APPENDIX

State of New Jersey
OFFICE OF THE OMBUDSMAN FOR INDIVIDUALS WITH INTELLECTUAL
OR DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES
P. O. BOX 205
TRENTON, NEW JERSEY 08625-0221

PHILIP D. MURPHY
Governor

SHEILA Y. OLIVER
Lt. Governor

PAUL S. ARONSOHN
Ombudsman

Testimony of Paul Aronsohn,
Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families
New Jersey Assembly Committee on Human Services
Thursday, October 22, 2020

Good afternoon, Chairwoman Downey and Members of the Committee.

Thank you for holding this very important hearing and for inviting so many individuals and families to be a part of this difficult, yet necessary conversation. I know that there is limited time today to provide in-person testimony, but it was good of you to encourage as much written testimony as possible.

Clearly, this is an issue-area that our state government takes very seriously, and over the years, steps have been taken to minimize, if not outright eliminate, abuse and neglect of individuals with disabilities in group homes and other congregate care facilities. The implementation of the Stephen Komninos Law, beginning in 2018, is just one of the most recent, most sweeping examples of the efforts that have been made in this regard.

Yet, we know that abuse and neglect still exist, and the testimonies presented today will speak to that ugly truth. We also know that there may be a very fine line between abuse and neglect. For some, neglect is arguably its own form of abuse.

My hope, therefore, is that today's hearing will be an important milestone in our collective efforts – across our two branches of government – to fix that which is broken and to make safer our system of care for people with disabilities. That might mean more oversight. That might mean more training. That might mean more use of monitoring technology. Or that might mean some combination of all of the above.

Regardless, at a minimum, it should mean more transparency with respect to investigations into abuse and neglect. Present practice is for allegations to be investigated, but not fully shared with the public or even the individuals or families involved.

1 X

More transparency would be the right thing to do as well as the smart thing to do.

- The right thing, because individuals and families deserve to know the details of any such investigation involving them or their loved one.
- The smart thing, because such investigative reports provide us all with opportunities to learn, to improve and to make necessary changes.

Again, today's hearing is providing a platform to jumpstart a difficult, yet necessary conversation – one that is long overdue, one that will hopefully move us closer to ending abuse and neglect of individuals with disabilities. Suffice it to say, we can't get there soon enough.

Thank you.

Testimony of Bonnie Brien: Parent, Chair Family Support Coalition of NJ; Co-Chair Regional Family Support Planning Council #3 - Somerset & Union County

New Jersey Assembly Committee on Human Services
Thursday, October 22, 2020

Good afternoon Chairwoman Downey and other members of the Committee,

One year ago today -- October 22, 2019 -- my daughter, Rachel, was admitted to the hospital the day after her 34th birthday. She never left. She passed away on November 15th from common medical issues that went unreported or addressed in a timely manner to us or her PCP. As a result serious complications developed from which she suffered terribly over 3 weeks that ultimately led to her death.

By all indications, Rachel's illness and untimely death were preventable. In fact, if her medical issues had been addressed appropriately, it is highly likely Rachel would have celebrated her 35th birthday with her twin sister yesterday.

Rachel became seriously ill while living in a supervised apartment under the care of a state licensed residential provider. While some might have referred to Rachel as a complex non-verbal individual as a result of her Cerebral Palsy, seizures, and chronic episodes of constipation & dehydration, her general care was no more complicated than caring for a young child. Indeed, daily monitoring of her health concerns -- when conducted in a proper, timely manner -- allowed her to live a full life in the community. In fact, she lived with us until age 31 during which she never experienced the serious medical complications that led to her passing. Unfortunately, her general physical care became dangerous for us and her as we approached our mid-sixties forcing us to seek residential care with a community provider.

That said, it was clear to us that some of the provider's staff lacked basic health oversight training, specifically the so-called "Fatal Five" – the five most commonly identified causes of preventable death in persons with Intellectual and Developmental Disabilities: aspiration, bowel obstruction, seizures, dehydration and sepsis. And not only did staff lack this basic training, they disregarded our numerous attempts – as her family and those who knew her best -- to provide ongoing education with respect to Rachel's daily care. Consequently, she experienced a series of health concerns that went unreported to us and unaddressed for weeks prior to her hospitalization. As a result, the lack of training and oversight led to a rapid deterioration of her health.

At our request, the Department of Human Services investigated this situation, but has denied our family a copy of the investigative report, leaving us to wonder "what" they investigated and "how" they came to their conclusion. At a minimum, we deserve a copy of the report and other relevant documents. Rachel deserves this and we desperately need to understand how the licensed provider failed to conduct simple oversight of her daily care in order to prevent her death.

3x

Needless to say, the loss of our daughter has been and continues to be unbearable on a personal level, but it also highlights concerns that demand attention. Significant gaps within the statewide system -- at both the state and provider level -- have resulted in unknown countless preventable illnesses, accidents and even death. We need to protect those vulnerable individuals who require constant and consistent health oversight in a manner that alerts paid caregivers when medical attention outside of an obvious physical injury is required. There is no accounting for subtle changes in behavior that may indicate a medical condition is developing or has worsened and the need to notify a parent/guardian as well as advice from a medical professional is warranted. A number of initiatives are currently under consideration within the legislature that have the potential to greatly improve current health & safety practices, including video monitoring, but fixing the entire system must be a priority.

As an advocate for this population for more than 30 years, I continue to work with the current Health and Safety Subcommittee of the Family Advisory Council, which consists of family members and the leadership of the state's Division of Developmental Disabilities (DDD). Going forward, I would also welcome the opportunity to work with this Committee.

What happened to our family shouldn't happen to anyone's family. What happened to our Rachel shouldn't happen to anyone's child.

Thank you.

Connie Shazar
737 Cooper Landing Road, Cherry Hill, NJ 08002
856-246-7790 (cell), cmancuso717@gmail.com

April 2018

Governor Phil Murphy
Office of the Governor
PO Box 001
Trenton, NJ 08625

Dear Governor Murphy,

I am a mother of a 19 year old special needs son who is multiply-disabled. He is on the Autism Spectrum, reads on a 3rd grade level, has anxiety, panic attacks, PTSD, learning disabilities, and Oppositional Defiant Disorder, and isn't caring for his own health (refuses even go to a dentist).

Since birth, it's been very difficult to get the correct services my son needs and, to this day, continues to be very difficult. He needs help so desperately, as he is beyond a handful, very easily mislead, and vulnerable.

He has been involved with PerformCare/CMO for approximately 10 years. Over the years, he's been in and out of several residential placements where he was traumatized from being abused (both by other peers and staff), although staff claim otherwise. To this day . . . my son jumps when I try wake him up for school.

His anxiety is so high. He has a hard time going any appointment, even school at times, and can only handle one instruction at a time. Transitions are very hard for him.

In December 2017 my husband, his stepfather (the only man that truly raised him, was there for him, went to most IEP meetings, CMO meetings, and father education classes) died in the most horrific way: from the pain of feeling hopeless in a broken system and never seeing a way out. We felt like prisoners in our own home.

My son is like so many children with mental health and developmental challenges who have fallen through the cracks. They struggle so long and so hard that they become exhausted and distrustful that things will ever get better. They adopt a survival mode that makes them appear hardened, uncooperative, illogical, nasty, and even manipulative. Yet they are "treading water" just trying to stay afloat. Their behaviors are primitive cries for help that they now lack the insight to even realize they need.

My son's survival mode clouds his judgment and tells him that fear is the way to gain respect. Towering at almost 6'6" tall and very strong, he threatens me daily that I better never try to get guardianship or . . . you can imagine the rest of that statement.

Underneath all this anger is excruciating hurt and pain. Medications have failed him, the school system has failed him, hospitals have failed him, residential treatment has failed him, and now, in my almost mid 50's, I worry for him. His defiance is big problem and he doesn't realize he spites himself.

He has hard time finding doctors that accept Medicaid. The CMO/Performance claim he aged out and should go outpatient therapy. He is not stable, I feel hopeless.

As you know, NJ has the highest rate of Autism and yet too many young adults with Autism and co-occurring disorders languish, falling between the cracks of the developmental and mental health systems. Something needs to change!

5x

Youth in NJ can, at age 14, choose to accept and refuse treatment. Sadly, most refuse treatment due to frustration or lack of insight. Ironically, parents and the children end up suffering the consequences because of their actions.

Even those that accept treatment are can sometimes be taken advantage of. Some treatment providers in the Children's System of Care allow (or insist) that gullible children sign off on the treatment providers' timesheet, without realizing what they are signing and without verifying that those hours and services are accurate.

The gap between ages 18 - 21 is horrific. DDD has a long Wait List (approximately 14 years) for residential services for these developmentally delayed and mentally disabled children. They languish at home with nowhere to get appropriate services.

My son tries work, but he typically gets frustrated and walks out or is asked to leave after only about 3 days. He's been turned down for SSI because they say he is too young and they want see if can work. Seven jobs later, a 3rd grade reading level, inability to read cursive or write, no understanding of even basic math, and no life skills . . . and SSI thinks he can still work.

I have been on the board of the Family Support Organization (FSO) for several years, hoping to be part of helping families get the services for their children and supports for themselves. Sadly, I've heard more stories of frustration than of successes. My husband often lamented "ENOUGH IS ENOUGH"!

No family should ever run out of options, to the point where they take their own life, which my beloved husband did that December day, just 4 months ago. I understand how my husband felt, as I am feeling hopeless myself and scared for my son. My son is very sick and mentally impaired.

The state needs to wake up and be accountable to these children that we have failed so desperately. If we continue to ignore these failures, we'll pay more when they make ill-conceived decisions that land them in jail. Between criminal charges and no proper education, what else will they resort to? Their impaired judgment and desperation can lead them to tragic consequences. As a community, we all suffer one way or another.

Prevention is the key: a better Children's System of Care; more education staff, teachers; and law enforcement trained to respond more compassionately/appropriately to individuals with such challenges. Now is the time to act before another life feels hopeless and tragically lost due to a failed system.

This year has been the worst year of my life. I am reaching out now for help. Please hear my plea and the cries of so many other parents, like myself, whose children and young adults are falling through the cracks of a still-broken system . . . before another life is gone.

I would like to discuss some experiences/observations of, and areas for improvement for, the NJ Children's System of Care. I look forward hearing from you. My contact information is in the letterhead. Thank you, in advance, for your consideration.

Sincerely,

Connie Shazar

Copy to:

- Senator James Beach

6x

- Assemblyman Louis Greenwald
- Assemblywoman Pamela Lampitt

7x

Fwd: Re letter to state reps

cm cmancuso717 <cmancuso717@gmail.com>

Wed 10/21/2020 1:11 PM

To:OLSaideAHU <OLSAideAHU@njleg.org>;

3 attachments (3 MB)

IMG-0759.PNG; IMG-0760.PNG; IMG-0761.PNG;

---------- Forwarded message ---------
From: cm cmancuso717 <cmancuso717@gmail.com>
Date: Wed, Oct 21, 2020 at 11:18 AM
Subject: Re letter to state reps
To: <paul.aronsohn@treas.nj.gov>

I wrote this letter to state reps to get help for my son, tried get them to understand the seriousness of this and this population of kids, now at age 22 on DAC ssa disability. in out hotels out of his mind with ddd calling me he lost Id. Out food. Throw out hotels refused or lost mask Covid , I feel I am fighting alone an uphill battle. I did meet with 2 policy makers and them me back they drafted a new policy for review any child in no system of care a caregiver or parent can get him evaluated at hospital as usual my son falls through the cracks of everything I fight for our kids. I hope to save another family from this nightmare thx u again connie shazar 856-246-7790
Ps. I did want request about hearing tomorrow or if you received my info I filled out thx u
Re: son Brandon shazar.

8x

Re group home hearing

cm cmancuso717 <cmancuso717@gmail.com>

Wed 10/21/2020 1:20 PM

To:OLSaideAHU <OLSAideAHU@njleg.org>;

These group homes and state need to be held accountable to our kids. My son was so traumatized in group homes when I'd question I got the run around or take him out. Just sad drugged pcp in system from group home to Trinitas hospital, bullied, abused, bedbugs, etc now ptsd so bad does not trust the system that hurt him. Group homes run so poorly all the families suffered. Thx u connie shazar

Mr Aronsohn,

A ms Maria Fischer reached out to me during a weekend zoom conference we were all on she wanted to speak with you about my situation and said she'd contact me back, I have not heard back from her. During guardianship hearing was a big problem it feel apart. I hope these kids free state prosecutors become educated on this population, not just old dementia patients . Due to his free lawyer insisting he did not need a guardian and all his drs knew he needed he tried make me keep wasting money 350 hr. And abuse of supena power. Got too crazy to handle and family was grieving loss of my husband. My son has been declined so bad sad. A mess and legal issues etc . He has such trauma and ptsd he effects all us, the kids lawyers need to do what's best for them not treat as a paying private client. Our taxes paid for him. Thx u again connie shazar 856-246-7790

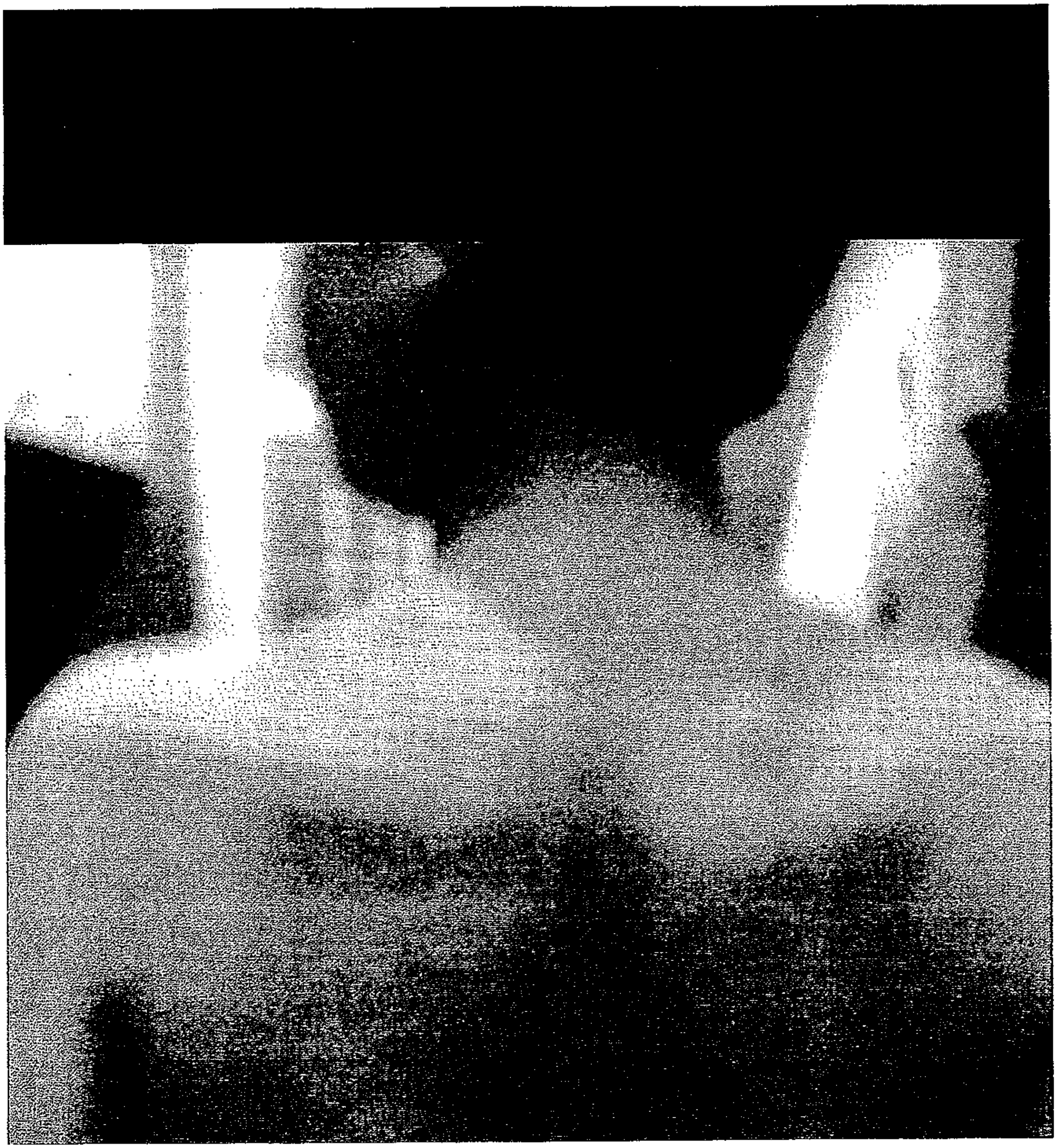
9x

Bedbug on my son in group home thx u connie shazar

cm cmancuso717 <cmancuso717@gmail.com>

Wed 10/21/2020 1:26 PM

To:OLSaideAHU <OLSAideAHU@njleg.org>;



[redacted]

10x

During group home pic

cm cmancuso717 <cmancuso717@gmail.com>

Wed 10/21/2020 1:51 PM

To:OLSaideAHU <OLSAideAHU@njleg.org>;

11x

Testify

Lisa Gutowski <lisagutowski12@yahoo.com>

Fri 10/16/2020 9:55 PM

To:OLSaideAHU <OLSAideAHU@njleg.org>;

Good evening,
I would be very interested in testifying. My son has been abused at two different facilities. The first one the abuse was so bad that it was the highest charge of abuse . Since my son is non verbal no one was fired . A year later they had another hearing that I was not informed of or invited to where they lessened they learned the charge to the least count of child abuse. My son this summer at another facility was being abused and they thought it was self injurious behavior. I said it wasn't since I know my son does not hurt himself. A nurse walked by and saw a staff member hitting my son in the legs with a hairbrush while screaming profanities at him. This man still has his job and is still employed by the facility. I want people to be accountable for there actions when they abuse those who have no voice . Please let me tell my story .

Thank you ,
Lisa Gutowski
(732)504-5537

Sent from my iPhone

12x

Testimony of Lisa McCauley Parles, Esq.
New Jersey General Assembly
Human Services Committee
October 22, 2020

Good afternoon. Thank you for giving me the opportunity to speak with the committee and address the issue of preventing abuse and neglect of individuals with developmental disabilities.

I am a partner in Parles Rekem, a New Jersey law firm representing individuals with disabilities, their families and non-profit organizations. I am a founding Board member of the National Council on Severe Autism and have been an invited speaker at the United Nations, the U.S. General Accountability Office and various legislative committees. In addition, I am the parent of a thirty year old non-verbal man with severe autism, bi-polar disorder and complex medical and behavioral needs.

Without question, the committee will hear from numerous families who present harrowing facts surrounding incidents of abuse and neglect of their disabled loved ones. I started my career as a sex crimes prosecutor in Brooklyn and never imagined that private practice would bring to me so many situations involving broken bones, bruising, sexual assault, medication errors and other horrifying scenarios. In the 27 years since my son's diagnosis I have visited programs throughout the country seeking information about program elements that lead to safer environments, engaged satisfied families, supported well-trained staff and healthy, safe persons served. I have particularly focused on the needs of individuals with little or no language, challenging behavior and complex needs, a population that in order to thrive must have well designed, frequently reviewed data-based programing.

In my view key components of abuse and neglect prevention strategies include camera/surveillance systems which are not only intended to catch wrongdoing, but are rather, properly used as training tools, support for staff and a mechanism for instructive feedback. One program I visited in Kansas had an elaborate camera system that allowed clinicians and staff to speak to each other in real

13x

time. When I asked staff how they felt about the cameras, they uniformly said that before the system was put in place, they were concerned it would be punitive and invasive. However, I was told that once they realized it was used to assist them and best serve the residents, they welcomed the input and the support they received.

A second key element is engaged, experienced clinicians who actually spend time with persons served, observing and working directly with them as well as modeling effective interventions and interactions for staff. A barrier to effective clinical services is caseloads that are too large and do not adjust the number based on the severity and complexity of persons served.

A third critical element is communicating and connecting with families in a meaningful way. Communications must not start with troubling incidents but rather, at admission, by committing to viewing families as partners who possess helpful information and useful ideas. Also, successful programs engage families in program development and design – not just fundraising - but rather on substantive committees such as Human Rights and Strategic Planning. Partnerships that lead to the sense of a joint mission committed to quality programming is a key component of safe, successful programing.

I would be remiss if I did not address some of the worst situations I have encountered involving peer aggression where individuals were frightened and harmed, providers were under attack and families were left worried and heartbroken. Among the most troubling were situations where programs failed to act quickly in communicating and failed to increase necessary staffing and support. In these situations programs failed not just the target of the aggression but also the individual engaging in aggression, as they all too frequently did not have the benefit of an analysis of the function of the behavior nor an effective intervention plan. One strategy that programs in other states have employed is creating projects with smaller individual units available, including one bedrooms, in clusters that allow for quick team response, intensive supervision, protection of victims, and most importantly the ability to remove, assist, treat and support an individual exhibiting aggression. Throughout these situations, families must be kept informed, effective treatment must be put in place and all persons served must be treated with dignity and respect. I would like to end by thanking the committee for investigating situations that cause unimaginable suffering for all involved.

15x

My testimony included one of my friend's affidavit she is an ombudsman Ms Ednah Holt , my own history and my experience at the group home

Queen Alima <queenalima2016@gmail.com>

Mon 10/19/2020 5:56 PM

To:OLSaideAHU <OLSAideAHU@njleg.org>;

My name is MARIE Ruth Alima Wargnye, my son is Christopher Alex Amie Manga going through hell in Willoglen Academy in Sparta Nj , locked in their horrible group home in Lafaillette Nj 84 Valley view Road my telephone number 646 944 6824 . My ombudsman is Paul Aronsohn tel 201 213 1811 I wish to testify Thank you
Sent from my iPhone

16x

On Monday, 10/12/20, I called the Willowglen Group Home in Lafayette, NJ, to let them know that I was going to see my son, Christopher, on Sunday, October 18th at 2:00. I spoke to Kevin a staff member and was told that he would let her know right away. On Thursday, October 15th, I got a call from Jessica Anastasia, who is the supervisor of Sarah Silvetri, Christopher's guardian supervisor. She told me to get a lawyer, because she is aware of an investigation going on regarding Christopher's guardianship and that she called to thank me for reporting what is taking place in the group home. That anytime that I report, they will go there and fix something and I said that was not the case. I have made several reports in the past and even called the police and nothing has changed. I also told her that I want Christopher to be living under better conditions and closer by me, because he is too far away and he also needs to get an education to be more independent.

Today, Sunday, October 18th, while I was on my way, along with my therapist and his two sisters to see Christopher, a lady called me, saying she was Jennifer Mendenhall, the director, and told me that she heard yesterday that I was going to see my son today and that I would not be seeing him. When I asked why, she told me that I could not see him without the guardian's permission. I told her that my son has been there for 20 years and I was never told before that I needed to get the permission. She was very arrogant and kept talking over me and I told her that I was on my way and that I was going to feed my child.

When I arrived there, I eventually saw him in the backyard, due to Covid 19 restrictions. I found him worse than before - like a skeleton, dirty, parts of his hair was missing and other was extremely long. His beard was really long and he looked like a caveman. In addition, his teeth were yellow with plaque and he couldn't close his hands. He was so skinny that his pants were dragging on the floor with no belt. He was starving and gulping down the food I brought him. I needed to go to the bathroom and a young man named Kevin refused, so I told him that I came from N.Y. and needed to relieve myself, because I had taken a water pill. He called the supervisor named Jana, and she told him to tell me to go back to a place along the way before I arrived there. I told Kevin that I would have to relieve myself in the backyard. I then was allowed access through the garage that leads to the bathroom. It was very dirty and excrement everywhere and also spiders. I had to relieve myself standing up and had to wash my hands outside, because I didn't want to touch anything. I then fed Christopher and send food for others in the house, as I usually do.

In the past I even saw a patient with phlegm coming out of his nose and mouth and another eating his own fecis. I have made several calls to get information about getting my son back and help for others in the house living under those awful and unsanitary conditions.

17x

SOME HISTORY

1) I am originally from Africa and moved to France when I was 16, or 17.

2) I went to High School there, got married and had 4 children (I girl and 3 boys (Christopher last one - now 34)

3) I endured emotional and physical abuse. He neglected the children. We got divorced in June 12, 1992. He put me out of the house and took the children away and had them institutionalized. A friend let me stay in a room under very poor conditions. I then went to court, where I was told that I needed to have a house and a good job to get my children back. I went back to school and I was doing several little jobs after school to sustain myself. I wanted to graduate and find a good job, so that I would have enough to rent a house so that I could take care of myself and my children and be able to show the court and get my children back.

4) In the meantime, I met Pierre and he offered me a job. He was very sympathetic to my situation and with the salary I was paid by him, I hired a lawyer to work on my case. Pierre was then transferred to New York and I came with him. Eventually we got married and bought a house in Leonia, NJ and went back to France to fight for taking back my children., since I was now in a different position. When I returned to France, I found my children in terrible condition. They were all separated and when I went to visit Christopher, I found him tied to a bed.

5) I eventually brought my son Christopher, 5 years old, from France to live with me. My husband kept telling me to either send my son back to France, or he wanted a divorce. He put me out and sold the house in Leonia.

18x

6) I put Christopher in a school. He didn't know English and was hyperactive, so he was put in a special class 101. I hired a tutor at home for him and also sought medical evaluation. I contacted many doctors and he was referred by the Hackensack children's service to Bergen Pines for brain evaluation, where nothing was found after testing. They kept him for one week for further evaluation, because he was running a fever and was constipated . They found that he had chronic constipation, which needed treatment and were surprised at his musical ability. They gave him all kinds of medications and nothing worked. Since he was hyperactive, I was asked to follow-up with the doctor who was treating him and did the brain evaluation. I took Christopher several times to see the doctor, who referred me to a social worker. The social worker referred me for legal help, due to the many issues I was dealing with, including my son's disability, marital status, etc.

7) I was under tremendous stress, which triggered an attack, due to my sickle cell Anemia. My blood pressure was out-of-control, which affected my kidneys and eyes. I saw an eye specialist and since my blood pressure was very high, he wanted to hospitalize me and I told him that I couldn't because I was by myself and had Christopher. He knew that I was exhausted, because I had no rest, due to the fact that when Christopher was not in school, he was restless all day and didn't sleep at night. The Dr. called Dyfus to get me help, so that I could be hospitalized. They came to see me and said they would take Christopher for 6 months, until I got well and then he would come back home. I told them that I didn't want that, because I didn't want to be separated from him. They told me that since, I was so sick, I wouldn't be able to care for him.

Also, due to blood transfusions in the past, when I was pregnant with Christopher, I got Hepatitis C and I contracted gout. They induced labor, at 6 months, because, jaundice was choking Christopher.

From: Edna Holt <eholt1948@gmail.com>
Date: March 17, 2020 at 7:58:56 PM EDT
To: MARIE RUTH MARIE RUTH ALIMA <queenofmyoho@yahoo.com>
Cc: eholt1948 <eholt1948@gmail.com>
Subject: Re: Visiting Christopher with Mrs. Wargnye at group home Sunday, March 8, 2020

You're welcome!

Much love to Patrick and Gregory and lots of winning victory prayers for tomorrow

On Tue, Mar 17, 2020 at 7:37 PM MARIE RUTH MARIE RUTH ALIMA
<queenofmyoho@yahoo.com> wrote:
Thank you so much I'm with PATRICK on the phone and Gregory 🙏

Sent from my iPhone

> On Mar 17, 2020, at 6:54 PM, Edna Holt <eholt1948@gmail.com> wrote:
>
>
> To Whom It May Concern,
>
> On Sunday, March 8, 2020, I was still visiting Mrs. Wargnye to support her while she was getting well and I had asked her how was her son, Christopher. Mrs. Wargnye said she had not seen Christopher in two years because of her illness, back and forth in the hospital and rehabilitation nursing home. Surprised, I told Mrs. Wargnye to get dressed and let's go visit Christopher while I was still there to support her.
>
> The trip to Christopher's home was about one hour and when we arrived, a van pulled into the parking lot of the group home at the same time we did. When Mrs. Wargnye and I got out of the car the smell of urine reeked everywhere outside of the group home to the point of making me want to vomit. Three young men came out of the van and one of them was Christopher, in which I told Mrs. Wargnye it was good timing that we arrived at the same time as the van. Mrs.Wargnye addressed Christopher with a loving hug and one of the other two young men named Walker also came up to Mrs. Wargnye. Mrs. Wargnye had brought several bags of food for Christopher but enough for the other young men that lived at the group home with Christopher. Mrs. Wargnye being on the rollator needed help with the bags and Walker grabbed the bags without being asked and helped Mrs.Wargnye and I to the stairs of the group home. The other young man, named Ronald that was also in the van started running pass the group home and the driver had to grab him to stop him which caused both of them to hit the ground. When we arrived at the stairs of the group home, a young man named Jimmy came out of the home to help Mrs.Wargnye up the stairs into the home. When we got into the home it also was reeking of urine. There were two other young men in the home. One was sitting outside where we entered and the other one came into the kitchen where we were directed by Jimmy

20x

later. Jimmy was the group home coordinator and he was by himself with the five young men. I asked Jimmy did he have help and he said no. He was the only one that lived with the five young men. I personally felt that Jimmy needed more assistance in taking care of the five young men

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> Meanwhile, Mrs. Wargnye had asked Jimmy the group home coordinator, was Christopher still playing the piano and Jimmy went to get the piano from Christopher's room He never let Mrs. Wargnye into Christopher's room. Christopher started playing and singing on the piano and Walker would join Christopher in creating music. What I heard from Christopher was very good. I had asked Mrs. Wargnye was Christoper receiving Specialized instruction for his music and she said no. Christopher had been in the group home for twenty years and they have never kept their word in sending him to get specialize instruction for his musical talent. She had also offered to pay for the specialized music instruction but to no avail.

>

> I also noticed Ronald had a continuous thick snotty substance coming from his nose and mouth in a string-like form. Mrs. Wargnye asked Jimmy why was Ronald so thin that his pants were falling continuously, to the point he had to hold then up. Jimmy said that the other young man always stoled his food in which Mrs.Wargnye and I witnessed as Mrs. Wargnye gave Ronald food and this other young man would fly across the room and snatch his food and drink, This young man also would lick the counters with his tongue and take food from the garbage. At one point he came over and grabbed my wrist, in which I calmly called Jimmy to come to my aide and take the young mans hand off of my wrist.

>

> I am a retired music teacher that taught special needs children. My first teaching job was Bellevue Hospital in New York, New York. Music was one of the specialized instruction educational resources that were given to my students along with other academic instruction. I did not see this happening in the group home, even though I was there for that day a short time. I did ask Jimmy were the other young men's parents involved and he said all except the young man that was sitting outside the kitchen, he did not have any parents. To add Mrs Wargnye son Christopher had a rash that she addressed that had been ongoing. Christoper's teeth were so yellow and he appeared sick. Mrs. Wargnye asked when was the last time Christopher seen a doctor or dentist ant Jimmy said he did not know because he is by himself with the young men and doing his best because of being by himself. Question? why is Jimmy by himself? How often are these young men seen by a doctor? Why are they not given specialized education? Why are they thin sick looking and hungry-looking? These are questions Mrs. Wargnye has been asking which brings her blood pressure up and most important of all where is the guardian of Christopher If she is taking care of Christopher where is it written in proof of all the above questions? When was her last visit? All the above needs to be seen in the writing of proof of her care for Christopher.

>

> Edna A Holt

>

>

21x

> To Whom It May Concern,

>

> On Sunday, March 8, 2020, I was still visiting Mrs. Wargnye to support her while she was getting well and I had asked her how was her son, Christopher. Mrs. Wargnye said she had not seen Christopher in two years because of her illness, back and forth in the hospital and rehabilitation nursing home. Surprised, I told Mrs. Wargnye to get dressed and let's go visit Christopher while I was still there to support her.

>

> The trip to Christopher's home was about one hour and when we arrived, a van pulled into the parking lot of the group home at the same time we did. When Mrs. Wargnye and I got out of the car the smell of urine reeked everywhere outside of the group home to the point of making me want to vomit. Three young men came out of the van and one of them was Christopher, in which I told Mrs. Wargnye it was good timing that we arrived at the same time as the van. Mrs.Wargnye addressed Christopher with a loving hug and one of the other two young men named Walker also came up to Mrs. Wargnye. Mrs. Wargnye had brought several bags of food for Christopher but enough for the other young men that lived at the group home with Christopher. Mrs. Wargnye being on the rollator needed help with the bags and Walker grabbed the bags without being asked and helped Mrs.Wargnye and I to the stairs of the group home. The other young man, named Ronald that was also in the van started running pass the group home and the driver had to grab him to stop him which caused both of them to hit the ground. When we arrived at the stairs of the group home, a young man named Jimmy came out of the home to help Mrs.Wargnye up the stairs into the home. When we got into the home it also was reeking of urine. There were two other young men in the home. One was sitting outside where we entered and the other one came into the kitchen where we were directed by Jimmy later. Jimmy was the group home coordinator and he was by himself with the five young men. I asked Jimmy did he have help and he said no. He was the only one that lived with the five young men. I personally felt that Jimmy needed more assistance in taking care of the five young men

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> Meanwhile, Mrs. Wargnye had asked Jimmy the group home coordinator, was Christopher still playing the piano and Jimmy went to get the piano from Christopher's room He never let Mrs. Wargnye into Christopher's room. Christopher started playing and singing on the piano and Walker would join Christopher in creating music. What I heard from Christopher was very good. I had asked Mrs. Wargnye was Christoper receiving Specialized instruction for his music and she said no. Christopher had been in the group home for twenty years and they have never kept their word in sending him to get specialize instruction for his musical talent. She had also offered to pay for the specialized music instruction but to no avail.

>

> I also noticed Ronald had a continuous thick snotty substance coming from his nose and mouth in a string-like form. Mrs. Wargnye asked Jimmy why was Ronald so thin that his pants were falling continuously, to the point he had to hold then up. Jimmy said that the other young man always stoled his food in which Mrs.Wargnye and I witnessed as Mrs. Wargnye gave Ronald food and this other young man would fly across the room and snatch his food and drink, This young man also would lick the counters with his tongue and take food from the garbage. At one point he came over and grabbed my wrist, in which I calmly called Jimmy to come to my aide

and take the young mans hand off of my wrist.
>
> I am a retired music teacher that taught special needs children. My first teaching job was Bellevue Hospital in New York, New York. Music was one of the specialized instruction educational resources that were given to my students along with other academic instruction. I did not see this happening in the group home, even though I was there for that day a short time. I did ask Jimmy were the other young men's parents involved and he said all except the young man that was sitting outside the kitchen, he did not have any parents. To add Mrs Wargnye son Christopher had a rash that she addressed that had been ongoing. Christoper's teeth were so yellow and he appeared sick. Mrs. Wargnye asked when was the last time Christopher seen a doctor or dentist ant Jimmy said he did not know because he is by himself with the young men and doing his best because of being by himself. Question? why is Jimmy by himself? How often are these young men seen by a doctor? Why are they not given specialized education? Why are they thin sick looking and hungry-looking? These are questions Mrs. Wargnye has been asking which brings her blood pressure up and most important of all where is the guardian of Christopher If she is taking care of Christopher where is it written in proof of all the above questions? When was her last visit? All the above needs to be seen in the writing of proof of her care for Christopher.
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> Edna A Holt
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Gwen Orlowski, Executive Director

Testimony before the Assembly Human Services Committee
Thursday, October 22, 2020 at 12:30 pm

Gwen Orlowski
Executive Director
Disability Rights New Jersey
For more information: DRNJ-COVID.org

Thank you Chairwoman Downey and members of the committee for inviting me to speak here today about the subject of abuse and neglect of individuals with disabilities and how to prevent abuse and neglect of individuals with disabilities in congregate settings including group homes.

Disability Rights New Jersey is the federally funded, designated protection and advocacy system for people with disabilities in the State of New Jersey. Under our federal enabling statutes, we provide legal representation, advocacy, education and training, and information and referral to people with disabilities, their families, and the professionals who serve them. Created in 1975 by Congress in response to a series of investigative reports which exposed abuse and neglect at a New York state institution for individuals with developmental disabilities, a core function of protection and advocacy agencies including Disability Rights NJ is to have a regular, ongoing presence in settings where individuals receive services, and to investigate incidents of abuse and neglect. In this role, Disability Rights NJ has been investigating allegations of abuse and neglect in state developmental centers and state psychiatric hospitals since it was formed in 1994. However, as individuals have moved from institutions into more community settings

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such as group homes, Disability Rights NJ has expanded its role to ensure that individuals with disabilities continue to be free from abuse and neglect wherever they might reside.

Disability Rights NJ recognizes the prevalence of abuse and neglect among individuals with intellectual and developmental disabilities. All research shows that individuals with intellectual and developmental disabilities are three (3) to ten (10) times more likely to experience abuse, and are more likely to experience repeated abuse. Individuals who live in settings dependent on round the clock caregivers are particularly vulnerable. Disability Rights NJ acknowledges that the crisis is real, but believes strongly that this serious concern must be addressed by strengthening services & training in ways that enhances an individual's rights to participate in the community while maintaining dignity and privacy, and prevents abuse through a more supportive service culture, competency-based training, and living wages for Direct Support Professionals.

Abuse comes in many forms such as physical, mental and emotional, and sexual. Individuals with disabilities are especially vulnerable to abuse as they tend to be reliant on caregivers, they may not be able to speak or their complaints may not be taken seriously, and they may have fewer family or support persons watching out for their well-being. Furthermore, in congregate settings, the power imbalance between the service provider and the individual creates greater opportunities for abuse. Abuse of individuals with disabilities unfortunately occurs in all settings – institutions, group homes, and independent living arrangements. There is some positive news, however, as research has started showing methods that will prevent abuse regardless of the setting or type of abuse.

In order to prevent abuse, a comprehensive approach is needed. First, it is important that all individuals with disabilities need to be empowered to protect their rights and autonomy. Individuals with disabilities should have as much control over their life and make their own decisions to the extent possible. In addition, individuals with disabilities should be encouraged to do as much on their own as possible. Finally, individuals with disabilities should be aware of their rights to be free from abuse and what to do to respond if they believe that they were the victim of abuse.

Second, families and other support persons should be engaged in the care and treatment of the individual with the disability. They need to be taught about how to identify possible abuse, including physical markings such as bruises and changes in behavior. This is especially important if the member is non-verbal, but families need to know that even verbal individuals may not report abuse out of fear or failure to realize that they were a victim. Families need to know where they can report any complaints of possible abuse, and need to be taken seriously when such complaints are made. Regular visitation and involvement by family members is a strong deterrent to possible abuse.

Moreover, investment is needed to build the competence of direct support professionals in order for them to have the skills they need to provide the high quality supports that people with disabilities deserve. Across the state and the country, there has been a long-standing movement to improve recruitment and retention strategies related to the direct support workforce in order to assure the availability of safe, ethical, high quality supports. Improving training and credentialing opportunities for direct support professionals can help raise the status of this workforce, reduce turn-over, prevent abuse and neglect, increase community inclusion, and promote better outcomes for people using their supports.

Investment also needs to be put into effective supervision and coaching of direct support professionals. Supervisors must make sure that staff are trained on an ongoing basis, provide mentoring, and conduct regular appraisals to ensure that direct care providers demonstrate a strong moral and ethical compass, adopt best practices, and address concerns that may arise. In addition, providers of services for individuals with disabilities must work to develop effective hiring practices that include realistic job previews, and matching of staff to the needs of the individuals with disabilities. Supervisors must make sure to identify those individuals at greater risk for abuse such as individuals who are non-verbal or individuals with a weak support system and limited family involvement, and monitor their care more frequently. Building a strong, and supportive staff with proper supervision has proven effective in minimizing allegations of abuse and neglect, and improving outcomes for individuals with disabilities.

Finally, service providers and families should develop collaborative relationships so that all involved in the care of the individual understand the needs of the individual, and work to develop and promote an appropriate care plan, and can address all concerns immediately and effectively.

Although there has been some discussion of using electronic monitoring devices (EMDs) in congregate living settings in an effort to prevent abuse and neglect, the use of EMDs in community settings brings forth many concerns related to potential human rights violations and other issues that could lead to unintended consequences adversely impacting people with intellectual and developmental disabilities. Individuals with disabilities have been fighting since before *Olmstead v. L.C.* to fully participate in their communities, something others take for granted. A huge victory came with the implementation of the Centers for Medicaid Services Home and Community-Based Services Settings (HCBS) Final Rule (CMS 2249-F/2296-F). This final rule provides the framework for states to develop a system of community-based services that truly integrate individuals with disabilities into communities, and supports them to have the maximum amount of autonomy and independence over their own lives. The Final Rule requires that providers receiving Medicaid HCBS funding support individuals with disabilities in settings that provide the opportunities and access to the community and "ensure individual rights of privacy, dignity and respect, and freedom from coercion and restraint." Video cameras that monitor the individual's movements and activities in living quarters violate the privacy of the individual.

There is a real concern that cameras will impinge on privacy, without preventing abuse or neglect. In New Jersey's state psychiatric hospitals cameras monitor common areas, but are not permitted in individual rooms or bathrooms. Notwithstanding the cameras, abuse still occurs in these institutions. Cameras may record the activity in the rooms where they are located, but if no one is actually watching the video at all times, abuse captured by the cameras may not be prevented.

Disability Rights NJ understands and shares the desire to protect our most vulnerable citizens. Collaboration among state agencies, individuals with disabilities who would be most affected, families and the federally mandated DD Act entities would be a good place to start exploring real and lasting prevention measures without sacrificing the privacy and dignity of those we are trying to protect. Disability Rights NJ is committed to addressing these efforts through sharing information about best practice, listening to stakeholders, promoting best practices in direct support professional workforce development, and upholding the civil and human rights of people with developmental disabilities.

Thank you again for allowing me to testify here today, and I would be happy to answer any questions you may have.

The Arc.
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Achieve with us.

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Hearing on the Issue of Abuse and Neglect
Assembly Human Services Committee
Sharon Levine, Director of Governmental Affairs & Communications
The Arc of New Jersey
October 22, 2020

Good Afternoon. The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and developmental disabilities (I/DD) 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 and their families through advocacy, empowerment, and education.

Thank you Chairwoman Downey for holding this hearing and for including The Arc of New Jersey among today's invited speakers. When we talk about abuse and neglect of individuals with I/DD, the conversation typically focuses on the actions of our Direct Support Professionals (DSPs). It is critical that as we have these conversations, we acknowledge the outstanding work of our DSPs during the COVID-19 pandemic. Although we've always known it to be the case, DSPs truly shined as the state shut down. Throughout this ordeal, DSPs cared for individuals recovering from COVID, they acted as substitute family members when social distancing prevented family and friends from safely visiting, and they put their own health and safety on the line by showing up each day and performing the intimate tasks that can't be conducted from six feet away.

To further illustrate their outstanding performance during these difficult months, I encourage you to compare the data of the long-term care facilities to the residential settings operated by community providers for people with I/DD. We all know that long-term care facilities were hit very, very hard by COVID and while there were certainly some cases and unfortunately, some deaths caused by the virus in our community as well, it is clear that our providers and our DSPs were able to manage the infection rates to minimize the spread among those they serve.

In regards to potential abuse or neglect, we always want to ensure that the staff who are caring for some of our most vulnerable citizens are of the highest caliber and that the service these individuals receive is of the highest quality. As a society, as a system, and as a state, we should never accept any acts of abuse or neglect. There must be zero tolerance of any incident that falls into one of those categories. One act of abuse or neglect is one too many, but as the state and lawmakers look to improve the system, they must do so in a way that roots out bad apples while recognizing the bad apples do not represent the majority of the DSP workforce.

We need regulations and licensing requirements to protect people with I/DD and I'm happy to say, we have them. The system has evolved and as the focus has shifted to the community, the protocols for keeping people safe have increased and improved to reflect that need. In addition to a myriad of regulatory requirements and the Central Registry of Offenders Against individuals with Developmental Disabilities, the creation of which The Arc of New Jersey spearheaded, the system has incorporated the legislative mandates of Danielle's Law, Tara's Law and most recently Stephen Komninos Law.

However, none of these laws include appropriations for community provider organizations that employ Direct Support Professionals. The best way to prevent abuse and neglect of people with I/DD is to appropriately fund the system and raise wages for DSPs. DSPs shoulder a significant amount of responsibility. Everything from tasks of daily living – toileting, feeding, bathing – to medication management and community integration. They do not earn a wage that is in line with the importance of their work of the vulnerable nature of those they serve. We are grateful to Governor Murphy, the Department of Human Services and members of the Legislature for the recent revised FY21 Budget which included $40 million in state and federal dollars to raise DSP wages starting in January. This is a significant recognition of this workforce. And so is the temporary wage increase that began October 1, to reflect the extra danger DSPs are facing in light of COVID-19.

But I would be remiss not to point out that DSP wages have been in need of an increase for many years. Or that community providers are competing for the same pool of workers as the hiring manager at Target. And most importantly, that as minimum wage is scheduled to increase every January 1st between now and 2024, the law raising the minimum wage did not include a simultaneous wage bump for our DSPs. So while we have always struggled to hire and retain staff because of low wages, entry-level workers at the fast food restaurant down the street who are not pureeing meals for individuals who have oral-motor problems, or administering medication, or helping someone in the shower, are now guaranteed a higher wage every year for the next four years. Vacancy and turnover rates are directly connected to wages.

If the state values the lives of those with intellectual and developmental disabilities, we need to pay the staff who care for them. This will eliminate DSPs from needing to work multiple jobs. This will attract workers with a higher level of education. This will keep employees from looking for something that pays better the first chance they get. We must also establish a plan to put the DSP profession on a career path. This will help reduce the system's high turnover rates. In addition, the state must increase funding for additional trainings so that DSPs can continue to increase and grow their skills.

We must always take whatever steps are necessary to prevent abuse, but we cannot design a service delivery system that believes all DSPs are on a mission to do harm to people with I/DD. I urge you to keep in mind that the majority of the workforce is dedicated and committed to those they serve. Not even a pandemic could keep these workers from nursing sick individuals back to health or offering comfort when family members could not. As you move forward with next steps on this

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topic please remember those DSPs, those who risked getting COVID when there was no readily-available PPE and who supported people throughout this horrid ordeal - those who genuinely care.

Thank you again for the opportunity to provide testimony today.

Good afternoon.

I thank you for the opportunity to present testimony and insights related to the care of adults with disabilities in New Jersey. For more than seventy years the New Jersey Institute for Disabilities (NJID)- formerly the Cerebral Palsy Association of Middlesex County- which is headquartered in Edison, has served persons with disabilities throughout New Jersey. From humble beginnings in an abandoned garage, NJID has evolved and transformed to meet the needs of more than 1500 infants, children and adults with intellectual, developmental and related disabilities.

The choices for adults with disabilities mirror choices available to all individuals. Through person-centered service models, NJID affords everyone the dignity and respect which they so rightfully deserve. NJID's comprehensive programs help adults with disabilities achieve fulfillment and individual success within the fabric of their local communities where they live and work.

Recognizing the uniqueness of every person, NJID programs are tailored to exceed the expectations of the individuals and families who turn to NJID for services. The decision of choosing a group home or day program is among the most important choices which can be made by an individual and family. At NJID, a team of compassionate professionals with years of experience offers understanding, information and guidance on the most appropriate and available options. NJID has helped hundreds of individuals and families make wise decisions about community living and participation including the successful transition of persons from developmental centers, family homes, residential schools and other settings.

In NJID's group homes, the person-centered design of each service extends beyond medical supervision and accommodations. Each person is encouraged to participate in home life from meal planning and preparation to leisure activities and the entertaining of friends. At NJID we develop services to provide a family like environment in our group homes with usually just four individuals sharing the home, sharing meals together and discovering pathways to independence with the support of a dedicated, skilled and compassionate staff.

NJID day programs also provide small group instruction and activities. Individuals are encouraged to participate in advocacy activities and have unlimited opportunities to share their opinion, discuss individual rights, and question operations in order to improve services.

The heart of every program is the person-centered programs we have developed and NJID invests a great deal of time and resources to assure that employees are educated, skilled and supported as they assume their responsibilities.

Potential Employees are screened prior to receiving employment offers with the following clearances:

DHS Clearance of Fingerprint Check
Medicaid Excluded, Unlicensed, or Uncertified Individual Check
CARI Checks
Central Offenders Registry
Drug Screening

Once hired new employees receive training on-site and through the College of Direct Support E-Learning classes, including:

The Recognition & Prevention of Abuse, Neglect & Exploitation
Life Threatening Emergencies, Danielle's Law The Stephen Komninos Law

These courses include knowledge tests with minimum 80% score to continue with training. These DHS mandated courses are regularly reviewed at staff meetings and annually through formal curriculum.

To further enhance employee knowledge, NJID provides training in:

Communication Styles and Its Importance
Understanding Personal & Self Care
Individualized Personal Care
Positive Behavior Supports
Disability Etiquette
Crisis Management Techniques

Foundations of positive behavior supports is designed to provide tools for employees to work proactively with the individuals who we serve. These proactive strategies enable staff to teach functional skills to enhance the quality of life for the individuals whom we serve.
The education and strategies discussed in the courses are designed to prevent abuse and neglect and they help to disarm resentment by teaching proactive approaches.

In Crisis Trainings a framework is provided for employees to recognize and give skills to intervene, when to step away, and how to assist an individual with normal routines.

Training emphasizes that the Direct Service Professionals know the individuals with whom they are working, recognize signs when help is needed, and remain calm and composed, which is fundamental to preventing abuse & neglect.

Trainings are annually reviewed and NJID provides its employees all the tools necessary to be successful in the responsibilities of their work.

NJID advocates for and ensures that the rights of individuals served are always protected. Procedures and practices regarding human rights and dignity of the individuals served have been written, adopted, and communicated to personnel through the organization's code of ethics and training. All NJID policies ensure that individuals are protected from abuse and neglect.

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NJID recognizes the need for incident management and review and has established policies and procedures to provide consistent, prompt, and accurate reporting as well as investigation processes. The use of the electronic health and incident reports expedites the process and allows for a multi-level review process within hours of a reported event which creates opportunity for immediate feedback and correction. There are clear expectations for staff involvement and cooperation in all unusual incidents.

General Event Reports (GERs) are completed for all individuals who are involved in an accident, may have an injury, and /or exposure (or possible) exposure to a blood borne pathogen, and unusual incident reports are in compliance with NJ DDD regulations.

ALL GERS are reviewed by supervisory staff, the Quality Assurance staff, upon the entry of the event and the incident review committee on a monthly basis. The committee may also react to incidents with specific protocols & identify areas of additional training, if needed.

The NJID incident review committee is an established committee of NJID professionals which makes recommendations for any needed policy and procedural changes and assess trends. The Incident Review Committee proactively identifies quality issues affecting individual rights, care, and satisfaction. Statistical information is identified and tracked for departmental and NJID use.

Behavioral events are also documented in the GERs and receive multi-level reviews similar as stated above. NJID uses a Behavior Advisory Committee (BAC) that consists of professionals with varying levels of expertise. The committee reviews the incident, related behavior support plans and data. The committee also updates, revises, and maintains procedures associated with behavior techniques and crisis management.

Comprehensive Quality Reviews are regularly conducted and involve physical site and vehicle inspections, medication reviews, financial audits, individual service reviews, and administrative assessments that are done at all sites. Administrative visits are conducted throughout the year, both unannounced and announced.

Programs are designed with staffing and clinical supports to meet each individual's unique needs. Therefore individuals who require support from nursing, behaviorists, as well as personal care receive services in their home, day program, or work environment

While NJID services are individualized, the opportunities are limitless. Beyond the policies and procedures and safeguards are the Direct Support Professionals who support individuals with complex needs that include physical, intellectual, or behavioral challenges and health conditions. It is the DSP who makes the frontline critical decisions concerning all aspects of the lives of the individuals they support. NJID applauds the initiatives of Governor Phil Murphy and the New Jersey State Legislature which address the salary requirements for Direct Service Professionals. The recent increases brings DSP wages to a level that favorably compares with other industries; industries that are aggressively competing for the New Jersey work force. Having the capacity to offer more favorable wages, NJID can recruit, train and retain more Direct Service Professionals and thus relieve the strain of overtime work schedules and the stress that is attendant to excessive hours worked.

With a caring compassion that spans seven decades, the New Jersey Institute for Disabilities remains committed to the dignity and well-being of every individual. NJID will continue to advance the development of relevant solutions and supports so that all individuals are not spectators but community contributors, respected, truly integrated and fully valued.

I thank you for this opportunity and I wish you well in your deliberations.

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Testimony on Prevention of Abuse & Neglect of Individuals with Developmental Disabilities
October 22, 2020

To The New Jersey Assembly Human Services Committee

Chairwoman Downey and Members of the Assembly Human Services Committee, thank you for the invitation to testify before you today at this important hearing on prevention strategies, recommendations, and steps to improve the effectiveness of response to abuse and neglect of individuals with disabilities.

I am Deborah M. Spitalnik, PhD, Executive Director of The Boggs Center on Developmental Disabilities at Rutgers Robert Wood Johnson Medical School, where I am a Professor of Pediatrics and Family Medicine and Community Health. In addition to the experience I bring to this issue from my role in New Jersey as founding director of The Boggs Center, I also bring my national experience as former chair of The President's Committee for People with Intellectual Disabilities (PCPID) across two administrations, member of PCPID in three different administrations, past President of the Association of University Centers on Disability (AUCD), as well as former board chair of the Council on Quality and Leadership, a national organization dedicated to ensuring quality supports that enable people with developmental disabilities to live full lives in the community. I offer this testimony in collaboration with Colleen McLaughlin, MEd, Associate Director of The Boggs Center, a nationally recognized expert on the Direct Support Professional workforce, co-author and strand leader on the topic of DSP Workforce Development for *National Goals in Research, Practice, and Policy for and with People with Intellectual and Developmental Disabilities* and co-chair of the American Association on Intellectual Developmental Disabilities (AAIDD) DSP Interest Network.

I want to thank the committee for all your efforts directed toward the concerns and well-being and security of people with developmental disabilities and their families. Ensuring the well-being and full participation of people with disabilities is an ethical, and I would add, sacred obligation. I am grateful for the opportunity to speak with you today and the contribution The Boggs Center can make to this dialogue. The Boggs Center is New Jersey's designated University Center for Excellence in Developmental Disabilities Education, Research and Service under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402. Your caring and leadership embodied in convening today's hearing, addresses the finding in the DD Act that

> "individuals with developmental disabilities are at greater risk than the general population of abuse, neglect, financial and sexual exploitation, and the violation of their legal and human rights" [Sec. 101 (a) (5)].

Our collective ability to prevent abuse is also deeply rooted in the DD Act and its purpose to

> "... assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity and integration and inclusion and all facets of community life......" [Sec. 101 (b)].

As well as the DD Act's recognition that

> "a substantial portion of individuals with developmental disabilities do not have access to appropriate support and services" [Sec. 101 (a) (6)].

In addressing the prevention of abuse of persons with developmental disabilities I offer three interconnected strategies for your consideration: 1] developing a culture of empowerment, respect and dignity for the lives of people with disabilities as active members of their communities; 2]addressing the crisis in the Direct Support Workforce; and 3]the role of the federal Home and Community Based Services Settings Rule in supporting services that in promoting community presence and inclusion, undergird central prevention strategies to address this complex issue. To realize our shared commitment to prevent the abuse and neglect of people with developmental disabilities, all of these strategies rest upon having a competent Direct Support Professional Workforce.

I. Creating a culture of empowerment, dignity and respect for the lives of people with disabilities as active members of their communities

These cultural elements, in addition to reflecting our shared humanity, also have an evidence base in practice. These enhanced positive practices can, in combination with addressing the workforce issues I'll address momentarily, contribute to preventing abuse and neglect.

In a comprehensive review of the literature, Dunbar (2020) has described a number of factors that contribute to abuse, neglect, and exploitation including social isolation and a lack of power and limited opportunities for people with disabilities to make decisions in their own lives. A counterweight to this is for organizations that serve individuals with developmental disabilities to create a culture of respect and dignity the involves active listening, response, and communication with all stakeholders; ensures access to frontline supervisors with an active and engaging presence; supports the autonomy of those receiving services; and ensures that people with disabilities are empowered to have power and control over all aspects of their lives and are not living in social isolation – they are supported to known and active members of their communities.

I want to reinforce the importance of these findings from the New Jersey based perspective of Nancy Razza, PhD., former Adjunct Assistant Professor at The Boggs Center and supervising Psychologist at the Arc of Monmouth Health Services in Tinton Falls, NJ. Dr. Razza is a national leader in the development of treatment models to address trauma for individuals with intellectual and developmental disabilities who have suffered abuse. She is also a co-author of the sections on PTSD in the DM-ID (Diagnostic Manual-Intellectual Disability) and the DM-ID2, co-published by the American Psychiatric Association and the National Association for the Dually Diagnosed. These books were designed as companion volumes to the DSM-IV-TR and the DSM-5 respectively, the diagnostic manuals of the American Psychiatric Association.

Based on her extensive clinical experience, Dr. Razza states emphatically:

> "Settings don't create safety. People create safety, and people create the lack of it".

And further that:

> "Each and every interaction teaches empowerment or disempowerment; that we are valued or devalued" (Razza, personal communication, 2020).

When individuals with disabilities are devalued and disrespected, they are disempowered and more vulnerable to abuse.

Dr. Razza, based on her clinical experience also enjoins us to apply the importance of empowerment to those who provide care and services to individuals with developmental disabilities. Her experience establishes the necessity of creating empowering and valued interactions.

> "... with every person you supervise: to staff members, subs, paid and volunteer employees, --everyone. When someone you supervise says something to you, make sure their interaction with you leaves them feeling valued" (Razza, personal communication, 2020).

The importance of these interpersonal skills and supports leads us to the necessity of addressing the structural elements of the Direct Support Professional Workforce Crisis.

II. To prevent abuse and neglect we must address the Direct Support Workforce Crisis

A competent and qualified workforce is essential in preventing abuse and neglect and assuring that people with disabilities have the high quality, stable supports they need. The Direct Support Professional (DSP) workforce is the foundation of the service system. Direct Support Professionals (DSPs) provide a wide range of assistance to individuals with intellectual and developmental disabilities daily, including addressing mental, physical, and behavioral health needs, personal care and hygiene, household management, employment, transportation, recreation, and building relationships and participation in community and civic life. Direct Support Professionals are essential to helping people live healthy, safe, and fully included lives in our communities.

The current workforce crisis and the lack of competency-based training and career pathways are a serious concern to entire human services system and contributes to instances of abuse, neglect, and exploitation. The President's Committee for People with Intellectual and Disabilities (PCPID) highlighted this crisis in our *2017 Report to the President*. The elements of this crisis cited in this national report (PCPID, 2017) include:

- High staff turnover
- Growing demand for services due to growth and aging of the US population in general
- Increased survival rates for people with complex health need found among persons with ID/DD
- Demographic shifts resulting in fewer people moving into the DSP Workforce
- Persistent non-competitive aspects of direct support employment including, low wages, poor access to health insurance, lack of paid time off and other benefits.
- High stress and demands of direct support employment including round-the-clock seven day a week work,
- Insufficient training and preparation for DSP roles; and
- Lack of professional recognition and status for skilled DSPs.

The importance of a competent and qualified DSP Workforce in the prevention of abuse and neglect is further documented in a study conducted by The Council on Quality and Leadership -CQL (Friedman, C., 2020). The findings demonstrate the impact of staff development on the health and safety of people with intellectual and developmental disabilities. Through the implementation of ongoing staff development, provider organizations can significantly improve their service provision and health and safety of those they serve. The analysis of Basic Assurances data obtained from 74 human services organizations serving approximately 8300 people with IDD, found that ongoing staff development resulted in not only a reduction of emergency room visits and injuries, but also a reduction in instances of abuse and neglect.

As Chairwoman Downey has recognized in other legislative undertakings, community-based services are dependent on the efforts of the Direct Support Professional (DSP) workforce. In order to assure that an effective, qualified and stable DSP workforce grounded in ethical practice exists, structural, policy, and funding issues need to be addressed. These include:

- Salaries that are commensurate with the job responsibilities and the skills necessary to meet the needs of those they support.
- Adopting practices that reduce turnover and reinvesting these savings into the provision of services and the Direct Support Professional workforce
- Improved recruitment, professional development, and retention of qualified Direct Support Professionals through:
    - Effective hiring practices
    - Professional development driven by an established set of national core competencies and the support needs of the individuals receiving services
    - High quality, competent Frontline Supervision
    - The implementation of career pathways and/or certification programs

National policy, undergirded by professional practice has underscored the importance of addressing the Direct Support Workforce and embedded these issues within Medicaid policy. In 2013, the Centers for Medicare and Medicaid Services (CMS) in collaboration with the former National Direct Service Workforce Resource Center published *Coverage of Direct Support Workforce Continuing Education and Training within Medicaid Policy and Rate Setting:*

A Toolkit for State Medicaid Agencies (CMS, 2013). A year later, CMS established a standard set of *Core Competencies for the Direct Service Workforce (CMS, 2014).* These two resources could serve to assist New Jersey in establishing processes that would contribute to the prevention of abuse and neglect and improvement in the quality of life for people with intellectual and developmental disabilities.

III. Implement the Home and Community Based Settings Rule

Federal policy, the CMS Home and Community Based Services Settings Rule (CMS, 2014), sets forth mandates that can help to reduce instances of abuse and neglect through the promotion and support of community integration. This regulatory requirement aims to maximize opportunities for HCBS recipients to access all the benefits of community life; receive services in the most integrated setting and to the same degree of community access that we all do. It sets forth requirements to assure that people with disabilities have the right to privacy, dignity, respect, and freedom from coercion and restraint; optimize individual initiative, autonomy, and independence in making life choices; and facilitate choice with regard to services, supports, and who provides them. Full compliance with the HCBS Settings Rule is not only essential to assuring community integration but in turn also lends to the prevention of abuse and neglect.

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Testimony of the New Jersey Council on Developmental Disabilities on the issue of abuse and neglect of individuals with disabilities in group homes and other congregate care facilities.

October 22, 2020

New Jersey has had a long and checkered experience with congregate care for individuals with intellectual and/or developmental disabilities. The seriousness of this problem and the barriers to safety and community life that people with disabilities face is also well-documented. It deserves decisive and immediate action. The New Jersey Council on Developmental Disabilities (NJCDD) would like to thank the Assembly Human Services Committee for providing input today and for listening to the stories you will hear. We suspect many stories will be difficult to hear and comprehend, but listening will bring us closer to resolution.

Government must continue to recognize and guarantee the civil and human rights of individuals with intellectual and developmental disabilities. This includes advancing laws and regulations that provide individuals with the information, skills, opportunities, and supports to pursue meaningful, fulfilling and productive lives and to live free of abuse, neglect, financial and sexual exploitation.

NJCDD believes that laws and regulations are the proper foundation for protecting these rights but that state policy including enforcement and accountability as well as staff supervision and training, are equally essential. Individual and family concerns and needs must be heard and respected by legislative and administrative leaders and given the highest degree of urgency. Providers of congregate living must embrace the voices of individuals and their loved ones. Services and supports must be driven by individual needs with goal oriented outcomes. NJCDD understands the many layers of complexity in ensuring the health, safety and positive outcomes for individuals with I/DD. NJCDD supports the provision of credentialing opportunities, career pathways, and ongoing competency-based training and mentoring, embedded in system policies and sufficiently funded, for staff responsible for the well-being of those in congregate living.

In accordance with the 1993 Family Support Act, the New Jersey Council on Developmental Disabilities established the Regional Family Support Planning Councils (RFSPCs) to provide a way for parents and family members of people with developmental disabilities to come together to exchange knowledge and information at the local and state level on issues that directly impact their lives. Since 1993, members of the RFSPCs have reported a number of incidents related to abuse and neglect in congregate living communities. These range from the sexual assault and victimization of individuals to the improper and unhealthy imposition of dietary neglect, as well as reports of loved ones suffering as a result of improper staff supports, supervision and oversight. Guardians have been subjected to threats and hostility to the point of being highly restricted from seeing their loved ones after complaining about poor living conditions. Government should not tolerate this activity, especially as it is in violation of state regulations and federal laws. It has been the topic of numerous visits with legislators.

Prevention of abuse and neglect is the best strategy and needs to become a priority. To that end, NJCDD has the following recommendations:

1. Individualized Services/Planning/Staff Training: For adults with I/DD, the state's Person Centered Planning Tool and Individual Service Plan are used to assess and document an individual's support needs. All staff must be specifically trained in these documents and with the individual and family before services are delivered based on individualized medical and behavioral needs.

2. Promote Equality with a Culture of Respect and Dignity: The service system must embrace a culture of respect and dignity whereby organizations respond with compassion and actively engage and embrace individuals and families. When people with disabilities are treated as second-class citizens, the unequal status contributes to abuse and neglect.
3. Need for Transparency: The provider and state should communicate more effectively and be transparent with individuals and families when allegations of abuse and neglect are reported. The individual and family are central to the care being provided. Withholding information is contrary to person centered services and can adversely affect people's lives.
4. Generic Training Considerations: It has been documented that there are five health conditions linked to preventable deaths for people living in congregate care/residential settings. Fatal Five training should be required pre-service training for all Direct Support Professionals. These topics should be further explored based upon each individual's health conditions to personalize these topics. Fatal Five training areas include:
    a. Aspiration
    b. Bowel Obstruction
    c. Dehydration
    d. Seizures
    e. Infection/Sepsis
5. Planning for Action Together: Establish a workgroup of all stakeholder groups to review training, policies and practices and make recommendations for system wide improvements. No one group has the answers but together we can make a difference.
6. Values: Value the role individuals and families in the delivery of supports and services.
7. Direct Support Professionals: DSPs are central to the quality of supports and services and must be paid a wage that validates the critical role they play. DSPs that are struggling financially are likely to not be able to perform this critical role, putting individuals with I/DD at risk.

Robert Titus, Policy Coordinator, New Jersey Council on Developmental Disabilities

October 19, 2020

To Adaline Kaser:

The following is my written testimony of the abuse and neglect suffered by my daughter in seven DDD licensed group homes in the State of New Jersey:

My daughter was abused and severely neglected for seven years in DDD licensed group homes. There is no way for me to write about every incident.

This abuse included (against Legal Guardian's instructions) sexual exploitation of my daughter. Additionally, I was repeatedly lied to and misled as to my daughter's physical and mental condition.

My daughter entered care in 2012. She was upset due to her father being in intensive care and called the number on Rohan Williams business card which he gave to her. At that time, full guardianship was recommended and her condition was documented as needing a guardian and that she was unable to make wise decisions. She was suffering from a psychotic disorder with developmental disabilities. She quickly became self abusive, violent and unable to care for her person in the group homes.

Her records (of what I have been able to piece together) show clearly that she was not able to conduct the day to day business of her life. She had serious mental health issues. The records were manipulated in such a way that her psychotic condition was downplayed and she was allowed to behave in a manner that was dangerous and socially unacceptable. The numerous psychological evaluations completed were ignored by DDD and the group homes.

We had agreed to become guardians prior to her placement in DDD. Our guardianship was delayed in the Court for over 14 months. During that time, the group home, knowing that Elizabeth needed a guardian, did not notify us of any health emergencies or serious behaviors that caused damage to not only my daughter but those around her. There were emergencies that we only have a list of. Unusual Incident Reports. We have a list of 84 of them.

My daughter was sexually exploited. The group home gave her alone time against the express direction of the THEN medical guardians. Melissa VandePolder and Jim Rankin of DDD told us that having unsafe unprotected sex with various men was her right. We protested vehemently and were ignored. We sent written directions that no "alone time" be given to Elizabeth since she was declared incompetent and we were her legal guardians. They invited Planned Parenthood to speak to Elizabeth. They put her on birth control and then they began "alone time" before that medication even had time to become effective. We would have never agreed to that PLAN. In fact, we refused to sign the IHP in protest of their ignoring the legal guardians.

My daughter was raped and suffered anal tears inside the Frankford home of Capitol Care. The group home told me to my face that she was a virgin and had been examined by an obstetrician on her annual visit. She was not a virgin and I have proof of her having pregnancy tests, sexually transmitted disease tests, etc. I NOW have a letter in my possession from that OB/GYN that she never had an internal exam (ever to todays date) to rule out physical damage. I told DDD, Jim Rankin and Melissa VanDePolder, that we as guardians, for medical reasons, were totally against their giving Elizabeth "alone time" in her room with several different men. It was a very bad idea. It was told to me by Jim Rankin that I had no say as medical guardian. It was her right.

I have since, when forced to sign the "Rights and Responsibilities Form" on an annual basis, attached comments to the form stating the rights that Elizabeth does not have since being declared incapacitated in August of 2014. Note: Men were not only brought into Elizabeth's home with Capitol Care and DDD approval, but she was taken to men's apartments and dropped off. She was allowed to spend alone time in those apartments because "staff was down stairs". We had forbid such actions. I have a record of over sixty times that she was allowed against our expressed directions to either have male guests or was taken to a male group home and dropped off.

I have now received from DDD the records of Capitol Care (group home and day program). It shows a consistent neglect of my daughter's physical, emotional and psychological health. My daughter was allowed to refuse to brush her teeth, refuse to attend doctor appointments and refuse to attend psychological appointments. She was allowed to roam the day program, not follow a routine schedule and she was allowed to obtain fraudulent credit cards during the time in the computer room. We were not allowed to take away the credit cards and Capitol Care said they would not. Again it was her right. To break the law????

In 2019 I found a memo that was signed by a Capitol Care Day Program staff member, Jessie Kozmoski, Clinical Specialist, BA, dated 9/11/14, wherein it is stated that Liz was very upset that she was being raped. For some reason - outside of HIPPA regulations -, another male peer member was in the meeting where she was upset. It is recorded that this man said he was glad that she was being raped because if the other guys did not do it then he would. This "man" went on to graphically describe how he would rape my daughter. I have records of over 60 times that either a man was welcomed into my daughter's home or she was dropped off at a male group home. I am furious.

These DDD licensed facilities are mandatory reporters.. If my daughter complained of being raped, then the police must be called. I did not see this memo until August of 2019. That is outside of the bounds of proper group home procedures. It is abuse, neglect and breaking of mandatory reporting regulations. Also, at that time we were guardians and should have been notified of a rape claim under the current laws.

My daughter, with our help, filed a restraining order against a man at Capitol Care Day Program for inappropriatelh touching her and for chasing her down State Highway 206. We were kept out of the hearing because Capitol Care had brought in NJDR to contest our fitness as guardians. Capitol Care conducted a purposeful attempt to remove us as legal guardians because we were trying to act like concerned parents. The hearing was carried. The next day Ecaterina Velez took my daughter back to court and had her drop the charges against this man. We knew nothing about the charges being dropped. If there had been a camera on the outside of the day program building, we would have had proof that this man chased her onto a major highway. If there had been a camera in the group home, we would have seen that Elizabeth was being coerced into going back to court the next day to drop "inconvenient" charges that the group home and day program did not want to face. Cameras need not only video but audio as well.

I do not see the value of just having cameras in group homes and day programs but they are better than nothing. My daughter has a list of 84 Unusual Incident reports ranging in date from 2012 to 2019. These incidents were investigated. However, the State of New Jersey will not allow me to see the reports. I have sent 84 individual requests to Steven Katz in the Legal Department asking him for copies of the reports. I have not had the courtesy of a reply. What is going to stop the DDD and these GROUP HOMES from just telling guardians that they have no right to see video tapes. That is what they have done to me 84 times. Group homes and DDD will get around the laws that are put into place. The system is corrupt from the top down. A legal and medical guardian should have access to UIR reports. Paul Aronsohn has included that in his yearly report.

I am told that I must obtain a court order / judicial order to get the UIR reports. I have also been notified that if I try to get them, the State of New Jersey will appoint a Deputy Attorney General to represent the interests of the State. I feel that they are threatening me if I try to get my daughter's records. It sounds like a threat and it surely feels like a threat.

I strongly feel that just video of the common areas is not enough. I feel that guardians should know what is being said to their loved ones. There needs to be voice audio. Capitol Care set out on a mission to destroy the relationship we had with our daughter. They told her we did not love her. They lied about why we would not sign a permission slip to go to a three day Special Olympics event when no staff were going to be with her. She was not even self medicating and she needed a one-on-one staffing. They told her that we were just being mean. If I had been able to hear Capitol Care tell her we were just being mean, I would have been able to tell my daughter that it was the organizer of the Special Olympics event that said he could not be responsible for a non-self medicating athlete with no staff for three days away overnight.

When we were not able to attend an IHP meeting, Capitol Care and DDD allowed Elizabeth to think that we did not care. They even included a comment in the IHP that Elizabeth said that if we cared about her we would have been there. Neither DDD nor Capitol Care told her that my mother was dying in Hospice and that we were at her bedside. If I had been able to hear that they did not explain why we were not at the meeting, I would have known to call Elizabeth and refute the idea that we did not care. Her grandmother was dying. Why didn't Capitol Care reschedule the IHP meeting??? It would have been very easy. They just did not want to cooperate with a family going through the loss of my mother.

The emotional and psychological abuse that these staff members inflict on our loved ones is sometimes more harmful than a broken bone. My older daughter gave Liz a mug with "I Love You" on it for Valentines Day. Staff told her to smash it on the garage floor because Becky did not love her. We need cameras and voice/audio. If Elizabeth smashed the cup because she felt Becky did not love her, then psychiatric counseling should have been an immediate issue.

Capitol Care had destroyed her and she was allowed to fight, be aggressive, steal, get hair cuts without paying for them, put her hands through glass windows, allowed to refuse showers, refuse to brush her teeth, etc. The paper records of Capitol records state that she was dirty and she smelled. They also state that she did not use menstrual products. They show they pulled her teeth rather than teach good dental hygiene. She was allowed to throw away all of her clothing so that the guardians would have to buy more. She was brought to our house to ask for money and when she did not get it, the MALE staff member told her to tell us to F___ off and she did just that. She was also brought to our house when we were not home. The staff allowed her to peek through our windows. When staff did not see pictures of Elizabeth on the walls, they told her that was proof we did not love her. They were not able to see into our living room where a whole wall of Elizabeth's pictures are hung!!! When she went to Capitol Care she had waist length hair. They took her to get it cut and her head was completely shaved. She was not able to make such a decision. To this date, her hair has never grown back in and she is fighting hair loss and bald spots.

Yesterday, October 18, 2020, I was continuing research on her medical records. I noted that she had a CT scan of her head on February 14, 2015. I went through all of the records I have. No records were found for that date. I did a computer search of the date. I found that the CT scan date matches a date on the list of Unusual Incident Reports that DDD has refused to allow me to see. My daughter had a CT scan of her head and yet I, as medical guardian, was never notified of this test or the results. I do not know why the hospital completed a CT scan. I do not know what happened to my daughter on 2/14/2015. As medical guardian, that is totally unacceptable.

I do not know why Elizabeth was given repeated pregnancy tests, HIV tests, Syphilis tests, gonorrhea tests and others. This is abuse and it is neglect. It is against mandatory reporting to guardians.

Elizabeth was hospitalized at Trinitas, Newton Medical Center and at Greystone due to emotional, behavior issues and suicidal ideation. When we went to visit her at Newton, she was not the person that she had been. After Greystone Park Psychiatric, she was just a shell.

After Greystone, DDD decided to place our daughter at Avro / Bellwether in Bound Brook, NJ. At Bellwether she again became a victim. At the time Elizabeth was placed at Bellwether, the state already knew of issues of abuse and neglect within that Agency. Why was she even placed there. She was already a victim of abuse and neglect!!!!

She suffered a beating by a staff member and had to run to another group home to call 911. We never learned of this incident until in 2019 as I am investigating charges on her insurance statements. She reported that a staff member had beaten her. The hospital found lacerations on her head and welts from her arm pits to her legs. This is unacceptable. The hospital told the group home to report it to the police. It was never reported. Both the hospital and the group home were mandatory reporters and no one reported it.

In a separate incident she had her arm broken by a staff member named Vicki. That was because Elizabeth wanted to call me and got upset when they refused her request. Vicki twisted her arm behind her back until it snapped. The house manager "George Sherman" was sitting there and rendered no aid to Elizabeth. She was not given proper medical attention until days later and the arm today is malformed and she has permanent loss of strength.

If there had been cameras in the home, we could have seen what happened. Are the videos going to be kept a certain amount of time?? We have just been given Capitol Care Records in 2019. I can see that when Guardians are able to know to request a certain video date, it will have been erased. I am looking into incidents that happed 6 or 7 years ago. Video alone will not S what happened.

Audio is very important. Psychological verbal abuse is very dangerous and it does not show up on video. I feel that if video cameras are ever installed in group homes and day programs, they should be kept for at least seven years. Or the rule for reporting incidents to guardians must be strictly enforced. My daughter was denied the ability to call me to report her injured arm and was threatened by the staff member who broke it that if she told me what happened "it would be much worse for her". These disabled clients are not allowed to call their parents or the police. The staff controls the phones. I was personally told by one client that she was forbidden to report assaults she suffered while at Capitol Care.

At Bellwether Day Program my daughter was stalked and raped by a few men. One in particular – Mike Pytel. He would find her in whatever room she was in and force her into a closet or bathroom. He was really perverted and used objects. She was again the victim of anal intercourse and forced oral sex. Sodomy If there were cameras in the day program buildings, perhaps one of the very inadequate and inattentive staff members would have noticed that Elizabeth had disappeared from sight. He forced anal intercourse upon her even when she said NO. He also raped her in a play area located behind the day program building. I hope that one day cameras are situated so that all angles of travel are covered. This man also brought a container of his sperm and gave it to Elizabeth. He sent her pornographic movies of himself. Where was staff during these times??? That is why I think video and audio should be installed. Staff lie all the time.

The state knows that Bellwether was giving substandard care and that is why they are no longer in New Jersey.

My greatest upset is that the state knew about these conditions BEFORE my daughter was sent there. WHY was she sent there???? She had already been abused. She was incompetent to make her own decisions and she was very afraid of staff.

She tells me that the staff would put a cardboard box over her head and continue to hit it until she would pass out. She tells me that when she woke up she asked to go to the hospital. They told her to just get up and continue her day.

We also discovered in 2019 that Elizabeth had a job while at Bellwether that she was getting paid for. The Social Security Administration told us that she owed them money for the months that she worked. She received no paychecks. We had no idea that Elizabeth had a job. Monies from her burial fund are missing. But no one can obtain Bellwether records. Is video cameras

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going to solve manipulations like this???? No DDD need to be reformed and the persons who run it now (and in the last seven years) NEED TO BE REMOVED.

Also while at Bellwether, Elizabeth was raped in an agency van during a trip to the mall. Due to inattentive staff, Zach Rodriguez was able to take her to the group home van in the parking lot and he raped her. Zach continued to threaten Elizabeth. He told her that he had connections to have her killed. He told her he would shove her through a glass door. Elizabeth was not able to deal with such threats. Staff should have known what was happening.

After Bellwether Elizabeth was sent to Everas. Everas had no idea what she was like or the level of care she needed. Bellwether handed over incomplete and inaccurate records. Everas tried. At least the Executive Level did. The daily staff workers knew nothing about how to care for her. But during the time at Everas, she was still being sent to Bellwether Day Program. The rapes continued. They continued until January of 2019. Elizabeth was hospitalized for three months at Robert Wood Johnson University Hospital in Somerset.

She stayed there for over three months. In the beginning she was in the psychiatric unit but that unit told us there was nothing wrong with her. Look at her records and history. There was PLENTY wrong with her. She had been in the ER repeatedly leading up to her admission. There had been police involvement on repeated occasions. They could not see that there was a difference BECAUSE she was not being raped and abused. Then they switched her to a medical floor with an aide that sat two feet from her bed. The hospital was upset because DDD was just leaving Elizabeth there because no group home in the state would take her.

Kate Honigfeld mentioned that there would be a private apartment ready in June. That appeased the hospital during the meeting on February 22nd. However, that apartment never materialized and the hospital continued to threaten legal action.

Then DDD suggested Community Access Unlimited. I talked to the intake worker and they declined Elizabeth based on her history. However, DDD raised her budget and forced Community Access Unlimited to take her. They were not at all able to meet her needs. I had told CAU that Elizabeth needed a calm place to heal. The first house she was sent to had a client who was extremely violent. She also was a Bellwether survivor. The first night Elizabeth was at the Westfield house, I was on the phone with Elizabeth. The police were there and I could hear the police and the staff shouting. Elizabeth had just spent three months in the hospital. I had asked CAU if they could meet the needs of Elizabeth as I had spelled them out in a handbook. They assured me they could. At least the salesperson, Tracy LeBaron, said they could. But it was not true. She stayed at Westfield until the other client became so violent she chased Elizabeth through neighboring yards and into the street.

She was not allowed sharp objects because of self abuse. Yet they allowed her to get to scissors. She locked herself in a bathroom and cut off her hair. They also let her have nail clippers and she was taken to the hospital for treatment. The group home never told me she went to the hospital. I found out by receiving a satisfaction survey email. I went nuts. I even received a letter of apology from the hospital that they did not notify me. Sharp objects and nail clippers where part of her NJISP. The group home is required to follow the NJISP. Cameras would be nice to be able to go back and see where was staff during all of this.

She was also locked out of the group home. I was in my car with my husband and we could hear her pounding on the door to get back in. I called the Hillside Police Department that time. But the staff was able to lie their way out with a half baked excuse. Even though I was on the phone and heard the incident, the UIR for that incident was marked "unsubstantiated". Why??? I was not even given an opportunity to testify. They call in an investigator and they sit with Elizabeth with staff present. Doesn't anyone realize that these clients will not speak to anything in front of staff for fear of payback. Cameras need to be installed in these group homes. Not only cameras but audio abilities too. As I said before, psychological abuse also scars our loved ones.

Elizabeth was left in a running car while staff went into a store to shop. That is totally unacceptable.

Elizabeth was also given the wrong medications at CAU. I was on the phone and had to argue with the staff about a PRN for anxiety. A male staff came on and I told him that I knew she had the medication. He told me I was wrong. I was the medical guardian and I was very involved at this point and knew what she had been prescribed. He found the medication and it was administered.

Another incident was when two female staff were there and they tried to give Elizabeth the wrong medication. Elizabeth knew it was the wrong color. The staff argued with me on the phone about the medication. Then I heard them making fun of Elizabeth because she could not read the name of the medication on the bottle. How cruel!!! I wish I could have climbed through the phone that day.

Elizabeth was also beaten in Conant Park in Hillside by staff member "Star" on July 14, 2019. It was Star's first day on the job. I had been dealing with Rolando, Jayden and Linda Woodard to get COMPETENT staff brought in to deal with Liz. CAU only took Liz because DDD raised Elizabeth's budget to a Da. They had plenty of money to properly staff Elizabeth. But they did not. The staff member told the policeman that I directed that Liz be taken to Trinitas Psychiatric. I had never even been told about the incident at that point. Trinitas released her back to CAU. The next day Elizabeth was taken to Overlook Hospital and treated for a sprained shoulder, sprained wrist and cuts and bruises. Perhaps body cams on staff should be considered. We now want them on policemen. Are staff any different?? NO. Staff have more contact with our loved ones. I vote for body cams on staff!!!!!

On July 18, 2019 Elizabeth again found other housemates eating her food. She had a behavior and was taken again to Trinitas and admitted. She was there for 6 weeks. During those six weeks we finalized an apartment under the Community Supports Program staffed by DSPs who are all family members.

My daughter today looks nothing like she did in 2012. She was beautiful. She now has less than half of her teeth. She refuses to eat because it hurts and as a form of self abuse. Now she is a skeletal remain of what she used to be. Her understanding and thought process has diminished greatly. She has a vacant stare. She has multiple personalities to deal with stress. She engages in self abuse. She has no concept of who she is. It is thought that she is having hallucinations. She is showing signs of frontal lobe damage. Is it from the beatings?? However, New Jersey Horizon NJ Health does not cover the PET scans that the neurologist needs to diagnose her condition. If she is under stress, she leans to the right.

I have documents to substantiate the above. It would take me weeks to go through 8 moving boxes of records. If you need documentation on any of my testimony, I will gladly provide it. However, please note, I have no records from Bellwether. I have asked for two years. I have contacted Marjorie Baker at Vineland Developmental Center. She said they are in no order and she does not know if I will ever receive the records. At this point, I think Bellwether should be fined and prosecuted for what they allowed to happen. They did not keep proper records. They were abusive and negligent in their care of my daughter. They did not communicate with Guardians regarding medical issues or abuse.

The fact that DDD knew of the ongoing abuse is unbelievable and inexcusable. My daughter's condition was greatly harmed by the three years at Bellwether. She will never recover. She is being treated by a trauma therapist once a week and is going to a counselor for general psychological care once a week. She is in very serious condition and risk of being institutionalized.

I am just letting you know that I want to testify.

We now have cameras in every room at Elizabeth's apartment. We also have voice / audio. When Elizabeth gets upset I can log onto the camera and speak to her. If she makes an accusation against staff members, I can review the tape and hear just what was said. This is the only way to protect one person who cannot protect themselves.

I am very worried that if cameras are put into group homes and day programs, the access by guardian to those videos will be handled the same way as the UIR reports. They will just find a way to deny guardians the truth.

Again, I repeat, I would like to testify.

Jennifer S. Worley

Please let me know if you need the documents and if so, which ones.

From: [redacted]
Sent: Tuesday, October 27, 2020 1:53 PM
To: [redacted]
Subject: [redacted]/20

Ms Ouedraogo ,

I appreciate the opportunity to share my concerns.

My Daughter Nicole Lusardi , is 26 and has been diagnosed with cerebral palsy and anxiety.

3 Years ago (October 2017) she went into crisis after finding out that her parents were divorcing.

- Nicole ended up at Trinitas hospital in Elisabeth, New Jersey,were she was beaten On her head by a nurse . (reported to police) she was sent to the medical unit for xrays and she was diagnosed with pneumonia- she spent approximately 1 month recuperating and was released without any counseling or therapy for what got her there in the first place.

From December 2017 to April 2018 she was In and out of different hospitals.

- In April 2018 she was admitted to Trenton psychiatric hospital (TPH) in Trenton ,New Jersey

- At TPH Nicole was abused and neglected .

She was very afraid of the other patients and also some of the staff.

- she did not get any significant therapy

- she gained 80 pounds , (TPH , refused to provide me with a menu of what food was being provided)

Nicole had several life stressors during her stay, including The sudden death of her beloved sister Francesca.

- she was provided with no counseling or grief counseling during her in patient treatment.

- she was mostly sedated and given antipsychotic medications that were making her suicidal and prone to outbursts.

Doctor Nagra , and doctor Singh Did Not listen to Nicole when she told them of the adverse side effects she was experiencing.

Even tough her father and I have power of attorney, we were not informed of changes in medications and ignored when tried to communicate of Nicoles side effects to the medications they had prescribed.

- It took me 8 months and me personally going to see the ceo of TPH , Ms Carporoso , for them to take her off of one of the medicines causing bad side effects .

- she was discharged on December 20,2019-

The next day she jumped out of my moving car on route 1 and ended up at Robert Wood hospital, New Brunswick with a skull fracture.

- in February 2020 she again jumped out of a car and ended up fracturing her Tibia and had surgery.

- In July , 2020 Nicole ended up at Raritan Bay hospital in Perth Amboy , New Jersey .

Here again doctors completely ignored the power of attorney ,and did not inform us of medications being added .

I was completely ignored by doctor Ahmed , the psychiatrist, when I told him that nicole had had an adverse reaction in the past to one of the medicines that he had put her on (Respidal)

After 3 months at Raritan bay hospital she was transported to Manmouth hospital , Long Branch , New Jersey were she is currently .

Thank you again for letting me share what we are going though.

Alexandra Lusardi (609) 7310224

November 21, 2018

Attn: Laura Foster
Perform Care
300 Horizon Drive
Suite 306
Robbinsville, NJ 08691-1919
Quality Department

Dear Ms. Foster,

As discussed on November 12, 2018, I am writing in regards to some items I have witnessed while visiting my son Daniel at Legacy Treatment Services in New Lisbon, NJ; Daniel lives in Mazie House run by Armando Morales under Director Grace Kelly.

Below are a few items that should be addressed:

- **Staff burn out:** How are the work hours being distributed on a weekly basis to assure the persons being served at Maizie house are getting proper care?
- **Staff is not prepared for when there is an emergency in regards to a person in the house having a meltdown.**
- **Lack of hygiene at the house:** There are: dirty clothes left on the floor mixed with wet clothes, dirty sheets not changed for days that reek of body odor, no behavior plan put in place to help with Daniel's teeth brushing (he currently has four cavities due to poor dental hygiene).
- **Individuals left unprepared for school:** Daniel's book bag is not being checked and staff members have been unaware of school trips although the manager stated that Daniel was being sent to school prepared.
- **Staff hostility:** Certain staff members are very disrespectful and aggressive when I voice my concerns. I was asked to attend a meeting by management after voicing my concerns, and without any prior knowledge, I walked into the meeting with the two individuals I complained about. This is a very unprofessional way for management to handle this type of issue. The last thing a parent with a son diagnosed with Autism needs is to deal with staff resistance and retaliation.
- **Lack of Transparency:** There is no transparency, no parent meetings, etc. I have gone days without being able to see my son because you need to give a four day notice before visiting.

Daniel is said to be aggressive with staff, but I would like to mention there are staff members who are also aggressive with him, but of course the Director will not admit to this. My son Daniel was taken out of Mazie House by police handcuffed in the middle of the night. Was there enough staff when this happened? Probably not, but of course Legacy will say they had enough staff and that proper procedure was followed to keep everyone safe. What they will not mention is that Daniel is the eldest resident there, 20 years old, and is about to transfer out with DDD. He would be the first person to send out by police because the other residents are protected under DYFS as they are minors. I strongly suspect foul play in what was done to my son that night of

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October 23, 2018. The suffering he endured at Lourdes Medical Center in Willingboro, NJ could have been prevented if Legacy had known what to do during a time of a crisis. Some of the other individuals at Mazie House are bigger yet younger than Daniel. What is management at Mazie house going to do if there is another crisis? Daniel was kept in an emergency room from October 24, 2018 until November 8, 2018 where he was restrained every day, and his teeth were not brushed for days. Also, he was only bathed when there was enough staff in the hospital. He was put on 4 point restraints on both arms and legs and left alone in a room with no staff present from Legacy until I advocated for staff to be with him. Legacy never advocated for Daniel's previous hip injury and how the restraints would affect him. Because of his disability, Daniel has been treated like a criminal. I was not allowed to bring anything into his room except food. When blood work was done to try to transfer him to Trinitas Hospital in Elizabeth, NJ, it was discovered that his CPK level was high due to all the restraints he had endured. Trinitas would not accept him, and he was transported to the 5th floor on November 8, 2018. When I visited Daniel on November 8th, he did not look well. An IV had to be kept in his vein to provide fluids and get his CPK level down. The nurse at Lourdes hospital poked him three times, and I was told it takes sometimes 5 to 10 times to get a vein. I could hear him screaming as his nurse Kevin kept poking him over and over with a large needle. My son is currently at Trinitas in Elizabeth, NJ. He was taken to the emergency room on Monday, November 19, 2018 while at Trinitas because he was left alone in his room and banged his head on the wall from all the medications he was previously given at Lourdes Hospital.

Since Daniel by law is entitled to live in a residential facility that keeps him safe and Legacy has not fulfilled this requirement, I am requesting Daniel be placed in a new residential facility. Daniel is due to be discharged on Wednesday, November 28th from Trinitas. If DCF cannot provide him with a new facility at the time of his discharge, he will be sent to a state psychiatric ward. Is it justifiable to send him to a psychiatric ward when it is Daniel's right for the state to provide him a safe and proper place to live? Please let me know how DCF will manage this crisis with a temporary living facility for him until a new residential facility for Daniel is found. Daniel's safety is my biggest concern as his mother and advocate. He will not be safe at Legacy.

Respectfully,

Maria Varghese

cc: Clarence Whittaker
Assistant Director, Children's System of Care

Sent Regular Mail and Certified Mail

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STATE OF NEW JERSEY
DEPARTMENT OF HUMAN SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES
PO BOX 726
TRENTON, NJ 08625-0726
609.633.1482
www.nj.gov/humanservices/ddd

PHILIP D. MURPHY
GOVERNOR

Sheila Y. Oliver
LT. GOVERNOR

CAROLE JOHNSON
COMMISSIONER

JONATHAN S. SEIFRIED
ASST. COMMISSIONER

SECOND NOTICE

August 15, 2019

Delores Thomas
78 Long View St.
West Orange, NJ 07052

Re: Glory Thomas
DDDID 212735

Dear Ms. Thomas:

The responsibility for an individual receiving residential placement from the Division of Developmental Disabilities (DDD) to contribute to the cost of his or her care and maintenance is established in New Jersey Administrative Code at N.J.A.C. 10:46D.

According to our records, you were notified of your obligation to contribute for CONSUMER. To date there is a past due balance, please see attached invoice.

We are writing you in an attempt to collect on this debt. You have fifteen days after receipt of this notice to dispute the validity of this debt. If you request in writing verification of this debt, or any portion thereof is disputed, we will provide you with verification of this debt. This verification will include the name and address of the original creditor. If you do not dispute the validity of this debt, or any portion thereof, within fifteen days the debt will be assumed to be valid. Please contact Consumer Financial Assessment Unit in writing:

DDD-CFAU
P.O. Box 726
Trenton, New Jersey 08625-0726
Attn: Collections

We wish to work cooperatively with you in this matter. If you have questions, please contact Consumer Financial Assessment Unit at 1-800-626-6011. **Please be aware that failure to pay this debt may jeopardize Glory Thomas's Medicaid eligibility.**

Sincerely,
Consumer Financial Assessment Unit

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State of New Jersey, Division of Developmental Disabilities, Contribution to Care

Thomas, Delores
On Behalf Of: THOMAS, GLORY HOLLY
Account Number: 303415
Amount Due: $6,256.84 Date Due: 08/15/2019

This billing statement does not include assessments and payments prior to AUG 2009 or payments received after 07/22/2019

THOMAS, DELORES
FOR GLORY H THOMAS
78 LONG VIEW ST.
WEST ORANGE NJ 07052

Please report questions or changes to:
DDD.C2CMailbox@dhs.state.nj.us
or 800-626-6011

Date	Activity Description	Credits	Charges
	Previous Statement Balance		$6,256.84
	New Statement Balance Amount Due		$6,256.84

Tear Here

State of New Jersey, Division of Developmental Disabilities
Contribution to Care

DHS-CCP

PLEASE RETURN THIS STUB WITH PAYMENT AND WRITE ACCOUNT NUMBER ON CHECK

	Account Number	Date Due	Amount Due
Thomas, Delores for THOMAS, GLORY HOLLY	303415	08/15/2019	$6,256.84

PLEASE CALL 1-800-626-6011 TO REPORT FISCAL AND ADDRESS CHANGE

Make check payable to:

TREASURER, STATE OF NEW JERSEY
DHS-DDD
PO-BOX 652
TRENTON, NJ 08646-0652

Payee ID: 400038
DDDID: 212735
InstID: 17

Additional Payment

Total Enclosed

CC0000000000021273517303415100000400038081520190000625684031

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Scanned with CamScanner

September 18, 2019

To: DDD-CFAU
P.O. Box 726
Trenton, N.J. 08625-0726
Attn: Collections

I apologize for the delay in responding to this letter. I would like to dispute the money owed because of the time Glory spent away from the assigned group home (Allies) and day program (The Arc of Morris) over the years she stayed there. She has had multiple unexplained accidents at the group home/daycare center. Each incident and complaint caused me to always have to take off work to keep her home until she was well enough to go back to the group home/ day program. I was told as a rule the group home did not have staff to watch Glory while she healed in most instances that took 2 or more days. She had to always be prepared to go to her day program everyday to stay in the group home. I don't recall every incident at this time but medical records are available if needed. I know 2016 was when things were at its worst with Glory because of the frequent staff changes and short staffing issues they had at the group home and day program. I was told Holly and another client had to wear extra diaper pads to the day program because they did not change them or help them to the bathroom properly and that the daycare program could not handle Glory because of her behavioral issues. I started bringing Holly home more often to keep her safe which again caused me to have to take off my job that supports me. It was explained to me that DDD had a new program coming out and they were trying to encourage me to take Holly home because she had a guardian and was not a ward of the state. The state was putting this program together because of the need for more homes for people who had no guardian etc and I feel we were pushed out of the home because of this need. The last fall she had where she had to come home because she again had a scar was in May 2016. I will always remember that call because it was the last. I was told I had to bring her home for a week because the group home had no one to watch her while she had to take an antibiotic for 5 or 7 days. When I brought Glory home I decided not to take her back.

Glory has been living in my living room from that date. She was finally released from the group home in June 2016. She stayed in my living room until March 2019 when she finally received housing assistance from DDD which she could afford to have her own bedroom. Prior to that DDD came to see Glory every month in my home from 2016 and never offered financial assistance for housing until she was offered the new DDD pay for fee program in 2019.

I work full-time on my high demanding job for 19 years and having Glory home has taken a toll on me as well. As a full-time Caregiver for Glory my life matters too. My goal with bringing her home has been to help her seek one on one assistance with her physical and mental needs and to prepare her for a group home life if she ever has to go back in the system again.

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I have complained to Mr. Jonathan Seifreid about being asked about my income and having to use my income for Glory's needs and he sent me to different people that made our life a nightmare. I have spoken with Mr. Paul Aronson several times about the housing issue Glory has and how it has always cost me money to keep her in a proper home and he sends me to the same people whose responses are incomplete. I reached out to Disability Rights of NJ about the mistreatment of Glory in the home and day program and they sided with DDD social worker using the fact that since I am employed I should not have complaints about something Glory cannot confirm because she cannot speak for herself. I feel that Glory has always needed one on one service which was not offered to her and now living with me she gets the attention she needs.

At this time, I ask that the amount you are asking for be waived do to the fact that I contributed more money through the years Glory has spent in the group home tending to the needs that should have been dealt with by the trained Service Providers. The money that was not paid was applied to the home she lived in as well as moving expenses, food, transportation, qualified sitters, my time off work to care for all her falls and incidences at the group home and day program, getting her re-established in my community with doctors appointments, a new day program which took 3 programs to get her settled in one that could handle her needs, etc.

There is no need to compromise Glory's benefits, as her court appointed guardian I am fully responsible for whatever decision is made but I will push forward with this issue because we have been treated unfairly because I have nothing in writing that says I was not allowed to make the decisions I made with Glory's best interest to keep her in a safe environment.

Now as an advocate for the NJ Family Support Planning Council that has given me support in handling this changed lifestyle. I am able to have a better insight of the issues that caregivers have that need to be addressed and not ignored. I want to be a part of the solution not the problem.

Thank you so much for your time. I will be looking forward to your reply.

Delores A. Thomas

Caregiver and Guardian for Glory H. Thomas- DDD ID# 212735

Cc Mr. Kumar Smith – Support Coordinator, Solutions for U

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Rights of Persons with Disabilities in America

• Author: *Wendy Taormina-Weiss* : Contact: *Disabled World*

• Published: *2012-02-27* : (Rev. *2019-09-06*)

Synopsis and Key Points:

- The basic rights of every person despite their disability status are presented through various different treaties.
- For People with Disabilities, issues with employment have always been troubling in America; always.
- The Department of Health and Human Services is making incredible strides in relation to People with Disabilities.

Main Digest

What Are Disability Rights?

The rights persons with disabilities have include; equality before the law, freedom of speech, respect for privacy, the right to both marriage and family, the right to education, the right to health, and much more.

The Convention on the Rights of Persons with Disabilities (CRPD) defines persons with disabilities as, "Those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." The United Nations states, "Everyone is likely to experience disability at some point during his/her lifetime because of illness, accident, or aging."

In the United States of America, awareness of this fact is becoming more prominent. The disability rights movement is the movement to secure equal opportunities and equal rights for people with disabilities. The specific goals and demands of the movement are: accessibility and safety in transportation, architecture, and the physical environment, equal opportunities in independent living, employment, education, and housing, and freedom from abuse, neglect, and violations of patients rights.

The Rights of Persons with Disabilities

The basic rights of every person, despite disability status, are presented through some different treaties. These treaties include the following:

» The Universal Declaration of Human Rights (UDHR)

» The International Covenant on Civil and Political Rights (ICCPR)

» The International Covenant on Economic, Social, and Cultural Rights (ICESCR)

» The Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (CEDPWD)

The rights persons with disabilities have include equality before the law, freedom of speech, respect for privacy, the right to both marriage and family, the right to education, the right to health, and much more. The year 2006 found the United Nations drafting the CRPD in recognition of the difficult and overlapping barriers persons with disabilities face. The CRPD is the first treaty that comprehensively addresses every aspect of discrimination related to disability, to include areas such as education, employment, self-determination, and privacy. The United States of America signed the CRPD in the year 2009, although it has not yet ratified the Convention.

The United States and Recognition of Disability Rights

The Constitution of the United States of America guarantees equal protection to every citizen, despite characteristics they may have such as disability, race, or gender. The United States Congress also enacted specific statutory protections for persons who experience forms of disabilities, most notably through the Americans with Disabilities Act. Laws in America prohibit discrimination against persons with disabilities in any:

» Education

» Workplaces

» Public program

» Private housing

» Access to polling places

Laws in America require employers, schools, landlords, as well as governments to make services accessible to persons with disabilities through the provision of reasonable accommodations or modifications. A number of the states in America have drafted their own laws addressing the rights of persons with disabilities. In combination with the laws America has, it is also legally bound to International treaties such as the UDHR or the ICCPR.

The United States and Fulfillment of the Rights of Persons with Disabilities

Millions of Americans with Disabilities are deprived of their rights, despite legal protections related to us, due to a lack of awareness and failure to provide us with reasonable accommodations in a number of areas. Persons with disabilities in this nation continue to face considerable levels of discrimination related to employment, services, education, and additional areas. Greater than 54 Million Persons with Disabilities live in America today; a number that continues to grow as the overall population ages.

The Safety and Security of Persons with Disabilities

Persons with Disabilities as a minority population in America experience an increased risk of becoming victims of violent crime. Women with disabilities specifically experience a high rate of sexual assault and domestic violence. For example; studies have suggested that women who experience forms of developmental disabilities are 4 to 10 times more likely to experience a sexual assault than other women in America. Children with disabilities also experience a high risk of abuse. Young people with disabilities are 1.5 to 3.5 times more likely to experience neglect and abuse and find themselves surrendered to the child welfare system.

When situations such as natural disasters occur, persons with disabilities are frequently denied our right to protection. A study on emergency management found a majority of Federal Emergency Management Agency (FEMA) emergency managers did not have the training to work with special needs populations, to include persons who experience forms of mobility impairments. The lack of consideration on the part of FEMA in relation to persons with disabilities proved to be disastrous during both Hurricanes Rita and Katrina.

Estimates demonstrate that around 73% of the fatalities related to Hurricane Katrina in New Orleans were persons over the age of 60, despite the fact that this population comprised a mere 15% of the overall population involved. Experts have suggested this occurred because many of the persons who died experienced medical, physical, or sensory limitations which made them move vulnerable.

Persons with Disabilities, Equal Protection, and Due Process

Social Service organizations in America are many times unprepared to address the needs of persons with disabilities. For example; shelters for battered women commonly lack staff members who have the training needed to work with the unique needs of women with disabilities. Police officers and other law-enforcement officials only receive minimal amounts of training related to accommodations related to us.

When investigators interview people with developmental disabilities who have experienced a crime against them, they repeatedly fail to pursue vital information concerning the incident itself and the perpetrator. The investigators may only make assessments that are inappropriate in regards to the credibility of the victims instead. A 2001 survey by the Boston Globe found that a mere 5% of serious crimes against persons with disabilities were prosecuted, compared to 70% for similar crimes against persons who experienced no form of disability.

Persons with Disabilities and Accessibility

Accessibility is the primary component in the fight against discrimination involving persons with disabilities. The Department of Transportation states that only 55-60% of public buses have wheelchair lifts. Even the buses that do have wheelchair lifts find persons with disabilities being denied access due to lifts that are not working properly, or bus drivers who do not have the training to operate them.

About This Image: A yellow sign hanging from white scaffolding with the symbols for a male, female, and disability bathroom, and baby changing rooms next to an arrow pointing right - Photo Credit: Paul Green on Unsplash.

Persons with disabilities in America are also commonly denied requests they make for reasonable accommodations or modifications they need related to housing in order to make the housing accessible for them. Almost 20% of housing providers with on-site parking have refused to make the reasonable accommodation of providing a designated, accessible parking space for a person who uses a wheelchair, for example. In the year 2008, 44% of the 10, 552 housing discrimination cases filed (a new record), were complaints involving persons with disabilities. A number of persons with disabilities also face barriers at polling places due to the inaccessibility of the polling place, or voting machines that are incompatible.

Persons with Disabilities and Non-Discrimination

Persons with Disabilities in America face systemic and direct forms of discrimination. Disability harassment can take a number of forms such as:

» Insults

» Isolation

» Shunning

» Daily mockery

» Physical abuse

» Disenfranchisement

Teachers and Principals in the schools of America have been involved in instances of encouraging harassment or intentionally instituting policies with the intention of punishing students simply for experiencing a form of disability. The United States government has started prosecuting cases of disability harassment in schools and workplaces, yet many courts in America continue to refuse consideration of disability harassment as a serious crime that is comparable to racism or sexism - something that leaves those who experience disability harassment without equal protections under the law.

Persons with Disabilities and Housing

Housing discrimination related to persons with disabilities in America is rampant. There is precious little in the way of housing that is accessible, affordable, or designed with persons with disabilities in mind. One study found that greater than half of all persons with disabilities in America faced housing inquiry discrimination compared to non-disabled persons seeking similar housing. Persons with disabilities receive less encouragement to pursue rental agreements and are less likely to be offered an application than non-disabled renters.

Some of the states in America try to force persons with disabilities into institutions instead of providing nursing assistants or personal care providers. Providing this type of assistance to persons with disabilities in their own communities is vital. It allows us to live independent and full lives; it is also many times less expensive than putting people who should be living independently into institutions.

Persons with Disabilities and Health

A disproportionate number of persons with disabilities in America face barriers to receiving quality health care, despite Americans with Disabilities Act (ADA) regulations. A number of health care facilities do not provide assistive technologies. Persons with disabilities many times find ourselves fighting with insurance companies to get the treatments and accommodations we need.

A study performed in the state of California found that 22% of persons with disabilities experienced difficulties with accessing health care facilities. The study also found that 12.9% of persons with disabilities reported unfair treatment by their health care providers due to the disability they experience. A wide-reaching study of disability health care coverage found that persons with developmental and intellectual disabilities were 3 times more likely than persons without to report unmet health care needs.

Persons with Disabilities and Education

The educational outcomes for children with disabilities have improved somewhat due to revisions of the Individuals with Disabilities Education Act (IDEA). Children with disabilities; however, are more likely to experience types of corporal punishments in America's schools. Out of the 223,190 public school students in America who were beaten with a paddle in the 2006-2007 school year, at least 41,972 of them or 19% were students who experienced a form of disability.

Students with disabilities are also less likely to graduate from high school. A scant 12.5% of persons with disabilities in America have a Bachelors degree, compared to the national average of 30.3%. A number of the colleges in this nation still do not have adequate support services, or even awareness of disability issues, and remain inconsistent in their interpretations of their requirements in regards to the accommodation of persons with disabilities. Many students with disabilities are forced to pay for the extra costs of their accommodations and may need additional time in order to graduate - something that increases their overall final costs related to education.

Persons with Disabilities and Employment

The year 2006 found persons with disabilities in America experiencing an employment rate that was at least 40 percentage points lower than the rate of working age persons without disabilities. Persons with Disabilities as this nation's largest minority population have always experienced the highest rates of unemployment; always. A whopping 70% of persons with disabilities in America who are unemployed cite discrimination in the workplace and a lack of adequate transportation as major factors preventing them from working.

Additional studies have demonstrated that persons with disabilities in America who do find jobs earn less than their co-workers without disabilities. Workers with disabilities are less likely to receive promotions as well. All of these things negatively affect our economic and living conditions. Persons who experience forms of mental health disabilities also experience particularly high rates of unemployment, as well as facing higher levels of employment discrimination than other persons with disabilities.

United States Government Obligations in Regards to Persons with Disabilities

The government of the United States of America, in order to ensure the rights of Persons with Disabilities, has a number of different obligations. The foremost obligation in this writer's mind is the obligation to Protect the Most Vulnerable - which means the U.S. government must actively reach out to those citizens with disabilities who are most marginalized and excluded from the communities of America and face the greatest barriers in the realization of their rights.

The United States government is obliged to ensure Nondiscrimination - meaning it must work to prevent discriminatory outcomes due to ability, race, gender, language, or additional factors with the goal of ensuring equity in the fulfillment of the rights of everyone in America. Our government is obliged to Protect us as persons with disabilities - meaning the U.S. government must take measures to prevent individuals or third

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parties such as employers or civil society organizations from interfering in any way from the realization of our rights.

The United States government is obliged to Respect us as persons with disabilities - which means our government must not deprive us of our rights under both domestic and International laws. Our government must refrain from taking retrogressive measures which are incompatible with our rights. The U.S. government is obliged to Fulfill our rights - meaning it must adopt necessary measures and create an enabling environment such that all persons with disabilities may enjoy our full rights.

The government of the United States of America is obliged to Meet Minimum Standards - meaning it must ensure the satisfaction of the minimal, yet essential, standard laid out in the UDHR and immediately address situations involving extreme abuse. Our government is also obliged to Monitor and Report - which means our government must monitor and report on its fulfillment of our rights as persons with disabilities, and ensure its accountability for its actions and inactions.

The Americans with Disabilities Act

The main page of the website for the Americans with Disabilities Act (ADA), presented by the United States government, is filled with efforts being made to ensure that people with disabilities in this nation enjoy the rights granted to us under this monumental Act. There are greater than 54 Million People with Disabilities in the United States of America, making us this nation's largest minority population. Ensuring that our rights are enforced is vital to the participation of every person who experiences a form of disability in America, despite their other form of social identification.

The passage of the ADA marked an incredible milestone in Disability History and the rights of persons with disabilities in America. There is; however, more that can be done - even in relation to the ADA. Much of the wording in the ADA includes terms such as, 'unless it presents an undue hardship,' and other terms that provide everyone from employers to businesses with a means of evading the very rights meant to be guaranteed under the ADA.

The Department of Justice

The Department of Justice (DOJ) has been and continues to be very diligent where pursuit of violations of the ADA is concerned. The sheer numbers of violations of the rights of persons with disabilities in America; however, is plainly overwhelming the DOJ. With every complaint and violation of the rights of a person with disabilities in America, large amounts of paperwork are involved. Government personnel are also involved, leading to even more paperwork.

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Many people with disabilities in America feel intimidated and hesitant to file complaints in regards to violations of our rights. One of the reasons for these feelings is due to the very processes involved with filing a complaint. Even more than two decades after the passage of this crucial civil rights Act, many Americans remain ignorant of the ways this legislation applies to People with Disabilities in America. This writer has personally encountered a number of people, some in positions of trust, who were actually unaware of what the ADA is.

The Department of Education

The Department of Education is doing what it can to include children with disabilities in education. While the efforts this department is pursuing have been and continue to be questioned by some parents, the fact remains that efforts are being made. Prominent issues remain however; ones that must be dealt with.

One of these issues involves bullying by non-disabled students. Children with disabilities, like children who are gay, lesbian, or transgendered, continue to experience bullying by students who perceive them to be the subjects of ridicule. The term, 'bullying,' is misleading because an act of bullying amounts to assault.

Another issue that must be dealt with in relation to children with disabilities and education involves abuse perpetrated by teachers themselves. Children with disabilities have been locked in closets, restrained to the point of bruising and worse, and ridiculed in front of their fellow classmates by teachers with little or no skills in working with students who experience forms of disabilities. Teachers who commit these acts of shaming or abuse often times simply walk away from their offenses.

Yet another issue that must be dealt with involving children with disabilities and education is the continued isolation of students who experience forms of disabilities from non-disabled classmates. Education for everyone means everyone - including children with disabilities. Isolating students who experience forms of disabilities is clearly not inclusive.

The Department of Housing and Urban Development

Housing is an interesting issue for People with Disabilities in America. Where housing is concerned, anything before a certain date is considered, 'uncovered,' by the ADA. What this means is that if a building is older than, 'X,' date - it is not required to meet ADA accessibility laws.

Due to this fact, a great many People with Disabilities in America find themselves living in housing that is not accessible to them or their needs. As a population, many of us live on fixed incomes, meaning we do not have the financial ability to rent, lease, or purchase newer housing. This writer is personally aware of this fact - over a period covering decades of time.

Section 8 Housing vouchers are cherished because they are hard fought for; there simply aren't enough of them. Apartment complexes where these vouchers can be applied are often in areas that are not well, 'the greatest,' and many times have limited numbers of accessible units. Finding a house that not only is accessible, but accepts a Section 8 voucher is akin to a miracle in America.

The Department of Transportation

"For the 2012 proposal and our upcoming reauthorization, we really wanted to think about how we can help make all modes of transportation accessible," said Polly Trottenberg, Assistant Secretary for Transportation Policy. Polly's statement is very noble, as well as a presentation of the exact demeanor People with Disabilities desire to hear from the Department of Transportation. As a population, we have experienced tired, ongoing issues with transportation in America.

Transit systems in America are so incredibly biased towards able-bodied persons they may as well have signs on them reading, "Non-disabled Only." Amtrak trains, for example, often times have one accessible car out of the entire train; one. Bus systems in America have been cutting entire bus routes, to include buses and paratransit routes that are accessible to people with disabilities, because of financial hardships on the parts of cities.

People with Disabilities who rely on these modes of transportation in order to get to everywhere from work to appointments or even to get out of their homes for a while find themselves further isolated from society due to a lack of adequate transportation services. Attempts to fly on an airline find us being picked out of lines in disproportionate numbers for TSA Agent molestation because of things such as knee braces, hip replacements, or other medical devices. The Department of Transportation has a great amount of work to do in relation to ensuring our human rights as citizens of the United States of America; a great amount of work.

The Social Security Administration

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Anyone at all in America can experience a form of disability, and the fact is that most Americans will experience a disability or serious illness during their lifetime. In this nation, people can apply for disability benefits through the Social Security Administration (SSA), a very needed and reassuring safety net for all Americans. Some issues involving the SSA and human rights remain; however.

Imagine that you find yourself experiencing a new form of disability that leaves you unable to work for a living. You decide to apply for Social Security Disability benefits - guess what? You will find yourself interacting not only with the SSA, but with a lawyer, a court, and spending a great amount of time waiting for a decision. It is most important to note that you will most likely be denied.

While select forms of disabilities people may experience are now sped through this process, vast numbers of People with Disabilities find themselves struggling to survive for years, only to be denied disability benefits by the SSA and having to pursue an appeals process. Through the appeals process, a person with disabilities may be denied again, or they may be approved. In the meantime, the person has to figure out how they are going to survive as they deal with this process presented by the SSA.

In the end, if a person with disabilities is approved by the SSA for disability benefits, they will find themselves living on a poverty income. The reason this income is so low is because the SSA is attempting to ensure no one is, 'ripping-off,' the taxpayers of America. In other words, even after approval by the SSA for disability benefits - a person with disabilities will still find themselves struggling to survive on a poverty income.

The Department of Health and Human Services

The Department of Health and Human Services is making incredible strides in relation to People with Disabilities. Take the HHS's perspectives on the Olmstead Act, or the pursuit of National Health care, for example. While the Community Care Act has not been passed, the HHS has been pursuing community living in relation to the Olmstead Act, something that is perhaps as worthy. As the HHS site states, "HHS Secretary Sebelius will be working with Secretary Donovan of the Department of Housing and Urban Development to identify ways to improve access to housing, community supports and independent living arrangements."

Issues do remain; however. A visit to Dr. Jane can be trying for a person with disabilities. At the front desk, which is many times above the heads of a person who uses a wheelchair, a person with disabilities may find themselves facing a receptionist who tells them, 'Sorry, we are not accepting new Medicare or Medicaid patients.' Trying to find a doctor or specialist who accepts the two most common forms of insurance used by People with Disabilities can be difficult.

Upon finding a doctor or specialist who accepts Medicare or Medicaid, a person with disabilities can find themselves facing an office environment that is not accessible, as well as an examination room that isn't. The need for a sign language interpreter can find a person with disabilities needing to postpone or reschedule an appointment, or find a doctor refusing to see them at all.

Many primary care physicians in America remain ignorant of various forms of disabilities. Awareness of the rights of People with Disabilities in relation to health care is another thing many health care providers lack. In short - America has a ways to go where health care and People with Disabilities are concerned.

The Equal Employment Opportunity Commission

A growing number of employers in America are waking up to the fact that employees with disabilities are among the most diligent, trustworthy, and dedicated employees they can ever hire. To these employers a huge, 'Thank You,' is in order. The Equal Employment Opportunity Commission (EEOC) has helped many employers in America with understanding the ADA and how it applies to their businesses and People with Disabilities.

Some employers in America; however, remain ignorant of the rights of People with Disabilities in relation to employment. Other employers choose to pursue perspectives of bias and even bigotry, refusing to hire People with Disabilities, or choosing to treat us badly if they do hire us. Where these employers are concerned, the EEOC pursues them first from a perspective of mediation, and should this fail - through a legal perspective and the ADA.

For People with Disabilities, issues with employment have always been troubling in America; always. We have always experienced the highest rate of unemployment in this nation. We have always faced employers who look at our resume's and choose to hire the young, able-bodied kid instead. We have always faced employers who find sneaky ways to weasel around the Americans with Disabilities Act, the EEOC, and dump on our rights in the area of employment. The fact is - the EEOC can only pursue so many cases of discrimination; it is limited.

What Does All of This Mean?

The government departments covered in this article are far from the only ones that affect People with Disabilities in America. The United States government, no matter how much it grows, or how many people it hires, will still be limited in its abilities to support the rights of People with Disabilities in this nation. Ensuring the rights of People with Disabilities in America is going to require further efforts - ones involving the people of this nation and more.

The very first thing the United States government needs to do is to ratify the Convention on the Rights of Persons with Disabilities and its optional protocols, enacting these vital items pertaining to us and our rights. Doing so not only outlines our rights in clear terms, it supports the Americans with Disabilities Act.

Legislation empowering People with Disabilities in America is also desperately needed. We need the power to work on an ad hoc basis with government departments with the intention of improving the departments that support services related to us and our rights. While many people with disabilities find themselves unable to work on a full-time basis, a great many of us are able to contribute incredibly meaningful, productive things on an ad hoc basis as our health allows; we simply need the legal ability to do so. The technology exists for us to contribute; we simply need the opportunity.

Vast awareness campaigns concerning the ADA and the Convention on the Rights of Persons with Disabilities (CRPD) are needed in America. The citizens of this nation - whether they experience a form of disability or not, need to be aware of the rights and abilities of citizens with disabilities. Awareness of these issues can no longer remain on the sidelines - People with Disabilities comprise America's largest minority population.

Fundamental Rights Of Persons With Disability Statistics and Charts (https://www.disabled-world.com/disability/statistics/maps.php) - Assessment and charts show statistics of world countries efforts to address the rights of persons with disabilities - *UCLA WORLD Policy Analysis Center.*

Related Documents

1 - During Pandemic, Disabled Activists Fight a Two-Front War for Their Lives (https://www.disabled-world.com/editorials/2-front-war.php) : *Op-ed by Abe Munder (2020/05/24)*

2 - In Service : U.S. Memorial Day 2020 (https://www.disabled-world.com/editorials/in-service.php) : *Tsara Shelton (2020/05/25)*

3 - McDonald's, Walmart and Other Companies Guilty of Wage Abuse Against People with Disabilities (https://www.disabled-world.com/editorials/guilty.php) : *Thomas C. Weiss (2013/07/20)*

4 - Title II of the ADA: Police Liability (https://www.disabled-world.com/editorials/police-liability.php) : *Thomas C. Weiss (2014/11/17)*

5 - The Issue of Ageism in America Today (https://www.disabled-world.com/editorials/ageism.php) : *Thomas C. Weiss (2012/09/12)*

6 - What Brexit May Tell Us About Hate Crime Committed Towards Disability (https://www.disabled-world.com/editorials/brexit-disability.php) : *Paul Dodenhoff (2016/07/25)*

7 - Are UK Welfare Reforms a Form of Hate or Hate Crime Conducted Towards Disability? (https://www.disabled-world.com/editorials/welfare-reform-hate.php) : *Paul Dodenhoff (2020/02/18)*

Important:

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PHILIP D. MURPHY
Governor

Sheila Y. Oliver
Lt. Governor

Carole Johnson
Commissioner

October 22, 2020

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

Dear Chairwoman Downey:

Thank you, Chairwoman Downey and the members of the Assembly Human Services Committee, for your attention to and support for the well-being of the nearly 25,000 individuals with intellectual and developmental disabilities served by the Department of Human Services' Division of Disabilities. The health, safety and well-being of the individuals served by our Department is our top priority.

The Stephen Komninos' Law

As you know, when the Murphy Administration assumed office, the Stephen Komninos' Law, which significantly strengthened the Department's tools to help prevent and respond to abuse and neglect, had not yet been implemented. We made it a priority to invest in the staff, training and support resources needed to stand up the new oversight and accountability process envisioned in the law.

In particular, the law required enhanced oversight of the 8,000 individuals with intellectual and developmental disabilities living in licensed community settings. To support these individuals, the law provided new tools, such as:

- Unannounced site visits to group homes and supervised apartments to evaluate if individuals residing in these settings are at risk of, or being subjected to, abuse, neglect or exploitation;
- Required reporting of incidents or suspected incidents by staff working in licensed settings and Department verification within 48 hours of a report of a suspected incident or allegation;
- Notification in-person or by phone within two hours by the service provider to an individual's guardian of physical injury related to incidents or allegations of abuse, neglect or exploitation; and,

- Drug testing as a condition of employment, random testing while employed, and drug testing for cause based on a concern or suspicion for all direct care applicants and employees of licensed or regulated programs for adults with developmental disabilities.

The Department quickly staffed our Office of Program Integrity and Accountability (OPIA) to manage the Stephen Komninos' Law implementation, and under OPIA's leadership, a team of well-trained experts are regularly in the field to monitor licensed settings. To date, OPIA has conducted 7,295 unannounced visits, over 10,600 visits within 48 hours of a report of an allegation, and 54,230 staff drug tests.

These important tools complement our ongoing licensing and monitoring efforts to help ensure the best outcomes for individuals living in the community, and we look forward to continuing to work with the Committee to ensure that those we serve have the supports needed to thrive.

Protecting and Empowering Individuals with Developmental Disabilities

The health, safety and the well-being of those we serve are our top priorities. While we know that the vast majority of the service community shares these priorities, we do not hesitate to act when we identify problematic practices.

In fact, when we identified significant health and safety concerns with the largest residential provider in the state and no indication of improvement in their practices, we took action. They no longer operate in our state and the hundreds of individuals in their care have transitioned to other providers. It was an enormous undertaking, but we cannot and will not allow operators who are not committed to the care and support of residents be a part of this critical work.

We also strongly believe in the personal autonomy of the individuals we serve and the need to ensure that our protection and oversight tools do not infringe on their rights and opportunities to make personal choices about their lives. We look forward to continuing to work with the Committee, self-advocates, and others to ensure that our programs and services are not only protective but also empowering.

COVID-19 and I/DD Provider Oversight

We know that the COVID-19 pandemic is most concerning for vulnerable populations with underlying health conditions, which includes many individuals with intellectual and developmental disabilities. The Department's oversight functions have continued throughout the pandemic, where possible adapting to online technology, but in all instances, maintaining critical functions to protect the health and well-being of residents. These include, but are not limited to:

- Conducting over 450 in-person Field Safety and Services field visits during the pandemic of individuals residing in licensed residential settings using an assessment tool aimed at identifying if individuals are at risk of, or are being subjected to, abuse or neglect;
- Our Incident Verification Unit completing more than 75 in-person visits during the pandemic;
- Our Office of Investigations Unit completing 226 civil investigations during the pandemic related to allegations of abuse, neglect and exploitation involving individuals receiving services;

- Performing over 7,500 tele-assessments of licensed group homes and supervised apartments during the pandemic; and
- The Department's Office of Program Integrity and Accountability (OPIA), which conducts background checks on new hires in the I/DD system, processed over 6,300 requests for hire.

OPIA staff have been trained in PPE donning and doffing, supplied with PPE, tested and otherwise prepared to safely conduct their critical oversight functions in community residences. Their dedication to the individuals we serve and commitment to ensuring that they are able to do this critical work has been tremendous and has ensured that these oversight functions could resume as soon as it was safe. OPIA also has worked quickly with the provider community to address any issues identified and ensure compliance with COVID-related safety protocols.

Oversight and Accountability

The Department maintains a robust system of oversight and monitoring functions critical to helping ensure the health, safety and well-being of individuals receiving services and supports. These offices and functions include:

- *Office of Licensing:* Ensures adherence to regulatory standards for the operation of group homes, supervised apartments and community care residences. Regulates, inspects and provides technical assistance to programs providing these services.

- *Field Safety and Services Unit*: Performs biannual visits to group homes, supervised apartments and community care residences in accordance with New Jersey statutes to assess whether individuals are at risk of, or are being subjected to abuse, neglect or exploitation.

- *Critical Incident Management Unit*: Provides oversight in all matters related to incident reporting and the tracking, response and follow up to reported incidents. Provides oversight of and technical assistance to providers to ensure adherence to incident reporting requirements.

- *Employment Controls and Compliance Unit*: Performs background checks for the on-boarding processes for the hiring and continued employment of staff working in programs providing services, including criminal history records through fingerprint checks, Child Abuse Registry Checks (CARI), drug testing, and adherence to the Department's Central Registry of Offenders against Individuals with Developmental Disabilities.

- *Incident Verification Unit*: Performs in-person verifications of reported incidents and allegations.

- *Office of Investigations:* Performs civil investigations of serious allegations/incidents of abuse, neglect and exploitation and other serious incidents involving individuals receiving services through the Department.

- *Risk Management System*: OPIA develops, collects and regularly reviews and evaluates specific performance indicators for providers of residential services using national and best practice guidelines.

Direct care staff interacting with an individual receiving Department-funded services have a duty to report. Staff who fail to report abuse, neglect or exploitation of an adult with a developmental disability face penalties under the law. The Division of Developmental Disabilities maintains a toll-free number to call to report abuse, neglect or exploitation that has continued to operate uninterrupted throughout the pandemic.

The Office of Investigations conducts thorough, independent, objective and timely civil investigations of unusual incidents and allegations involving individuals served by the Department and community agencies. When necessary, the Office of Investigations partners with appropriate law enforcement agencies.

Parents or guardians have the opportunity to attend an Office of Investigations interview of the individual the guardian represents, unless their attendance would impede the investigation. Additionally, the guardian may provide information to facilitate an investigation. If the individual does not have a guardian, a family member may provide information, unless the individual expressly prohibits the family member from providing information.

The guardian of an individual is provided with a summary of the findings of an investigation involving an alleged incident of abuse, neglect or exploitation of the individual. If the individual does not have a guardian, a family member may receive the information, unless the individual prohibits the family member from receiving it.

OPIA also maintains the Central Registry of Offenders against Individuals with Developmental Disabilities. The Central Registry is a confidential list that now reflects the names of 305 former caregivers who previously worked in licensed, regulated programs, determined through a Department investigation to have abused, neglected, or exploited an individual with a developmental disability and the caregiver's actions met the statutory criteria for registry placement.

Employers providing services to people with disabilities are required to check the Central Registry and determine if potential and existing caregiver names are listed. Individuals identified on the Central Registry are barred by law from being employed by, or volunteering in, Department-funded, licensed, contracted or regulated programs. In 2020, the names of 31 former caregivers were placed on the Central Registry, 14 of whom were added during the pandemic.

The Department believes the work of OPIA and the critical functions outlined above are fundamental to our mission of serving adults with intellectual and developmental disabilities. We will continue to use all tools available to us to protect the health and safety of those we serve, while ensuring that they have access to the services and supports needed to live well in their communities.

Dual Diagnoses

The Committee has expressed a keen interest in coordination of care for individuals with intellectual and developmental disabilities and co-occurring medical and/or behavioral complexities. Of note:

- The Governor's budget for last fiscal year included a new $9.5 million initiative, which is continued in the Governor's current fiscal year budget, focused on improving programs for individuals dually diagnosed with developmental disabilities and behavioral issues.
- This investment marked one of the first new initiatives targeting these critical needs in many years.

Although the timing of this initiative has been complicated by the coronavirus (COVID-19) pandemic, the Department, in partnership with the Rutgers Center for State Health Policy, has begun the planned statewide review of in-patient stabilization services and associated funding mechanisms proposed in the budget. In the coming days, the Department will issue a request for proposals to support new, community-based behavioral health stabilization homes, with more complete wrap-around services, for the purpose of preventing emergency room visits and creating in-patient step-down capacity for individuals experiencing a behavioral crisis. New, re-imagined community-based emergency beds will provide more opportunities for stabilization. We look forward to continuing to work with you and the Committee on this initiative.

Care Transitions

We also appreciate the Committee's interest in the issue of care transitions as individuals age-out of youth services and into adult services. We welcome your attention to this important issue and value the importance of lifespan planning.

The Department's Division of Developmental Disabilities, which is responsible for adult services, has worked with the Department of Children and Families' Children's System of Care on information-sharing regarding young people receiving residential services who are aging into the adult system. This has included a streamlining of the Division's application process.

The Division does not always have the same visibility from local education authorities about the population of young people receiving school-based services from their local education authorities until late in their school years, often nearing the time when their educational entitlement is set to cease. We would welcome the opportunity to work collaboratively with the Committee, school districts, families and others to better streamline this process and provide the Division ample time to work with families on planning and transition. We are committed to making this process work best for families, while ensuring that we meet our legal obligations.

Division of Developmental Disabilities COVID Response

In addition to our critical oversight role, the Department – through the Division of Developmental Disabilities – is responsible for service delivery to the adult developmental disabilities community. Throughout the pandemic, the Division has provided regular guidance and direction to residential providers informed by the Centers for Disease Control and Prevention and the New Jersey Department of Health. The Division acted quickly in the early days of the pandemic to temporarily close congregate day programs where individuals gather in large numbers on a daily basis. However, the Division knew that would mean increased needs in residential settings as individuals needed supports to spend more time at home. This lead to several actions, for example:

- Between March and September, the Division has made about $134 million in additional payments to I/DD group home providers to help them staff and support individuals in their group homes during the day as congregate day programs, sheltered workshops, and other employers were closed;
- The Department 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;
- The Division has provided bridge payments to day program providers during their closure and as they begin the re-opening process (Day programs were able to begin re-opening with reduced capacity limits as of September 21, 2020);
- The Department has delivered PPE to I/DD providers to help support their needs and this week announced a new investment of $25 million from the Coronavirus Relief Fund to support the added costs of pandemic preparedness for community-based providers, including residential programs and day program providers; and,
- The Division has issued extensive guidance consistent with federal and state public health guidelines to ensure the health, safety and well-being of residents and of staff providing 24/7 care. All guidance documents can be accessed at nj.gov/humanservices/coronavirus.

Supporting the Workforce

Direct Support Professionals (DSPs) are truly the backbone of the service system for individuals with intellectual and developmental disabilities. They have worked tirelessly throughout the pandemic and are critical partners in our response efforts.

The Department took several actions early in the pandemic to support workforce needs and to allow for quick hiring to help prevent staffing shortages, and is continuing to work to support this vital workforce. For instance:

- The Department implemented a $24 million wage plan to temporarily raise DSP wages by $3 per hour for three months for staff working in group homes at a critical juncture in the pandemic;
- The Division modified its rules to quickly allow families to hire parents as self-directed employees to support their loved ones at home if they chose to do so; and,
- The Department's Office of Program Integrity and Accountability (OPIA), which conducts background checks on new hires in the I/DD system, quickly reviewed and approved about new workers to work with provider agencies during the pandemic and to support individuals who self-direct their services and hire workers directly rather than through a provider agency.

To continue to support this critical work, the Governor's budget for the state fiscal year that began October 1st included additional investments in DSP wages. This funding comes in two tracks:

- First, $24 million will support an additional temporary wage increase for DSPs working in group homes to recognize their critical work in continuing to protect and support individuals during the pandemic.

- Second, $41.7 million in new funding will help ensure that DSPs are paid above the state's increasing minimum wage and raise the wages of group home managers as the minimum wage increases in January 2021.

In addition, the budget invests in the health care workforce with $20 million to increase hourly rates for Private Duty Nursing and Early and Periodic Screening, Diagnosis and Treatment.

Supporting Families and Providers

To help families, guardians, caregivers and the provider community navigate this challenging time, in March, the Division began a series of regular webinars specifically related to COVID-19 and its impact on the community. Webinars have addressed infection control, emergency planning and preparation, understanding guidance documents, protocols for screening staff and visitors, masking policy, and other areas. Various other important updates have been provided regularly by the Division.

The Division also has worked with providers to support communication with families about the safety and well-being of their loved ones. And, as soon as the Department of Health approved outdoor visitation in other congregate settings, the Division issued guidance so that individuals residing in residential settings had the same opportunity.

In addition, as soon as public health guidance allowed, the Division also acted to ensure the congregate day programs could reopen by late September at reduced capacity if they are able to demonstrate compliance with appropriate public health measures. To date, 194 programs have reopened and more are planning to do so. The Division continues to financially support day programs both through ongoing state payments to help with their sustainability and with the availability of the new CRF funding to help with the costs of PPE and other unanticipated COVID-related costs.

Thank you again for the opportunity to discuss New Jersey Human Services' efforts to support individuals with intellectual and developmental disabilities, their families, guardians and caregivers. We look forward to continuing to work with the Committee on our shared goal of supporting the needs of the community, especially during this unprecedented pandemic.

Sincerely,

Carole Johnson
Commissioner