of day programs and some families choosing to care for their loved ones at home. Providers were issued retainer payments to offset some of the financial loss, and a temporary $3.00 per hour increase was issued for DSPs. Going forward, providers cannot absorb reductions in funding, and in fact, they need increased funding to sustain services.

Thank you for your time. I would be happy to answer any questions.

If questions arise after the hearing today, I can be reached at 908-698-3000.

Darren Blough
Senior Vice President, Bancroft
Testimony to NJ Assembly Human Services Committee
June 25, 2020

Good afternoon, Chairwoman Downey and members of the committee.

Thank you for inviting me to give testimony today. I'm Darren Blough, and I am senior vice president at Bancroft, one of the state's largest nonprofit service providers supporting individuals with autism, intellectual and developmental disability and brain injury. I am also immediate past president of the New Jersey Association of Community Providers - NJACP.

Like all of New Jersey, Bancroft has faced challenges presented by COVID-19. But today, we count ourselves among New Jersey's success stories, and I'd like to share why we believe that is; what worked for us - and where there is room for improvement.

First and foremost: Thank you to our partners at the state - from the Governor's office, to the legislature, to DHS, DDD and DCF. We are grateful for the swift, yet thoughtful guidance and responsiveness to the issues service providers faced, from day one.

We also appreciate your commitment to ensuring agencies like Bancroft remained financially secure through this crisis - ensuring that payment for services continued without interruption, and providing additional funds to compensate the staff who provide our essential services.

Bancroft took the COVID threat seriously weeks ahead of the state shutdown. The steps we took to prevent spread of the coronavirus in the earliest days of the pandemic - we believe - are directly responsible for a low infection rate among both staff and those we serve.

- We suspended community outings early on - implementing our own "stay at home" order.
- We closed day programs, with the support and guidance of DDD, shifting resources to providing in-home support for our residential clients during the day.
- We mandated staff wellness checks, and limited the number of programs where staff could work, to make contact tracing easier.
- And we suspended visitation, even from family. This was a difficult, but critical, decision to protect both our staff and those we serve.

Throughout the process, having the autonomy to make the **right decisions** for those we serve has been essential.

Like everyone else, we struggled in the early days of the crisis to secure PPE and testing for our staff.

And breakdowns in communication - as well as a lack of understanding from local, county and state agencies about the work we do and how we operate - proved to be unnecessary stumbling blocks along the way.

Perhaps our greatest challenge has been navigating local, county and state departments of health, and navigating conflicting guidance, which often resulted from a lack of education about what human services providers like Bancroft do, and who we serve. Similarly - that lack of understanding affected our ability to seek help from local hospitals.

- Case in point: An ER doctor threatened to have one COVID-positive individual dropped off on our doorstep, rather than keeping him in the hospital where he could be isolated. While we had isolation plans in place for our general population, this particular person's behavioral acuity meant he simply could not be isolated and kept safe in our facility. The hospital did not understand the reality of our situation, because they didn't understand the population in question.

We deeply appreciate the state's recognition of Direct Support Professionals - DSPs - and the essential role they play in caring for the individuals we serve. The temporary wage increase was meaningful to them and to us as a provider who values their contributions to care and support every day, but especially through the pandemic.

In all - we commend the state for its response to this unprecedented situation, and while we expect the coming fiscal year to be a tough one, we are grateful for the support we have received - which has enabled us to weather this storm without diminishing our services.

What is clear, is that as we move forward toward this "new abnormal" - as I like to think of it - we will need to do so together. We know that some things will likely NEVER go back to the way they were -- and while that may sound daunting, I believe it also presents an unprecedented opportunity to assess the way we do things - and re-evaluate the relationship between service providers and our partners at the state.

Thank you for your time, and I'm happy to address any questions you have.

N A S W. NEW JERSEY CHAPTER
National Association of Social Workers

Testimony of the National Association of Social Workers - New Jersey,
Jeff Feldman MSW, LSW
Director of Advocacy & Communications
before the Assembly Human Services Committee
regarding the needs of the Developmental Disabilities community and COVID-19
June 25, 2020

Good afternoon Chairwoman Downey and distinguished committee members. Thank you for the opportunity to testify before you today. My name is Jeff Feldman and I am the Director of Advocacy & Communications at the National Association of Social Workers – NJ Chapter. We represent the interests of the more than 20,000 licensed social workers in NJ and the clients they dedicatedly serve. With regard to the Developmental Disabilities community, social workers are most often found in the ranks of Senior and Executive Management at agencies and facilities that serve the DD community, including day programs, residential facilities, social service agencies, and more. In these rolls, we are well situated to see the needs of organizations, the direct service workers (DSPs / PCAs) they employ, and the clients they serve.

I'd like to take a moment to define and clarify the population we are considering today when we say "Developmental Disabilities." To be diagnosed with a Developmental Disability, an individual must document that they have a **chronic physical** and/or **intellectual** disability that has:

- manifested in the developmental years, prior to age 22, and
- is lifelong in nature, and
- substantially limits the individual in at least three areas of life activity: self-care; learning; mobility; communication; self-direction; economic self-sufficiency; and the ability to live independently.

Many, but not all, individuals diagnosed with developmental disabilities have both a physical and intellectual component to their disability. We are talking not about a monolithic population, but a community that encompasses a range of disabilities and syndromes including for instance, vision loss, hearing loss, autistic spectrum disorders, cerebral palsy, and Down syndrome.

In recent decades, the provision of services to individuals with developmental disabilities has focused on person-centered approaches that center the dignity, respect, and inherent worth of the person receiving services. Our state's rapid-response to the first wave of the coronavirus—lockdowns, and the discontinuation of services in the name of public health—was an understandable response as we were faced with an unprecedented crisis. However, this response unfortunately left many individuals being served by DD programs without the very supports that allowed them to live with dignity and in some cases created situations that increased an individual's exposure to COVID-19 rather than lessened it.

I want to reiterate that social workers and agencies responded admirably to protect the health of all, but with a bit of reflection, there are certainly opportunities to grow our response capability and install systems and procedures that will allow us to better serve the DD community in the time of COVID-19.

Based on lessons learned, we have a few recommendations that will help ensure the community receives consistent and appropriate levels of care, if and when we face another COVID-19 lockdown scenario.

1. At the start of the pandemic, there was a lack of adequate PPE among DD provider agencies and staff to ensure the health and safety of all individuals served. **Going forward we must ensure that agencies, direct service providers and personal care staff have sufficient PPE to safely provide services to clients in their homes and at other locations where they receive services.** Based on current COVID-19 trends we have seen around the nation, it behooves us to begin amassing this stock immediately, including designating a subset of the PPE supplies for DD providers.

2. The abrupt stoppage of day habilitation programs (agencies were notified on Friday, 3/13 at 7:29 pm that "all Division-funded, facility-based day services are directed to close until advised otherwise, no later than Tuesday, March 17) left providers with no time to create new/temporary enrichment and habilitation programming for individuals who would be remaining in their homes—either family homes or residential group homes. **We must ensure, prior to the onset of the Fall season—when risks of exposure to COVID-19 will likely increase—that all agencies and service providers develop contingency plans for how they will continue to provide services to individuals in the event of another lockdown.** Contingency plans should be reviewed quarterly so they reflect the most current learning and forecasting about COVID-19 and steps that must be taken to safely provide services in the midst of an outbreak.

3. With the medical system essentially shut down, individuals had to be taken to hospitals for non-emergency but urgent medical issues. During the first month and a half of the lockdown, hospitals would not allow for direct service professionals or caregivers to accompany individuals in the hospital. For individuals with developmental disabilities, this often stripped them of their dignity and voice as many were unable to communicate, or effectively communicate on their own, what type of care they needed. Many individuals were forced to sit in the ER waiting rooms for extreme lengths of time—in part because they lacked a service professional to advocate for their needs—thus being exposed to COVID-19 while waiting to be seen by a medical professional. **We need to ensure that individuals with developmental disabilities, as well as other medically fragile individuals, are able to seek and receive treatment in more tightly controlled, less populated environments—in small group or private practices or in their homes via mobile services—rather than in hospital ERs.** Telehealth may be a feasible option for certain persons with developmental disabilities, but in general we cannot assume telehealth is a practical treatment modality for the DD community when in-person treatment is limited.

Thank you for your time and consideration on this important issue. Our team is available to you for further consultation if you require.

The New Jersey Council on Developmental Disabilities

Paul Blaustein, Chairperson
Mercedes Witowsky, Executive Director

Testimony: Assembly Human Services Committee ~ June 25, 2020
Virtual via Zoom

Impact, Challenges and Recommendations Related to COVID-19 on the DD Community

Chairwoman Downey and Members of the Human Services Committee:

The New Jersey Council on Developmental Disabilities (Council) is authorized by the federal Developmental Disabilities Assistance and Bill of Rights Act, and in New Jersey State government by NJSA 30:1AA 1.2 and is codified in Title 10 of the State Administrative Codes. State law places the Council "in but not of" the New Jersey Department of Human Services.

Many public and private agencies are involved in the lives of individuals with developmental disabilities. The Council provides a platform for these agencies, together with citizens with developmental disabilities (I/DD), family member/caregivers, and advocates, to develop a coordinated social policy. To this end, the Council commissions research on policy issues and funds model programs. The Council also funds projects to inform citizens with I/DD, family members, caregivers, decision-makers, legislators, and the public about developmental disabilities.

Background: According to the, "State of the States in Intellectual and Developmental Disabilities, 11th Edition 2017":

- Approximately 141,000 individuals with I/DD live in NJ, of whom 106,000 (75%) live with a family caregiver; 27,000 (25%) of those family caregivers are over the age of 60
- Along with family member caregivers, direct support professionals are the backbone of the supports and services used by citizens with I/DD

Considering that three quarters of individuals with I/DD live at home with family caregivers, the Council provides education and forums for discussion for individuals with I/DD and family members/caregivers. The Council hosts over 200 forums each year around the state and continues to do so using virtual platforms.

Twenty-one years ago this week, the United States Supreme Court ruled in *Olmstead v L.C.* that people with disabilities cannot be unnecessarily segregated into institutions (like nursing homes and other facilities) and must receive services in the most integrated setting possible. Olmstead has transformed the way our nation thinks about, and funds, services for people with disabilities of all ages.

This ruling and the passage of the Americans with Disabilities Act almost 30 years ago as well as other disability rights legislation mark critical disability rights milestones. Together, they continue to create new opportunities for people with disabilities and older adults to participate fully in their communities.

The principles of nondiscrimination and community inclusion and integration are even more critical as we face the global COVID-19 pandemic and its economic consequences.

The pandemic has strained many of the home and community-based systems and supports that people with disabilities and older adults rely on to live safely and independently in the community.

New Jersey stakeholders and networks have risen to the challenge of this emergency. From developing creative new service delivery models, to supporting transitions back into the community after hospital visits, to ensuring that state and local policies are consistent with Olmstead and the ADA.

COVID-19 Impact and Challenges: Like most NJ residents, everyone with I/DD has been impacted in some way and noticeably some have been impacted more significantly. National and state data gathered in the past few months indicates a higher percentage of individuals with I/DD test positive for COVID-19 and die at a rate about twice as high as others who contract the illness. Reasons for this disproportionate increase include the presence of preexisting health conditions, such as respiratory disease and as the chart below indicates, the greater the number of people who live in congregate settings, the higher the percentage of positive testing and deaths.

As of 6/21/2020 DDD Reporting:

Settings	**Developmental Centers**	**Licensed Settings**	**Own Home/Family Home**
Total Population	1,238	8,000	16,000
# of Individuals Positive	450	617	128
% Positive	36%	7.7%	.008%
# Deaths of # Positive	32	54	30
% Deaths of Total % Population by Setting	2.6%	.06%	.018%

NJCDD's active individual and family groups participate in virtual meetings and discussions on a daily basis. The most common factors reported by individuals and families of individuals with I/DD include but were not limited to:

1. **Health and Safety:** Individuals with I/DD and their families share concern for their health and safety. They ask many questions including:
    - How do I/my loved one avoid contracting COVID-19 and remain safe?
    - What happens to my loved one if I contract COVID-19?
    - How do I balance 'stay at home' orders while I watch my loved one regress from the effects of social isolation?
  - **Recommendation:** As the COVID-19 data illustrates, positive tests and death rates increase significantly in larger congregate settings. NJ must continue to build upon community-based services in smaller integrated settings.
  - **Recommendation:** NJ DOH received a comprehensive report from Manatt Health concerning how COVID-19 impacted residents and staff in the state's 370 nursing homes. This report calls for a Long-Term Care (LTC) Emergency Operations Center as the centralized command and resource center as well as a task force on transforming NJ's LTC delivery system and taking a closer look at individuals with I/DD living in LTC facilities and how we best meet their needs. The state must act on this recommendation.

2. **Testing:** When will testing be available on a more wide-scale basis, especially testing of individuals living and spending their days in congregate settings? Testing DSPs is equally important to control spread.
    - **Recommendation:** Until a vaccine is FDA approved, consider making rapid testing widely available for congregate settings so that proper protection and cohorting can be implemented.
3. **Personal Protective Equipment (PPE):** Access to an adequate supply of PPE is critical across I/DD settings.
    - **Recommendation:** The County Offices of Emergency Management (OEM) and DDD must provide access to an adequate supply of PPE for providers and individuals/families receiving services in their own home. While some providers and individuals/families have been resourceful in obtaining PPE, many have not. A centralized purchasing and distribution center is critical to having sufficient PPE supplies across our service system.
4. **Sanitation:** Proper cleaning and access to sanitation supplies is critical across I/DD settings.
    - **Recommendation:** Access to sanitation supplies is critical across I/DD settings. A centralized purchasing and distribution center is critical to having sufficient sanitation supplies across our service system.
5. **Transportation:** How will transportation providers offer safe transportation options as the state reopens?
    - **Recommendation:** For many years, individuals and families have advocated for access to Uber, Lyft and other widely available means of transportation that are funded through the individual's budget. The state must expand transportation options so that individuals can access their community.
6. **Accessing services:** Early Intervention, Special Education, Transition to Adult Services and Adult services remain unattainable for many individuals/families. Family support services and supported employment equally remain challenging. Family caregivers are overwhelmed. Individuals with I/DD who work at essential jobs creates another layer of challenges.
    - **Recommendation:** Early Intervention, Special Education, Transition to Adult Services and Adult Services, including family support and supported employment remain unattainable for many individuals/families. Navigators within these systems must provide critical information/linkage and follow-up with individuals/families to ensure that all options are pursued to return the individual to needed services and provide critical bridge services until services can be restored.
7. **Children to Adult Services:** Critical transition services take place every spring as children move into the adult service system. These transitions did not take place. These new adult system users will need to make the necessary critical connections to adult services as soon as practical as NJ reopens; including assessments and intakes into adult services.
    - **Recommendation:** Children transitioning to adult services must receive the necessary critical connections to adult services that would have taken place over the past few months. The Department of Education- Office of Special Services, Department of Labor- Division of Vocational Rehabilitation Services, Department of Children and Families- Children's System of Care and the Department of Human Services- Division of Developmental Disabilities must establish a triage team to ensure that all children transitioning to adult services within the Division of Developmental Disabilities have the resources and plans in place for successful transitions.
8. **Hospital Visitation:** Fear plagued families when the state announced a ban on hospital visitors.

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- **Recommendation:** The fear and lack of access during hospital admissions was avoidable if disability advocates remain at the table in making policy. People with disabilities and their families must be represented in all policy decision making from the start, not as an afterthought. The state must integrate disability factors into all state decision making by having self-advocate, family member and system partners represented.

9. **General Visitation in Congregate Settings:** Many individuals and families were overwhelmed by the inability to provide the love, support and encouragement for loved ones living in congregate settings.
    - **Recommendation:** State systems should continue to monitor and expand visitation as data suggests.
10. **Direct Support Professionals (DSPs):** DSPs have repeatedly shown that they are essential to the care of our state's most vulnerable citizens. A temporary $3.00/hr. increase to only DSPs working in licensed settings does not correlate to the work that all DSPs across the state have done to keep individuals with I/DD safe and healthy. Advocacy work for the past three years has urged the state to pay DSPs a wage that aligns with their high degree of responsibility. Waiting to make this investment is a mistake and will place individuals with disabilities and their families at risk.
    - **Recommendation:** All DSPs are essential workers and should be compensated with hazard pay for back wages and wages going forward. DSPs must earn a wage above minimum wage in order to recruit and retain a stable workforce.
11. **Parents/Spouses/Guardians as Direct Support Professionals**: DDD allowed parents/spouses/guardians to become their loved one's DSP early during the pandemic. This created an option that families have been advocating for over the last several years.
    - **Recommendation**: Parents/spouses/guardians should permanently be able to become paid caregivers within DDD services. This is permitted in other Medicaid programs like the Personal Preference Program. A stable workforce is needed and permitting more options for paid family caregivers also expands the worker pool for this vulnerable population.
12. **Remote Services:** Virtual/remote service offerings remain minimal and are challenging depending upon the individual's disability.
    - **Recommendation:** The state and providers need to explore greater access to remote services when appropriate. Alternate options should be explored when virtual services are not an option.
13. **Technology Divide:** Many individuals and families report lack of access to technology and compatible internet access to participate in remote services and receive critical information during this pandemic.
    - **Recommendation:** If COVID-19 has taught us anything, we have learned that without technology, information and options are extremely limited. The state should use every possible measure to permit service recipients to obtain equipment/internet access to bridge the technology divide.
14. **System Flexibility:** The service system offered individuals and families flexibilities that make sense to keep individuals safe and healthy. COMBO of in person and remote
15. **Loss of Current Placements/Services:** For individuals who left their group homes, they fear that their 'spot' at the agency service will be lost if they do not return. As day programs are moving toward reopening, there is added concern that day program 'spots' will be lost if the individual/family seek to delay the return to day programs and other services.

    - **Recommendation:** Families/caregivers must be given assurance that their decision to protect the health and safety of their loved one does not negatively impact the return to an individual's home or day program.
16. **Summer Camp:** While limited children camp opportunities are available, there are currently no adult camp offerings.
    - **Recommendation:** The system must present viable alternatives to services, like camp, that are currently not an option.
17. **Reopening Impacts:** As more businesses are reopening, families/caregivers are struggling with their need to work while day services remain closed. People also fear returning to day programs and other services.
    - **Recommendation:** The system must make an array of options available for families/caregivers to explore.
18. **Maintain some of the COVID-19 practices:** Family/spouse/guardians being self-directed employees (SDEs), electronic signatures, overtime pay for SDE DSPs, remote services, hazard pay
    - **Recommendation:** Service practices put in place over the past three months must be maintained with stakeholder input and a review of the data.
19. **Budget Impact:** COVID-19 has caused serious state budget concerns across the country. Families fear that disability services will be targeted to save states money.
    - **Recommendation:** We have come too far to go backwards. Cuts within NJ's Medicaid funded programs are not an option and every effort must be made to protect the current service systems.
20. **Communication:** System users are not consistently connected to information. State system administrators need to communicate to all system users.
    - **Recommendation:** State departments must evaluate their means of communication and improve communication strategies with stakeholder input. COVID-19 materials are predominately published in English; documents should be translated into Spanish.

This list scratches the surface in uncovering how frightening a time it has been for individuals with I/DD and their families. NJCDD is working in collaboration with the state and system partners to support individuals with I/DD and their families as they try to reconfigure their lives and make sense of the impact upon this vast array of challenges.

NJCDD remains eager to connect with state and all system stakeholders to implement practical solutions and minimize the disproportionate impact to individuals with disabilities and their families during this pandemic.

Thank you for your leadership and the opportunity to testify before you today.

Mercedes Witowsky

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Carole Johnson
Commissioner

June 25, 2020

The Honorable Joann Downey
Chair, Assembly Human Services Committee
802 West Park Avenue, Suite 302
Ocean Township, New Jersey 07712

Dear Chairwoman Downey and Members of the Committee:

Thank you for the opportunity to share information with the Assembly Human Services Committee on the steps taken by the New Jersey Department of Human Services' (DHS) Division of Developmental Disabilities (DDD) during the COVID-19 pandemic. We truly appreciate your attention to the impact COVID-19 has had on New Jersey residents with intellectual and developmental disabilities (I/DD), their families and their caregivers.

This unprecedented pandemic has exacted a tragic toll across our state. We mourn the loss of our fellow New Jerseyans and express our heartfelt condolences for every precious life lost to this virus.

NJ Human Services also recognizes those in our community who have demonstrated their caring, dedication and resilience throughout the pandemic, including the I/DD community we serve and their families. We have regularly engaged with those we serve and their families and guardians throughout our response to ensure that we are best able to respond to their needs. The frontline staff at the developmental centers, as well as the teams of professionals at group homes and provider agencies, have shown their indefatigable support for those we serve. This includes our Direct Support Professionals, Self-Directed Employees, Support Coordinators, individuals receiving services, their family members, guardians and providers. We acknowledge the tireless work and sacrifices they have all made during this unprecedented time.

Since the start of the pandemic, NJ Human Services has worked to provide extensive assistance and support to our network of community-based providers so that they are able to continue operating and serving clients. Specifically, NJ Human Services has:

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- Provided a temporary wage increase for Direct Support Professionals totaling $24 million;
- Provided $60 million in enhanced payments to residential providers, recognizing the added costs in staffing, food and other essentials associated with supporting individuals at home during the emergency;
- Helped to sustain day programs through bridge payments to providers following the necessary closure of congregate day programs;
- Modified rules to quickly allow families and providers to hire direct care staff to support their loved ones;
- Implemented a Medicaid policy to ensure no one loses Medicaid eligibility during the federal public health emergency regardless of when they are up for renewal;
- Permitted as many flexibilities as possible to support individuals, families and providers who need to access services or do business differently during this emergency;
- Provided more than 22,500 N95 Respirators, 367,000 surgical masks, and 472,000 gloves to our community partners and agencies;
- Published a transparent weekly Coronavirus Disease Data Dashboard with regularly updated information about the number of COVID-19 positive individuals and deaths in the I/DD community, including in settings not managed by DDD, and in the state's developmental centers; and
- Issued extensive guidance consistent with federal and state public health guidelines to ensure the safety and welfare of residents and of staff providing 24/7 care of clients in developmental centers and community-based settings. All guidance documents can be accessed at https://nj.gov/humanservices/coronavirus.

Increasing Wages for Direct Support Professionals

Direct Support Professionals (DSPs) are truly the backbone of our service system. They have gone above and beyond the call of duty, in some cases electing to isolate themselves within group homes with the residents to ensure that there was not exposure to the virus. They have saved lives, and we are honored to have them as critical partners in our response efforts.

In recognition of the essential work provided by DSPs during the emergency, in April, the Murphy Administration announced $24 million in state and federal resources for temporary wage increases for these professionals who care for adult individuals with intellectual and developmental disabilities living in group homes and supervised apartments - $10.6 million in state funding and $13.4 million in federal matching resources. With these funds, NJ Human Services was able to implement a temporary $3 per hour wage increase for DSPs for three months in response to the COVID-19 pandemic.

Actions Taken in Developmental Centers

NJ Human Services provides direct care to over 1,200 individuals at our five developmental centers across the state, where we and our dedicated staff began preparations for the COVID-19 pandemic in February. We worked with each center to ensure they were as prepared as possible, which included reviewing pandemic policies and practices and updating policies as public health authorities provided additional guidance and information.

Protocols were put in place based on best practices recommended by various agencies, including the Centers for Disease Control & Prevention (CDC), Centers for Medicare and Medicaid Services (CMS), and the New Jersey Department of Health. These actions include, but are not limited to:

- Implementation of staff temperature checks and symptom monitoring before staff report to work on every shift, resulting in symptomatic staff being sent home;
- Suspension of congregate activities, including changing common dining and day service activities;
- Suspension of community outings;
- Re-education of residents and staff on hand hygiene, with regular re-enforcement;
- Renewed staff training on cleaning and disinfection procedures, with regular re-enforcement;
- Enhanced and more frequent cleaning of highly trafficked areas and surfaces;
- Re-enforcement of universal precautions with staff;
- Increased ordering of personal protective equipment (PPE) supply and stocking;
- Review of food, medication and medical supply levels in the event of supply disruption;
- Advanced ordering of medication supply;
- Additional monitoring and observation of signs and symptoms of respiratory illnesses for center residents;
- Updated staff workflow to reduce the number of personnel who pass through common or shared areas;
- Cohorted residents based on public health guidance;
- Universal testing of all residents and staff, in addition to regular testing of symptomatic residents, which assisted the centers in identifying those who are asymptomatic, providing a mechanism to better protect each center's vulnerable population;
- Communicating via letters and telephone with families and guardians about cases in their loved ones' individual center, including telephone and video visits with their loved ones;
- Released a Frequently Asked Questions document for family members of residents;
- Transparently reporting case numbers of COVID-19 positivity specific to each center's residents and staff on the Department's web site; and
- Implemented Department of Health guidance on family visitors with appropriate safety protocols.

Throughout the pandemic, the health and safety of our residents, clients and staff has remained our top priority, and we remain committed to taking all available steps to provide the best possible care to all.

Actions to Support Group Homes and other Community-Based Residential Programs
COVID-19 has had a measurable impact on New Jersey's vulnerable populations, and individuals with I/DD are no exception. In addition to the care provided in state developmental centers, Human Services provides support to roughly 8,000 individuals residing in licensed settings across New Jersey. These include homes and apartments in every county of the state.

We recognized early in the pandemic that extraordinary actions would need to be taken to protect those we serve. We were among the earliest states, if not the first state, to close congregate day programs for individuals with I/DD to reduce their risk. At the same time, we knew that residential programs would need to absorb the impact of individuals being home throughout the day and in need of staff support, meals, and other critical services.

To address these changes, the Administration made critical investments to support I/DD individuals including a temporary $3 per hour wage increase for group home staff and a 20% increase to residential support rates to support group home providers as they provided for the additional daytime staffing and other service needs.

Concurrent with planning that occurred for our centers, aggressive actions were taken and guidance provided to protect the individuals in community-based settings as well. In March, we started a series of weekly webinars specifically related to COVID-19 and its impact on our community. Webinars have addressed infection prevention, emergency planning and preparation, understanding of guidance documents, protocols for screening staff and now visitors, masking policy and other common questions. Various other important updates have been provided.

To protect our clients, NJ Human Services made the difficult decision to close all congregate day programs, pause visitation to licensed residential settings and curtail community outings. These actions were not taken lightly as they affected people's lives in real, tangible ways. It caused families to be physically separated from their loved ones for months. During this time, we worked with providers to identify innovative ways to connect loved ones through video conferences and ensure communication occurred with families about the safety and welfare of their loved ones who were directly impacted. After reviewing the current state of the pandemic and its occurrence across New Jersey and with assistance from the Department of Health, we made the careful decision to allow outdoor visitation to begin again Sunday, June 21, requiring facemasks and with social distancing protocols in place.

Other actions taken include, but are not limited to:

- Curtailing community outings for those who reside in congregate settings and cessation of outings between people who do not reside together;

- Through a streamlined hiring process, the hiring of numerous additional Direct Support Professionals since the start of the pandemic to support individuals with I/DD;
- Conversion of previously approved goods and services classes to remote instead of in-person;
- Temporary allowance through the public health emergency of parent, spouse, guardian to be a self-directed employee;
- Temporary allowance through the public health emergency of the remote provision of services;
- Conversion of in-person monitoring to remote oversight;
- Providing telephonic Risk Assessments at 100% of all licensed DDD group homes to ascertain COVID-19 preparedness, implementation of screening protocols, and other important areas – with overwhelmingly positive results;
- Curtailment of residential placements not related to COVID-19;
- Universal masking as a requirement for all staff;
- Working with providers on surge planning and isolation space, creating over 300 additional beds;
- Completion of a webinar specifically related to individuals moving from the educational to the adult system in the time of COVID-19; and
- Formation of a committee to re-open day programs which includes agencies, family members, advocates and other important stakeholders.

The Division of Developmental Disabilities, as well as DHS as whole, continues to review and follow public health guidance, develop policies to help our system of services adapt to re-opening and the current environment, and prepares for the possibility of increased Covid-19 cases in the state in the coming months.

Protecting Residents and Clients

Throughout the pandemic, we have continued to provide oversight and monitoring of community-based programs. The Human Services Office of Program Integrity and Accountability – which oversees abuse and neglect prevention and response, the Central Registry, background checks, and fingerprinting for community-based staff – has continued to operate using innovative strategies, such as remote visitation and telephonic wellness checks.

Resources and Equipment

Having critical supplies like personal protective equipment (PPE) in our facilities and community-based agencies is a priority for DHS. We have worked closely with the State Office of Emergency Management on needed supply for the vulnerable populations we serve while recognizing that New Jersey faces the same challenges as many other states and health care providers in accessing PPE amidst an international shortage and severely strained supply chains. Despite those hurdles we were able to maintain sufficient PPE supplies for our developmental centers and were also able to provide more than 22,500 N95 Respirators, 367,000 surgical masks, and 472,000 gloves to our community partners and agencies, including group home and families who utilize self-directed employees who reside outside of their household.

We also continue to encourage providers to apply for Federal Emergency Management Agency (FEMA) financial assistance for the unanticipated financial cost of PPE purchases during COVID-19. Eligible non-profit agencies may be able to receive 75% reimbursement for certain COVID-19 related expenses, which includes PPE. To assist eligible providers in this process, we have facilitated FEMA webinars with opportunity for Q&A for our contracted providers and vendors.

Supporting Individuals and Families

We understand that much has been asked of all New Jerseyans during this pandemic – and that it has impacted many of the things that give the individuals we serve joy and fulfillment, including their employment, day programs, community outings, family visits and other vital supports. We are so very impressed with their resilience and the support families and guardians have given to our staff and agency staff throughout this challenging time. It has not been easy, but residents have been adaptable and families have been gracious and understanding. We are grateful to all. And, together, we have helped to flatten the curve in New Jersey and reduce the terrible burden of this virus.

At the same time, we remain concerned about the mental health of many New Jersey residents, including those with I/DD, their families, and staff. Our Division of Mental Health and Addiction Services has expanded the NJ Mental Health Cares hotline at **866-202-HELP** to seven days a week from 8 a.m. to 8 p.m., and added a texting feature accessed by texting NJHOPE to 51684. This service is available for emotional support, education, information and referrals. It is highlighted in each webinar DDD hosts and provided as a resource to all. In addition, there is a free emotional support videophone helpline for sign language users provided in partnership by the Department and ACCESS at St. Joseph's Health. The phone number is 973-870-0677 and is available Monday-Friday from 9 a.m. - 5 p.m.

NJ Human Services is incredibly grateful for our hardworking Direct Support Professionals, developmental center staff, and agency partners across our service system who have committed to taking on the new challenges presented by COVID-19 without losing their unwavering commitment to the support of the individuals we serve. It has been impressive to see and we want to continue to support this work. We know that it will not be easy, and we are anxious to learn from the witnesses today about the many challenges ahead, but together we stand ready to help ensure individuals with intellectual and developmental disabilities continue to thrive in our great State.

Thank you again for the opportunity to share the efforts NJ Human Services has made and the work we continue to do during these unprecedented times. We look forward to continuing to work with the Committee on the critical tasks ahead and our shared goal on supporting the needs of the I/DD community.

Sincerely,

Carole Johnson

Carole Johnson

From: Tom Grady* Brain Injury Alliance of NJ
Subject: Please vote "yes" on both A-4138 and A-4239 on Thursday, June 25, 2020 [FROM THE BRAIN INJURY ALLIANCE OF NEW JERSEY]

Good morning, honorable members of the General Assembly Human Services Committee -

On behalf of the Brain Injury Alliance of New Jersey and those we serve, I am writing to respectfully request that you vote "yes" on both A-4138 and A-4239.

Thank you for your attention and consideration.

Respectfully submitted,

Tom Grady
Brain Injury Alliance of New Jersey

Tom Grady • Brain Injury Alliance of NJ
GovNetNJ.com® • #125545 Date: 06/18/2020 Time: 02:17 PM • © Government News Network

NJAMHAA

New Jersey Association of
Mental Health and Addiction Agencies, Inc.

June 25, 2020

The Honorable Joann Downey, Chair
Assembly Human Services Committee
802 West Park Avenue, Suite 302
Ocean Twp., NJ 07712

Testimony in Opposition of A4239

Allows in-person visitation for immediate family members and legal guardians of residents of certain community-based residential programs and group homes during COVID-19 pandemic.

Dear Chairwoman Downey, Vice-Chair Chiaravalloti and Members of the Assembly Human Services Committee:

On behalf of the New Jersey Association of Mental Health and Addiction Agencies (NJAMHAA) and its members, thank you for this opportunity to provide testimony in regard to Assembly Bill 4239. While NJAMHAA and its members recognize the value of visits to residents in congregate care settings and appreciate the intent of the bill, we firmly oppose the bill on the grounds that it is not a policy that should be placed in statute as it does not offer the flexibility necessary to combat the spread of Covid-19 in residential facilities.

Both the Division of Developmental Disabilities and Department of Children and Families have issued updated guidance in the last 10 days that outline the circumstances under which residents may now receive visitors. Those directives will continue to be regularly updated to adhere to the latest Executive Orders regarding stay at home orders, social distancing and all the other levels of restriction that the state might find itself operating under at any given time.

Placing rigid demands for visitation in statute during a still unfolding pandemic does not allow the flexibility that programs need given changing state dictates, the local/regional environment, staffing challenges, space restrictions and more. Policies around visitation are best left to the Divisions and Departments that work closely with programs on a daily basis and with the clinicians who fully recognize the benefits of visitors and support coordinating such visits as the ability to do so safely permits. If placed in statute, residents, staff and all they come in contact with are placed at higher risk if such statute is enforced when the immediate environment, staffing, protective gear, etc. do not present a safe way to accommodate visitors.

We respectfully urge all members of the Committee to vote "no" on A4239.

Sincerely,

Debra L. Wentz

Debra L. Wentz, Ph.D.
President and CEO

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Megann Anderson Fischer

Chairwoman Downey, Vice-Chariman Chiaravalotti and members of the Assembly Human Services Committee. My name is Megann Anderson Fischer and I am the Executive Director of the New Jersey Alliance for Children, Youth and Families (NJACYF). Thank you for the opportunity to submit this written testimony regarding the mental health needs of children, youth and families, frontline healthcare workers and minority communities in New Jersey due to COVID-19.

ABOUT NJACYF

The NJACYF is an advocacy organization representing children, youth, and family service agencies throughout New Jersey. Our members care for children and adolescents:

- **Experiencing emotional and behavioral challenges;**
- **Children living with developmental and intellectual disabilities;**
- **Youth who have experienced physical or sexual abuse and neglect;**
- **Pregnant and parenting young adults;**
- **Survivors of human trafficking;**
- **Youth experiencing substance use disorders;**
- **Youth in need of independent living skills and housing; and**
- **Other treatment and support services to give youth the safety, stability, comfort and support every young person deserves and to help ensure children and youth thrive in their communities and in their families.**

Our organization and many of our members are part of the not-for-profit community in New Jersey, a community that employs nearly 10 percent of the state's private sector workforce and more people than many major industries including construction, utilities, transportation, finance and insurance. Over 1.5 million people volunteer at New Jersey not-for-profit organizations annually, providing over 160 million hours of service valued at more than $3.4 billion.

Specifically, NJACYF members:

- **Serve children, youth and families in every county in New Jersey;**
- **Operate cumulative budgets of over $450 million;**
- **Employ over 6,500 citizens in New Jersey; and**
- **Have 600 board members, over 4,789 volunteers, and more than 100,000 individual donors.**

Most importantly, NJACYF organizations help improve the lives of children, youth and families in New Jersey every day.

THE CHILDREN'S MENTAL HEALTH CRISIS HAS BEEN MADE WORSE BY COVID-19

New Jersey was experiencing a **children's mental health crisis** prior to COVID-19. More children and youth in New Jersey were in need of mental health services at a time when the number of available services was decreasing. Prior to COVID-19, **suicide was the second leading cause of death for children & young adults ages 10- 24 and one in five children suffered a mental health related crisis in 2019.** It was further estimated that **at least half of the children with a treatable mental health disorder did not receive needed treatment**.

COVID-19 has unfortunately exacerbated the children's mental health crisis in New Jersey, and the impact of the pandemic on children, youth and families cannot be overstated. We know that young people thrive when they are safe, healthy and connected. COVID-19 and the measures in place to control its spread, while absolutely necessary, have disrupted nearly every aspect of familial life. Social distancing and changes to the way children and youth experience schooling and connecting with friends and loved ones will likely have a lasting impact, particularly on those individuals cared for by the child welfare and behavioral health systems. For adolescents and those who have 'aged out' of care, job loss is a significant problem that has caused disruption to housing, food insecurity and loss of connection. For children in families vulnerable to caregiver substance use, domestic violence, or mental health challenges, the stress of the pandemic, loss of work and the need to stay at home may be a tipping point.

With children spending more time at home away from the supervision of teachers, coaches, extended family members, and physicians, there are fewer opportunities to identify the need for intervention. Nationwide calls to child abuse hotlines have decreased during the pandemic, however we know there will be a corresponding spike in calls for help as children and youth are back in contact with these important adults in their lives. In this anxious and uncertain time, with youth away from the school and community programs that may address some of their mental health needs, and caregivers disconnected from social networks, it is particularly important for the social service community to monitor and be prepared to address the mental health effects of the pandemic.

We have already seen an increase in the need for services as a result of COVID-19 and experts agree that the need will continue to increase. **There are more young people in out-of-home care than there were prior to COVID-19.** This increase happened despite the fact that admissions to out-of-home programs were halted in New Jersey during the height of the pandemic except in emergent cases.

As an example, one NJACYF member reported that they normally perform 140 intakes per month in their locations. This organization has seen an increase to **over 250 intakes per month for the past two months**.

As the demand for services is increasing, children and youth are waiting longer to access care because there are not enough beds in the system. Prior to COVID-19, youth were already waiting for care at certain levels of treatment. We are seeing these wait times grow as the impact of COVID-19 is felt throughout our community. **We must do everything in our power to ensure that youth in crisis receive the care they need, when it is needed, and in the most appropriate setting to meet their needs.**

FRONTLINE WORKERS NEED OUR SUPPORT

The staff that care for children and youth are heroes each and every day, but their heroism rose to a whole new level during this public health emergency. As the pandemic started to impact New Jersey, NJACYF members began planning for the impact if staff stopped coming to work - either to care for their own families, because they became ill, or because it may actually be more financially beneficial for them to collect unemployment benefits. But while our member organizations have had staff test positive for COVID-19 or miss work for other personal reasons, **a majority of the workforce at NJACYF member organizations continue to show up for work each and every day.**

Staff are caring for their own families including elderly parents and children home from school and caring for the children and youth at our member organizations all while trying to ensure their own health and safety and the health and safety of their families. They do so in part because they need to support their families however the real reason they chose this profession and they continue to choose it, is because they have answered a calling to care for children and youth in need and they are committed to caring for the young people in their care no matter what.

There are several things we can do to support these frontline workers during the pandemic and beyond. **The first is to increase rates so that providers can increase wages.** NJACYF has been advocating for increased wages for direct support professionals for many years. Our members are not able to offer benefits comparable to state workers and staff work around the clock including evenings and weekends. Many of them are even on call during their personal time. These individuals deserve to be paid a wage that reflects the meaningful work they do each and every day, especially for the work they are doing during this pandemic. The Department of Human Services (DHS) was able to offer their direct support professional staff an increase of $3 per hour for the duration of the pandemic. **Unfortunately, DCF was not able to offer staff wage increases during the pandemic.** This is a discrepancy we are all too familiar with as direct service professionals caring for adults in the DHS system have received wage increases for years while professionals providing care to children and youth through DCF have not. The explanation for the discrepancy is that DCF does not recognize the term direct support professionals in the way that DHS does. NJACYF members are willing to use whatever term the legislature and DCF would like for these professionals so that they may receive the wage increases they desperately need and deserve as well.

Another critical need for our frontline workers is COVID-19 testing and the provision of personal protective equipment (PPE). NJACYF member organizations have reported positive COVID-19 cases in youth and staff since March. We developed a list of recommendations that included streamlined testing for staff and youth and the provision of PPE to ensure the safety of staff and youth. NJACYF members have been in communication with DCF regarding their needs, however shortages of PPE throughout the state and limitations on testing capacity have caused NJACYF members to struggle to meet those needs. NJACYF member staff deserve to have access to streamlined testing on site at the organization where they provide care.

PPE and testing is critical since, as compared to the general child population, youth in care have higher rates of asthma, metabolic conditions, and other health conditions, including cognitive and mobility impairments. While young people overall seem to be more resilient to the virus, these underlying health conditions may make youth in care more susceptible to COVID-19 complications.

Despite the many challenges, there are several heartwarming stories from our member organizations which show the dedication of staff to the children they serve.

- The workforce in one of our member agency's DCF funded residential treatment homes serving young girls is staffed by an all-female workforce. Staff are predominantly African American females who are the heads of their household. Because day care centers were closed and families need to work, these dedicated women began providing around the clock child care services for one another's children so that they each could continue to work and care for the youth at the organization. Out of need and lack of access, comes ingenuity, and solution-focused, forward thinking. This close group of women supported each other, their own families and youth in care through this pandemic.

- At another one of our member organizations a youth in care was informed that his father, who is in law enforcement, was diagnosed with COVID-19 and pneumonia. This crisis opened up a door and the resident was the most emotionally accessible he had been with staff in an exceptionally long time, discussing his concerns. The potential loss of his adoptive father reignited the sense of abandonment that he felt in losing his own biological family at a young age and resurfaced the extreme, pervasive, abuse and trauma that he experienced for the first seven years of his life. The professionals at this member organization are offering the youth additional supports and helping him to thrive during this very difficult time. Another youth shared the following; "I hate this pandemic, but I am so grateful to be here. If I were at home, I would not have food to eat or people who were focused on keeping me safe."

- One of our member organizations also shared with me that, "We have endured COVID-19 and perhaps the silver lining is that the youth in out of home care were in a nurturing and therapeutic environment to help cope."

COVID-19 HAS INCREASED FINANCIAL STRESS ON PROVIDERS

NJACYF members are acutely aware of several concerning facts:

- **Unsustainable rates and program models have caused many programs in New Jersey to close their doors.**

- **There are currently not enough beds in New Jersey to meet the needs of children, youth and families in need of care.**

- **The beds that are currently operating are doing so at unsustainable rates and program models and without change they will be forced to make difficult decisions regarding closure.**

- **As more programs close, access to care will continue to decrease and wait times for youth in crisis will increase.**

NJACYF and our members work closely with the Department of Children and Families (DCF) to provide care to children, youth and families. Prior to COVID-19 we were working with DCF to calculate rates and set deliverables that are sustainable to provider organizations. Without sustainable rates and deliverables organizations will not be able to stand up new programs or add beds to existing ones.

During his February budget address Governor Murphy proposed an investment of at least $45 million more in the Children's System of Care to rebalance out of home and in-community service rates **for the first time in fifteen years** so that New Jersey may better serve children with emotional and behavioral health care needs and intellectual and/or development disabilities. Governor Murphy's proposed investment of at least $45 million is critical to ensuring that services are available to children, youth and families when needed. Without this investment the Children's System of Care in New Jersey will continue to implode.

Unfortunately adding additional resources to the system to meet the identified needs is not easy. As the members of this Committee are all too aware, the State now faces an extreme fiscal challenge which threatens this investment. To further complicate matters, NJACYF members were unable to accept new admissions beginning in mid-March. Because most of our members operate under fee-for-service contracts they only receive reimbursement when youth are in a bed receiving care. While necessary, the freeze on new admissions has had a tremendous impact on organizations revenue. Organizations still have all of the same expenses for staffing, facilities, etc. despite experiencing this decrease in revenue.

At the same time revenues were decreasing, expenses were increasing exponentially. NJACYF members had to purchase cleaning supplies, personal protective equipment, extra cleaning by professionals, more food for youth while not in school, hand sanitizer, computers and other equipment to assist with the transition to virtual schooling, and additional therapeutic materials to help youth foster mindfulness, process trauma and loss and self-regulate emotions and emotional reactions. All of these expenses were unanticipated and were not provided for in NJACYF member budgets. **A survey of NJACYF members found that members spent over $7.2 million dollars on these additional expenses just in March and April.**

We are very grateful to Commissioner Beyer and DCF for utilizing federal medical assistance percentage (FMAP) dollars to help NJACYF members with these additional expenses. NJACYF members are also working with FEMA to apply for assistance to help cover some of these expenses. **We know that the FMAP dollars and the FEMA assistance will not be enough to ensure the sustainability of our member organizations.**

The loss of revenue and increase expenditures described above are further exacerbated by the loss of revenue through fundraising. Because contracts with DCF do not cover the full cost to provide care, our members are forced to fundraise. For many organizations these fundraising dollars are a significant percentage of the organization's budget. In April and May our members lost millions in anticipated fundraising dollars due to the inability to hold in-person fundraising events.

In summary, the convergence of decreased revenues, increased expenses, and unsustainable rates and deliverables has created an environment where children and youth may be without options for care very soon.

CONTINUING TO ADDRESS PROVIDER NEEDS DURING THE PUBLIC HEALTH EMERGENCY

There are still so many unknowns about the impact of COVID-19 on society and the economy. We know for sure that this unprecedented event will affect us all, and especially children, youth and families in under-resourced communities.

Just like there are so many touching stories that have come from dedicated individuals caring for others during this difficult time, there are changes to society that may have a lasting beneficial impact on the work we do. The Centers for Medicare and Medicaid Services (CMS) has issued temporary measures to make it easier for people enrolled in Medicare, Medicaid, and the Children's Health Insurance Program (CHIP) to receive medical care through telehealth services during the COVID-19 Public Health Emergency. This expanded access to telehealth services created opportunities for connecting in ways that would not have been possible and with individuals that would have been unable to connect before this pandemic, and the quick action of policymakers to expand tele-health may be one of the great achievements from this crisis.

As the public health emergency continues, government will continue to play an important role. We would respectfully request your assistance by:

1. Supporting the delivery of healthcare through telehealth beyond the pandemic. One of our member organizations reported that the *kept appointment ratios* since telehealth allowance was expanded has increased from just over 50% to just over 80% across outpatient services.

2. Assisting NJACYF members to receive priority in accessing personal protective equipment and testing in the same ways that long term care facilities and other congregate setting have. It is imperative for our organizations to test both staff and youth in care to identify positive cases of COVID-19 and to isolate individuals who test positive. As of today there is not a mechanism in place for our members to receive priority testing for staff or youth in care.

3. Ensuring that quality services are available when needed by children, youth and families in New Jersey by supporting Governor Murphy's proposed investment of at least $45 million for the Children's System of Care and supporting the legislation introduced by Senator Diegnan, Assemblywoman Lopez, and Assemblyman Johnson that provides a cost of living adjustment based on Consumer Price Index for children, youth and family services organizations (S-1933 and A-1412).

CONCLUSION

Thank you for taking the time to examine the impact of COVID-19 on the mental health of New Jerseyans including children, youth and families. We know that prolonged issues that go untreated in childhood may become chronic issues in adulthood. It is imperative that we work to keep the Children's System of Care from continuing to implode and that we ensure access to care when needed by children, youth and families.

On behalf of the New Jersey Alliance for Children, Youth and Families and the organizations we represent, I thank you again for the opportunity to provide this testimony, for your continued leadership, and for your ongoing commitment to children, youth and families in New Jersey. If you have not had the opportunity to visit one of the organizations we represent, I would invite you do so. A personal visit is the best way for you to experience the tremendous impact the amazing individuals at these organizations have on our State. You will see compassionate, talented staff who dedicate not only their work hours but in many cases their personal time and money to helping to make sure that each and every youth has the tools they need to succeed in life. You will also see children and youth who are thriving despite the many odds against them. These children and youth are the real heroes and their stories will inspire you just as they inspire us each and every day. Please contact me at (609) 586-9092 or megann.anderson@njacyf.org to arrange a visit to one of our member organizations in your district.

NEW JERSEY DEPARTMENT OF
CHILDREN AND FAMILIES

Guidance to Emergency Child Care Centers on Client Eligibility and Tuition

This guidance is issued pursuant to delegated authority under Executive Order 110. The following requirements, effective on and after April 1, 2020, until further notice or as long as Executive Order 110 is in effect, are in addition to those applicable to child care centers under existing guidance, law and regulation.

1. During the month of April, 2020, subject to extension upon further notice, all Essential Persons, as defined under Executive Order 110, shall be eligible to receive child care assistance through the Emergency Child Care Assistance Program (ECCAP) program. All essential persons, including those who are normally eligible for the Child Care Subsidy Program, shall be required to enroll in the ECCAP program in order to receive child care assistance through the ECCAP. The Department of Human Services, through the Child Care Resource and Referral Agency in each county, shall determine eligibility for the program.
2. Emergency child care centers ("centers") authorized to operate after April 1, 2020, shall not enroll or provide emergency child care services to persons not approved for participation in the ECCAP.
3. For previously operating centers – Tuition for emergency child care centers is not expected to rise except to account for increased operational costs. DCF reserves the right to review any increase in tuition from what the center charged in February 2020. Under no circumstances will tuition exceed 110% of rates charged as of February 29, 2020. New centers are expected to charge tuition that is reasonable and in accordance with operational costs. Under no circumstances will tuition exceed 110% of the statewide averages published in the Division of Family Development's Cost of Care Survey.
4. Families with income at or below the thresholds established for participation in the CCSP during non-emergency periods shall not be charged any tuition in excess of the amount paid by the State under ECCAP. Families with income in excess of those thresholds may be charged for the difference between up to 110% of the center tuition, and the amount paid by the State under ECCAP. Centers shall report their tuition rates to the DCF Office of Licensing no later than April 15, 2020, and shall report on any changes thereafter.

5. Subsidy rates for all ECCAP participants shall be, per week and per child:
   - Infant (Ages 0 to 18 months) rate = $450.35
   - Toddler/preschool (ages 18 months to 6 years) = $415.70
   - School age (ages 6 to 13) = $336.03
6. Child Care Resource and Referral Agencies will be contacting centers for additional information to help inform families about programs, rates and availability.
7. Centers shall not discriminate in admissions based on income, participation in the CCSP, or limitations on tuition imposed by this guidance.
8. Any tuition paid by families in excess of what is owed, as described in paragraph 4 above, prior to the receipt of State funding on their behalf shall be refunded to families within 2 business days of receipt of State funding for those services.
9. All persons enrolling children to receive emergency child care center services must complete an application and submit information on their occupation and employer to the designated Child Care Resource and Referral Agency for their county no later than April 3, 2020. A child not approved as the child of an essential person under Executive Order 110 shall not receive child care center services after April 7, 2020.

Christine Beyer

Christine Norbut Beyer, M.S.W.
Commissioner
Department of Children and Families

Carole Johnson
Commissioner
Department of Human Services

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ADVOCATES for CHILDREN OF NEW JERSEY

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The Workforce Behind the Workforce: Child Care Workers and the Need to Address Their Compensation

June 22, 2020

njaeyc New Jersey Association for the Education of Young Children

ADVOCATES for CHILDREN OF NEW JERSEY

By Cynthia Rice, Senior Policy Analyst, ACNJ and Meghan Tavormina, President, NJAEYC Co-Chairs, *Think Babies* Child Care Workgroup

It was no surprise when Governor Murphy deemed child care an "essential service" as part of his stay-at-home executive order in March. Parents working in hospitals, nursing homes, food and drug stores and gas stations could not have gone to work without a safe place for their children to be cared for and educated.

65x

And the child care community rose to the occasion.

While public schools were required to close, approximately 500 of New Jersey's 4,200 child care programs remained open to educate and care for children whose parents were needed to provide for our neighbors. These programs' teachers and aides came to work every day, providing nurturing and caring experiences under new stringent standards that included social distancing, wearing face masks, frequent hand washing, cleaning and temperature checks. These increased standards—and increased work—was all meant to keep children and staff safe and healthy.

For many child care staff, however, one thing that didn't change was their salaries. Even during a pandemic, when child care was deemed an essential service and staff were responsible for caring for young children, their wages continued to be low.

Share

Many child care workers make less than cashiers and other entry-level jobs. In fact, most early childhood educators earn so little, they qualify for public benefits, including programs they work for because those programs target low-income families. And according to New Jersey's 2018 Early Childhood Workforce Index, the median wage for a child care worker was $11.51, with 51 percent of these workers being eligible to participate in one or more public income support programs. Cynthia Soete, President of the Coalition for Infant Toddler Educators (CITE) shares the constant challenge of this reality. "Finding qualified staff has always been hard because of what we pay our early childhood care workforce. It will now be even harder because their responsibilities will increase in order for us to meet the new safety standards. We are asking so much from them professionally, for so little compensation.

The problem of child care's continued low staff salaries became glaringly evident in recent months when child care directors reached out to their staffs to discuss reopening. Many directors got "pushback" from their staff because they were making significantly more money on unemployment than they would if they returned to work.

Some directors are finding that their staffs are also hesitant to return to work because of safety reasons. They fear that they are putting their own health and the health of their families at risk because they will be working with a population in which enforcing social distancing is an uphill battle.

Young children are not wired to stay six feet apart. They want to play together and hug each other and our staff, and that makes social distancing very difficult," said Stephanie Anderson, Director, West Essex YMCA Peanut Shell Early Childhood Learning Center in Livingston.

6dox

Finding new jobs offering the same or often higher salaries with a lower risk of infection is far more enticing to child care staff, particularly since many programs do not offer health insurance and private-paid insurance is often out-of-reach to these low-wage employees.

"We find ourselves competing with Walmart and Target, and often, we cannot," said Winifred Smith, Senior Director, Zadie's Early Childhood Centers in Summit and East Orange.

One of the biggest lessons from this pandemic experience is that we all need child care. It was essential to support employee families who were on the front-line of the emergency and remains essential as our state reopens the economy. We have learned that child care is "the workforce behind the workforce," and parents cannot return to their jobs if their child Share care options have been drastically reduced. But that means that a stable, qualified workforce needs to be in place. That can only happen when the compensation of child care staff moves towards matching the "essential" role they play in the health and development of the children they care for and educate every day.

As highlighted in the National Association for the Education of Young Children's (NAEYC), *Power to the Profession*, assuming comparable qualifications and experiences, child care salaries must reflect compensation on par with other educational colleagues, such as kindergarten teachers. This is no easy feat at a time when the economy is struggling as a result of COVID-19's overall devastation. But we can't return to a system that was not meeting or addressing the needs of the child care workforce.

Whether it is bigger federal or state investments, new systems or new laws that will provide child care staff with other forms of revenue, like child care tax credits, we need to make workforce compensation a higher priority. Doing so is directly linked with both the success of our children and our economy. We must learn from our experiences and improve the compensation of our child care workforce. Otherwise, staffing problems that became glaring during the last few months will continue to impact the quality and accessibility of the child care infrastructure that remains and will not allow our economy to have a fighting chance in moving towards a "stronger and fairer" New Jersey.

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Emphasizing the Importance of Family Visits for Children Living in Foster Care >

5 Responses to *The Workforce Behind the Workforce: Child Care Workers and the Need to Address Their Compensation*

REPLY ↰

Malika Jafri June 22, 2020 at 5:28 pm #

we are penny makers subsidy is paying $3.50 an hour $125 a week and DCF told to the parents that don't pay the copayment to the providers . And We Are Essential workers working 52 hours a week . we are getting lesser than a cashier or a telemarketer. Unions are deducting an amount from our biweekly payment from subsidy . Pl make a loud voice for our right. We the family childcare providers are taking care of America's future and getting very less . I am a provider for 20 years.

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REPLY ↰

Milsa Cerpa June 22, 2020 at 10:16 pm #

I Agree to this statement childcare service during this pandemic was a challenge for all the preschool teachers and teacher assistance we work really hard during this time to help our first responder workers. we need people to see our effort and recognize how important is our labor as educators. programs working with subsidize children should get an increase rate for childcare services to improve our preschool salaries. also we should get grants to help our center during this pandemic. childcare are experience a very low enrollment. families are afraid to send their kids to school. we still need to keep our teachers working even without the same capacity that we use to have before. we need to cut hours when they need the money to keep their families is very hard for all of us. PLease we need HELP!!!!

REPLY ↰

Julie Rogers June 23, 2020 at 10:30 am #

Excellent article, Cynthia Rice. Now more than ever it's become apparent that early childhood educators are the very essential workforce behind the workforce. Early learning for our young children now prepares them to be contributors to our society later and contributes to our future collective prosperity.

REPLY ↰

Rebecca M Cleveland June 23, 2020 at 12:45 pm #

I agree with this statement because child care workers are essential more than ever during the entire pandemic and we should continue to be once the pandemic is fully gone. Child care workers need more compensation and more recognition for the long hours, challenging days, setting the stepping stones for our FUTURE society and being educated with such a precise scaffold that all educators implement for their students.

We need more recognition and assistance for the staffing in the early childhood education field to hold a job and maintain their credentials. Fewer people are majoring this in college due to their lack of funds, which then leads to fewer reliable, educational and purposeful educators in the field with young ones.

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Cindy Shields June 23, 2020 at 1:30 pm # REPLY ↰

Well said, Cynthia & Meghan! Now is the time to speak-up and keep our momentum going for children and early childhood educators in the state of New Jersey...

Leave a Reply

Name (required)

Email (will not be published) (required)

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ACNJ releases a roadmap to close inequities for NJ babies

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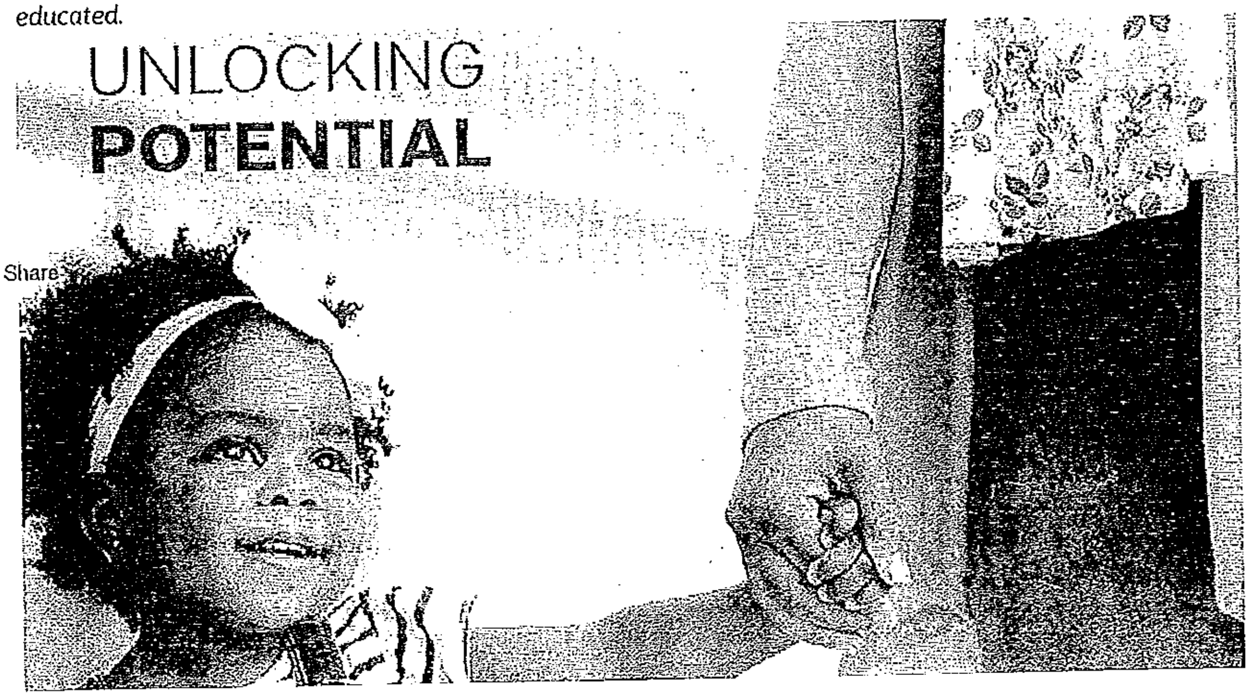

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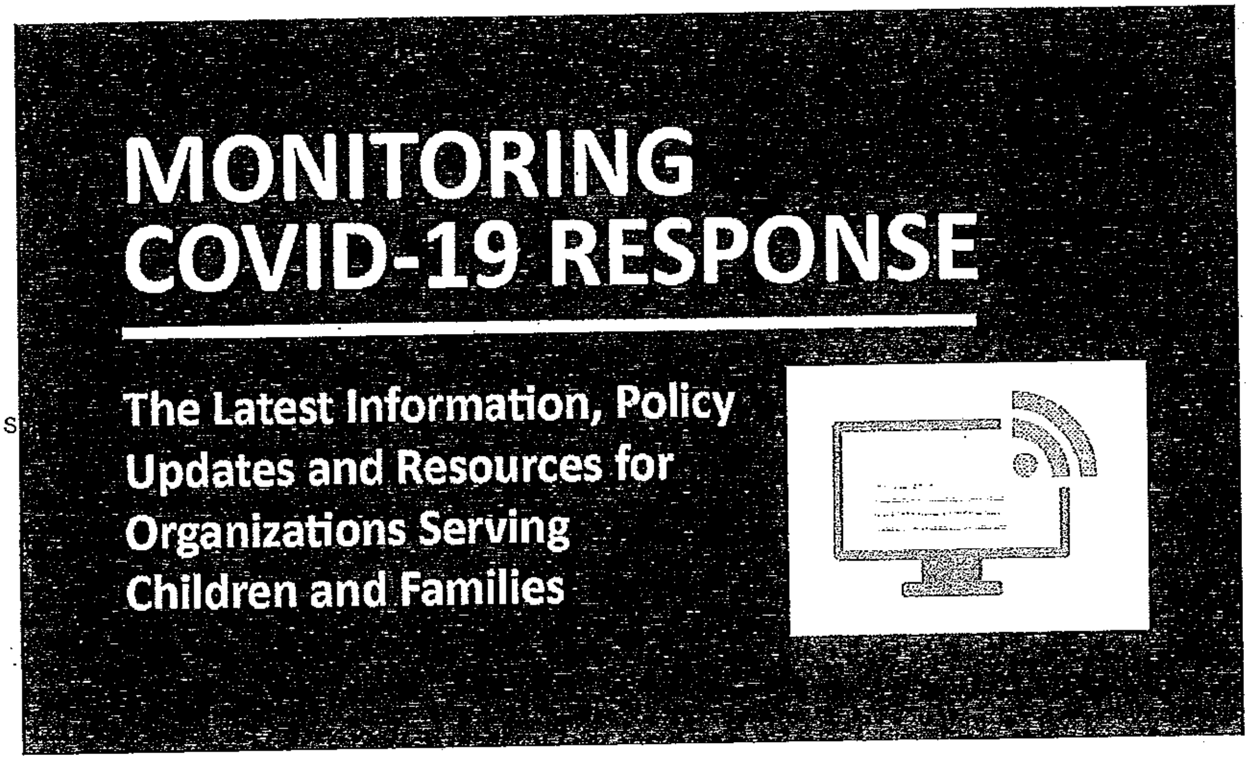

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