COMMONWEALTH OF PENNSYLVANIA
HOUSE OF REPRESENTATIVES
HUMAN SERVICES COMMITTEE

IRVIS OFFICE BUILDING
ROOM G50
HARRISBURG, PENNSYLVANIA

PUBLIC HEARING
CHOICE OF A FULL CONTINUUM OF CARE FOR
INDIVIDUALS WITH DISABILITIES

TUESDAY, APRIL 30, 2019
9:02 A.M.

BEFORE:
HONORABLE GENE DIGIROLAMO,
MAJORITY CHAIRMAN
HONORABLE JOE HOHENSTEIN,
ACTING MINORITY CHAIRMAN
HONORABLE STEPHANIE BOROWICZ
HONORABLE BARBARA GLEIM
HONORABLE JAMES GREGORY
HONORABLE DOYLE HEFFLEY
HONORABLE JONATHAN HERSHEY
HONORABLE MIKE JONES
HONORABLE NATALIE MIHALEK
HONORABLE LORI MIZGORSKI
HONORABLE TOM MURT
HONORABLE ERIC NELSON
HONORABLE TODD POLINCHOCK
HONORABLE JAMES STRUZZI
HONORABLE TARAH TOOHIL
HONORABLE DANILO BURGOS
HONORABLE ISABELLA FITZGERALD
HONORABLE KRISTINE HOWARD
HONORABLE MAUREEN MADDEN
HONORABLE DAN MILLER
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SUBMITTED WRITTEN TESTIMONY

* * *

(See submitted written testimony and handouts online.)

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Brenda J. Pardun, RPR

Reporter, Notary Public
MAJORITY CHAIRMAN DIGIROLAMO: Nine o'clock, we're going to get this hearing underway.

And I would like to call this meeting or hearing of the Human Services Committee to order. And if I might ask everyone to stand for a Pledge of Allegiance.

(Whereupon, the Pledge of Allegiance was recited.)

CHAIRMAN DIGIROLAMO: Okay. Thank you all for being here today. I think we got a really, really important meeting to examine as full continuum of care for individuals with all types of disabilities. Really important issue.

And I thought I might just start out, instead of taking roll call, let everybody, members that are here, just give them the opportunity to say hello and let you know where they're from.

And, Lori, I'll start out with you.

REPRESENTATIVE MIZGORSKI: Good morning. My name is Lori Mizgorski. And I represent the 30th District, and that is in
Allegheny County.

REPRESENTATIVE MIHALEK: Good morning. I'm Natalie Mihalek. I represent at 40th District. It's parts of Allegheny County and Washington County.

MAJORITY CHAIRMAN DIGIROLAMO: Good morning, everyone. Gene DiGirolamo, from Bucks County, 18th Legislative District.

REPRESENTATIVE TOOHIL: Good morning, everyone. State Representative Tarah Toohil, Luzerne County. White Haven Center is right on the edge of my district, after redistricting.

REPRESENTATIVE BOROWICZ: Good morning. 76th District, Stephanie Borowicz. And I cover Clinton and part of Centre County.

REPRESENTATIVE FITZGERALD: Good morning. Isabella Fitzgerald. I represent the 203rd District in Philadelphia, West Oak Lane, East Oak Lane, and the lower northeast.

REPRESENTATIVE MURT: Tom Murt. I represent part of Philadelphia and part of Montgomery County.

REPRESENTATIVE MADDEN: Good morning. Representative Madden, representing Monroe
REPRESENTATIVE STRUZZI: Good morning. Jim Struzzi, 62nd District, Indiana County.

CHAIRMAN DIGIROLAMO: Okay. With that, just a couple quick ground rules.

We are being recorded so the cameras are on. I'm not sure. I hope PCN picks up the hearing and broadcasts it because it's a really important issue.

And the way we're going to conduct the hearing is we're going to let everybody testify first, and then, with the time we have remaining till 11 o'clock or a little before 11:00, we'll open it up for questions and answers. So, when you testify, if you can please stick around. We might have some questions for you.

We do have to be finished before 11 o'clock. We are not allowed, by our House rules, to go past 11 o'clock when we start session. So, a few ground rules.

And with that, we'll have our first testifier, Susan Jennings. And her topic is going to be keeping intellectual disabilities
Susan, you can begin whenever you'd like. And I would ask you to try to talk as close into the microphone as possible so everybody can hear. Thank you.

MS. JENNINGS: Thank you, Chairman DiGirolamo.

And thank you to the members of the Human Services Committee for allowing us a platform to speak.

My name is Susan Jennings, and I am one of the founding members of KIIDS, Keeping Individuals with Intellectual Disabilities Safe. We are a grassroots organization of parents, friends, families and advocates. And some of you have met us before when we came to lobby against HB 1650, which would have eliminated the services our loved ones so vitally needed.

And I'm proud to announce that we held a petition drive. We pounded the pavement. We gathered ten thousand one hundred twenty-three signatures in the space of about two months, which we will present to you later today in this hearing.
I am the mother of an autistic child named Joey, who found a wonderful quality of life and safety in one of our treasured state developmental centers, White Haven state center, after three years of suffering in the community.

My advocacy stems not only from my own son's residential experiences, but also because there will be a tsunami of young autistic adults entering the system who will be denied much needed care and the care that is appropriate for them because of an outdated, unrealistic deinstitutionalization ideology.

Group houses in the community were the only services offered to my son. His behaviors are severe. He could not be managed safely in the community. He was discharged from six different group homes. They section 302'd him into five different psychiatric wards. They tried to put him in a chemical straight jacket with powerful psychotropics, which backfired, and his life became a living hell.

Then we discovered the existence of
the intermediate care facilities, the state --
the Pennsylvania state developmental centers.
But we ran into a brick wall. And that brick
wall was the policy of closed admissions. In
order to enter a Pennsylvania state
developmental center, a -- [inaudible] --
developmental programs.

We took them to court. It cost us
thousands of dollars. It cost the taxpayers
thousands of dollars. And we won, all the way
up through the commonwealth level, based upon
the merits of our case. But no parent should
have to go through that.

The thing that hurt me the most was
that bureaucrats who are tasked with helping
my son were the ones who were battling us to
prevent him from getting the type of
environment and living situation that was
right for him.

Legal fees would be out of reach for
many of parents. And so, their children
languish on the waiting list.

The deinstitutionalization advocates
with advanced degrees who do not have the same
challenges as our parents with severe autism
and with medically fragile conditions are vexing because they would deny our children the right living situation for them, even if it's not something they would chose for themselves or their loved ones.

The need for appropriate housing is vast and growing. The CDC announced in 2018 that one in fifty-nine births would be an autistic child. Over the next decade, five hundred thousand of those autistic children will become adults. And there's nearly four hundred twenty-four thousand today on the waiting list for residential services.

We want to alert the new policy makers and new lawmakers to the systemic concerns we have with community group houses in the community and other -- those other types for the severe and profoundly disabled. The deinstitutionalization ideology denies the reality of their specialized needs and what kind of care.

Breaking up the institutions was done without -- without considering the ramifications of separating vulnerable people from specialized care and without considering
that you are eliminating a critical safety net for those people.

And it's been already officially acknowledged that a joint report from the Health and Human Services from the Office of the Inspector General, from the Administration for Community Living, and from the Office of Civil Rights acknowledged that group home beneficiaries are at risk of serious harm. It is a systemic problem. And we will go into why it's a systemic problem.

Additionally, you may have all seen the media exposes of abuses, particularly in Philadelphia, with the group homes there, the Blossom group homes, and media exposes all across the country, which, as Dr. David Mandell, who's the director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania, said, Small, diverse settings are often not up to the task of caring for individuals with more profound impairments.

And here's just a small sampling of -- for example, Nowhere to Go series. Young people with severe autism languish weeks
or longer in hospitals. And that's what
happened to my son.

And what happens is, when the group
homes are unable to safely manage the care,
then the profoundly disabled are shuttled back
and forth from one dangerous setting to
another, from community group houses to jails,
from community group houses to hospitals, from
community group houses to the street, from
community group houses to nursing homes and
back again. They have no safe haven. They
have no consistency. They have no stability.
They have only pain, fear, and trauma. And it
strips them of their dignity as human beings.
And that's why we entitled this Open the Doors
to Dignity.

And you may say to me, But
institutions, they cost too much. Actually,
we're spending far more on escalating prison
and court costs and inpatient
hospitalizations. Large institutions are, in
most instances, less expensive than community
residences for challenging populations.

The closure advocates play a shell
game with the legislature and with taxpayers.
It's called cost sharing. The community group homes are not all-inclusive. They rely upon other bureaucracies to pick up the costs that they don't. And when they cannot manage severe and challenging cases, they turn to police, the courts, the jails, the hospitals. So, while the cost for the Office of Developmental Programs looks like it's going down, the cost to the taxpayer and to you legislatures is going up for police, for courts, for jails, for hospitals, for psychiatric wards, and for emergency services.

The deinstitutionalization advocates insult our intelligence when they tell us that you can -- you can care for our people at less cost in some small, scattered diverse settings. But we know, from common sense, that businesses do not react this way. There's cost savings in consolidation. They do not house each executive in a separate building. It costs more to heat, build, light, and maintain thousands of small, diverse settings.

The deinstitutionalization advocates also tell you that, if you take -- if you rob
the money from the institution for the community waiver services, you will eliminate the waiting list. This is demonstrably false.

Eliminating the state centers will not eliminate the waiting list. Opening the state centers will eliminate the waiting list.

As you can see -- and I'll let you look at this at your leisure, a hundred ninety-six million more dollars were poured into the community with the community waiver services. That is actual fifty-eight million more than the entire state developmental center budget cost. And yet, they only decrease the waiting list by thirty-nine people. That is a disgrace.

So, they will also tell you that if you just put enough money in community waiver, they can do everything that the -- that the institution can do, that the intermediate care facilities can do, and that's just not true.

Here are the systemic shortcomings. Group home businesses have to make a profit, so they delegate front-line care to inexperienced caregivers with negligible training and minimal supervision. This is a
cost-cutting combination that leads to harm.

There are no supervisors on the premises. There are no clinicians on the premises. There are no doctors or nurses.

In a nursing home or an ICF, they're required by law to employ on-site registered nurses. Not a group home. Any nonmedical personnel can handle the drugs and is supposed to recognize the daily crises and emergencies that our folks have.

Additionally, the noncontiguous rule, in order to meet community group home regulations, group homes must be located a certain distance from one another. Consequently -- and I have ridden in the car with supervisors of group homes -- they spend the entire day driving from one group home to another. What do they not do? They don't interact with the staff. They don't interact with the residents. And the rest of their day they fill out paperwork. So, there is minimal supervision.

Front-line caregivers are expected to handle life and death situations on a fast-food budget -- on a fast-food wage. This
is why you have staff shortages. This is why you have 30 to 70 percent staff turnovers, because you're asking too much for too little. In addition, because you are unwilling to provide a therapeutic environmental or skilled training for the aides, you have -- you have to rely upon psychotropics as a chemical straight jacket, which is brutal and inhumane to the patients.

So, what we're asking for is that -- that the legislature -- that you pass legislation opening the Pennsylvania state developmental centers to admission; you reverse the closed admissions policy; you invest and promote a wide range of residential service options, to include farmstead, homesteads, villages, campuses, and ICFs; and that you sponsor an objective, independent cost study on what will happen if this deinstitutionalization is carried out; and to stand with us, the voters and the families who are battling for the safety, health, and welfare of our loved one against powerful organizations who are promoting an unrealistic ideology.
The answer to this problem was codified in the supreme court decision Olmstead, when they said, quote, But we recognize as well the state's need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities and the state's obligation to administer services with an even hand.

You have heard, ad nauseam, the hallmark propaganda phrase "everyday people, everyday lives." Well, I have a new one, I have a new quote, "real life, real people, real suffering, and real consequences," when deinstitutionalization takes place.

People -- and then I'm going to end with a quote from ethics professor Dominic Sisti said: People really do deserve the best care that suits them. I don't see how that's even debatable.

Thank you.

CHAIRMAN DIGIROLAMO: Susan, thank you for your testimony.

And, next, we have of panel of four people who are going to testify. I'd ask them to come up. I think we have the chairs up
front. Dr. Lee Wachtel, who's a psychiatrist at the Kennedy-Krieger Center; Hugo Dwyer, executive director of Voice of Reason; Amy Lutz, who's the president of EASI, National Council of Severe Autism. And I believe we have one testifier who's going to testify via Skype, and that's Dan Torisky, who is the past president of the Autism Society of America.

Is that all set up to Skype now?

Okay. It's all ready to go.

And before we get started, there's some more members that have come in, and I'd like to give them a chance to say hello and let you know where they're from.

Joe.

REPRESENTATIVE HOHENSTEIN: Joe Hohenstein, 177th District, which is northeast Philadelphia.

REPRESENTATIVE BURGOS: Good morning. Representative Burgos, Philadelphia, Temple Hospital area.

REPRESENTATIVE POLINCHOCK:

Representative Todd Polinchock from the 144th, central Bucks County.

REPRESENTATIVE HOWARD: Hi. Kristine
Howard, from the 167th, Chester County.

MAJORITY CHAIRMAN DIGIROLAMO: Okay.

I think we are ready. So, Lee, I guess when you get started.

MS. JENNINGS: I'd like to introduce Dr. Lee Wachtel, medical director at the Kennedy-Krieger Center.

DR. WACHTEL: We are going to switch the order. No problem.

Good morning. Thank you so much for having me here with you this morning and for giving me the opportunity to speak from the physician's perspective on behalf of a very expanding group of individuals who don't have the capacity to advocate for themselves but whose needs demand our immediate attention.

I was just wondering the same, if this is working well. Okay. Is that better? Sort of. Okay. It's seems -- it didn't seem right.

So, I'm a psychiatrist. And I specialize in the care of youth and young adults with autism and other neuro developmental disabilities, often in tandem
with intellectual disability, ranging from mild to profound.

I'm the medical director of the neurobehavioral unit at the Kennedy-Krieger Center Institute, which is in Baltimore, Maryland. And I run an inpatient service. So, the neurobehavioral unit is an inpatient service dedicated to the care of children and adolescents who have neuro developmental disability who present with what are known in the field as challenging behaviors. That typically includes behaviors that are either self-injurious, aggressive, or disruptive, and often times in combination with each other.

My unit services patients from across the United States and from overseas, and typically represents what is known somewhat affectionately as the end-of-train line for individuals who present with the most horrific, intractable behavioral presentations that have literally brought their lives and the lives of their families and caregivers to a grinding halt.

My patients, if you will, are the ones who have hit themselves in the head so
many times that they've caused retinal detachment, traumatic cataracts, and concussions, whose bodies may be covered in open wounds or wounds that are various stages of healing and scarring, who have sent caregivers to the emergency department in the aftermath of assaultive behaviors, who live in full-body protective equipment with large in-home workers or exhausted parents attempting to simply block their most dangerous behaviors and live to see the next day without another medical crisis, a fruitless call to help -- for help to the police or ambulance or emergency service or a useless trip to the emergency room to only be told that nothing can be done to help them.

These kids and their families are really the black sheep of the autism and disability community, and often don't have a place at the table in autism advocacy circles as they don't really represent the currently popular neuro diversity movement where everybody is just a little bit autistic and autism or developmental disability are presented as gifts to be cherished and
embraced, rather than major health concerns
that no parent in his right mind would choose
for his child anymore than he would choose for
his child to have cancer or organ failure.

In fact, if you discuss the alleged
gift of autism with most of the parents I see,
they'd probably suggest that you take it
outside so they can punch you in the face, or,
perhaps more charitably, ask if you'd like to
come and live at home, wear protective
equipment worthy of an ice hockey goalie,
sleep maybe two or three hours a day, clean up
blood, urine, feces, and vomit as it
accumulates around your house, while you also
try to take care of yourself, the other kids
living in your home, and maintain employment,
so you can keep the electricity and water on.

The fact of the matter is, in the
real world, that people exist on the entire
range of the autism and neuro developmental
disability spectrum, including those who
aren't nice to see and who don't represent
what every parent with a toddler who's just
received an autism, Down syndrome, or other
development disability diagnosis is hoping to
have twenty years down the road.

These people are citizens of your state, citizen of the United States and the world beyond, deserve our care just as much as those on the much higher-functioning end of the spectrum might need special initiatives so they can be mainstreamed in classrooms, participate fully in sports and community activities, or attend universities with necessary supports.

Helping those at the most dire end of the spectrum neither obfuscates or negates assistance or attention to the less-afflicted end of the spectrum.

So, I've mentioned that I work largely with youth or people under age twenty-one, but I'm really here today to speak on behalf of all the severely afflicted children in my career who've already become adults and those who are heading into adulthood.

A lot of resources are focused on children with disability, but at the end of the day, these children are going to spend a much greater percentage of their lives as
adults with disability, and most likely are
going to have the same degree of impairment
and associated needs as during their
childhoods. Only, as adults, now they are
faced with aging parents, diminished
resources, and programming options, as they no
longer qualify for school services, diminished
safeguards such as substituted decision-making
from parents or appointed proxies, and often
most importantly, an all-too-frequent lack of
quality, safe, and meaningful living options.

This is a public health concern for a
segment of our adult population that can't be
dismissed simply because their challenges
don't warm our hearts in the same way that the
story of the autistic adult who ran the Boston
Marathon in two hours and forty-six minutes a
couple weeks ago might.

So, "choice" is a key word in the
adult disability world and is often invoked
with more than one false notion. First, that
everyone with a disability would necessarily
make the same choices as those on the
higher-functioning end of the spectrum. And,
secondly, that everybody is capable of making
an informed choice.

The fact of the matter is that, while some autistic adults can engage in discussion and analysis of living options, there are others whose ability to choose doesn't extend beyond choosing between an M and M or a Skittle as a reinforcer. While some adults with disability could manage basic household tasks and take a bus to work, others can't toilet themselves or brush their teeth independently. And some continue to engage, throughout their entire life span, in very dangerous behaviors that are a function not only of their disability but the frequent comorbidity of additional psychopathology.

These might not represent politically correct statements, but they do represent the hard truth, and PC behavior and fantasy thinking can't change biology. Regardless of the severity of said biology, every one of these individuals should still have access to safe and dignified adult living solutions, as they transition away from the primary childhood home -- because truly, no one can live at home forever -- solutions that allow
for meaning and joy according to each person's unique attributes, challenges, and potential.

I urge you to listen carefully to the families and other providers who speak here today on behalf of those who'll never have their own voice in this chamber and move towards meaningful change to better their lives and those of the families who hold them most dear.

Thank you.

CHAIRMAN DIGIROLAMO: Okay, Doctor.

Thank you.

And, Hugo, whenever you're ready.

MR. DWYER: My name's Hugo Dwyer, and I'm the executive director of VOR. We're a national nonprofit, started thirty-six years ago in Chicago. Our original name, back in the days before we stopped using the "R" word, was Voice of the Retarded, because that was the operative word. We took that out. We changed it. Now, we are A Voice of Reason, but we still are the ones who speak up for people with intellectual and developmental disabilities.

I need to talk louder? I'm trying.
I'm not a loud talker. It's probably -- is that better? There we go. I was going to say, it's probably not the microphone. It's probably me. I'm not a loud talker.

Thank you all for being here today. I'm hoping that you are here with open minds, trying to figure out how to deal with the problem that we've never really dealt with correctly. For centuries, we treated everybody with any level of developmental or intellectual disability like they needed to be cast aside, warehoused, kept out of major -- regular society and so on.

In the '60s, we got a more enlightened attitude, maybe we can treat these people, maybe some of them are able to integrate into society. We created group homes. We started doing more therapy for people. We created ICFs, which instead of an institution that just warehouses people, was more like a hospital, and it treated people as treatable patients. And the residents were given protocols for care and so on.

Our opponents still like to refer to us as institutions. They like the idea that
if they call us an institution, it brings --
it evokes the memory of warehousing
facilities. A modernize ICF is nothing like
the old Pennhurst, the old Willowbrook. It is
much more like a treatment center.

But starting, I guess, about twenty,
thirty years ago, we sort of overshot.
Instead of treating everybody like they
belonged in a warehouse and then moving
towards let's try these other things, we took
the success of the higher-functioning people
in group homes and said, Hey, this is working
for them. Let's do it for everybody.

So, instead of having everybody in
warehouses, now we're trying to put everybody
into inclusive environments. That's not right
either. This is a wide spectrum of people
with a wide range of abilities and
disabilities, needs for different levels of
care and treatment. And until we accept that
fact, we're never going to get it right.

We need more money for services,
because at the time being, we've got people on
one end of the spectrum fighting for the same
piece of the pie that other people on the
other end of the spectrum are trying to get. We've got people who are left out of the kitchen and can't get a piece of the pie. We have to figure out a way to help everybody. And the way you do that is you make a more efficient, more effective system.

The people with higher needs are always going to cost you more money. That's -- I think you can all figure that one out. So, no matter whether you put them in a group home or an ICF, they're going to cost you more. The difference is, if it's the right facility, you are going to save money. If it's the wrong facility, you're going to be wasting money. So, let's get this right.

I have a brother who's sixty-two years old. Dr. Wachtel described him fairly well. He had self-injurious behaviors. He banged his head all the time, detached a retina. He's got pica. So, if you have anything loose, he will pick it up and put it in his mouth. He is in a special cottage for people with pica. They can't wear clothing with buttons on them, because buttons might fall off and get picked up.
And he had a roommate at one time, who left and went into a community, a special pica group home, with four people and two caregivers. One caregiver was late for his shift. One of the residents was acting out. The caregiver looked after the resident who was acting out, and my brother's ex-roommate, Larry, swallowed a hot dog and choked to death three weeks after starting at this home.

So, you get the care in a larger facility. It is a higher level of care. I truly believe my brother would not be alive if he had been in a different, less -- lower-monitored environment.

His best friends are his caregivers. They -- you know, it's not just because they're hired to do it. It's a calling for them. They want to show up to work. They want to try to relate to Tom. They want to speak with him.

He has -- over the years, he's had one or two caregivers who really can get through to him and ask him to do things and he will do them. You know, whether it's trying to brush his teeth -- which he still doesn't
do very well -- or pulling up his pants after toileting. One or two people can get through to him and get him to do that, and others have a harder time. This is Tom. This is what it is.

But if you were to take Tom out of the ICF and put him with only one or two caregivers and people who haven't been exposed to Tom for very long, maybe worked there for six months or a year -- because the turnover rate in group homes is very high -- you're isolating him. You're not integrating him. If you want to integrate people, you've got to -- have to do it with people you can integrate. Tom is not one of those people.

You know, in the deaf community, there was an effort to integrate people in with hearing people. And they'd put them into classrooms with hearing people and so on. And they found right away that what they called the lease restrictive environment wasn't working because these were people who couldn't communicate by anything except American Sign Language. So, they stopped doing that. They put them in what they called the language rich
environment, put them with others like them who they could communicate with, and they all thrived.

So, they made an exception for one disabled population to do what was best for them, and it worked. And we're asking the same for our population. They don't integrate well. But they do thrive in a certain environment. They're not isolated. And this is, you know, the best way to do it.

The elderly community, they're free to choose among their peers, in the elderly communities, retirement communities, assisted living communities. We encourage this. We promote this. And these facilities are designed to take care of people who are aging. We should do the same with our kids and ICFs.

When your kids go to -- finish high school and go off to college, you're probably going to put them all into a dormitory. And these are not the least restrictive environments. And God knows, you don't necessarily want your kids to leave high school, go into college and be in the least restrictive environment. You want
protections. You want to know that somebody's looking after them, that they're in an environment that's geared towards their needs.

The only time we don't do this is with people with I/DD. We've decided that the least restrictive environment is right for everybody. We've decided that integrating into society of nondisabled people is right for everybody. It's right for some. It's not right for everybody. We can't look at this community as if what's right for one person is right for everybody. But that's what we've been doing.

This -- the people who want to do that refer to Olmstead, which Susan brought up earlier, as a integration mandate. They say that it mandates integration into the community. It does not. It offers that -- it offers a pathway for those who want it, but it's actually a very balanced decision. There are several key provisions that determine whether or not people can go in.

Which slide are we on? Go back one. First slide.

Supreme court recognized the need for
states to maintain a range of facilities for
the diverse needs of people with developmental
disabilities. They wrote: Unjustified
isolation, we hold, is properly regarded as
discrimination based on disability. But we
recognize, as well, the states need to
maintain a range of facilities with the care
and treatment of persons with diverse mental
disabilities and the state's obligation to
administer these services with an even hand.

And they went on to say: We
emphasize that nothing in the ADA -- American
Disability Act -- or its implementing
regulations condones termination of
institutional settings for persons
unable to handle or benefit from community
settings. Nor is there any federal
requirement that community-based treatment be
imposed on patients who do not desire it.

So, in these two paragraphs, they
recognize the need for both types of
facilities and they maintained that. They
went on to say that they have a need for
standards, determining the appropriate level
of care: Consistent with these provisions,
the state generally may rely on the reasonable assessments of its own professionals in determining whether an individual meets the essential eligibility requirements for habilitation in a community-based program. Absent such qualification, it would be inappropriate to remove a patient from the more restrictive setting.

So, what -- they weren't talking about having legislators or people in agencies, government-funded agencies, make these decisions. They were talking about having the health care professionals who deal with our loved ones make those determinations. And they said that they should make those determinations based on a three-pronged program.

Under Title II of the ADA, states are required to provide community-based treatment for persons with mental disabilities, one, with the state's treatment professionals determine that such a place is appropriate; two, the affected persons do not oppose such treatment, and that includes parents and guardians as well as the affected person;
three, that the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.

So, it's -- there's a real balance here that you probably will not hear from the people who just say that Olmstead is all about integration.

The justices, in their majority opinion, concurred that, As already observed by the majority, the ADA is not responsibly read (sic) to impel states to phase out institutions, placing patients in need of close care at risk. Some individuals may need institutional care from time to time -- [coughing] -- excuse me -- to stabilize acute psychiatric symptoms.

Here we go.

For other individuals, no placement outside the institution may ever be appropriate. For these persons, institutional settings are needed and must remain available.

So, that's the law. That's federal supreme court decision.

They went on to say it would be --
Justice Kennedy went on to warn about the possibility of tragic consequences for ICF residents if this is misinterpreted. He said:

It would be unreasonable, it would a tragic event then, were the Americans with Disabilities Act of 1990 to be interpreted so that states have some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision. In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, states may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.

So, again this is the federal law.

This is one of the things you've got to keep in the back of your mind as you determine how best to treat the population of individuals with intellectual disabilities in Pennsylvania.

So, in spite of the supreme court's
ruling in Olmstead, several states have closed their intermediate care facilities. What happens to those who do not transition successfully? Does anybody know?

Well, one thing that happens is they die. There is a thing called transfer trauma or relocation stress syndrome. A lot of people just die within six months of moving from an old-term home -- long-term home into a new setting, no matter what the setting.

But, beyond that, sometimes it gets worse. That happened in Georgia, when the justice department forced the closure of all the state's ICFs. They moved really quickly to shut everything down, moved people into group homes. And in 2013, five hundred people died in community care while under the auspices of Georgia Department of Behavioral Health and Developmental Disabilities. Eighty-two were classified as unexpected deaths, including sixty-eight who were developmentally disabled.

In 2014 -- because they stopped the program and restarted it -- so, in 2014, an additional four hundred ninety-eight people
who were receiving community care died,
including a hundred forty-one who were
considered unexpected deaths.

So, that's an example of really doing
it wrong.

The other way -- [coughing] -- sorry.
I'm not used to talking much.

The other consequences of people who
are not receiving the right level of services,
if -- when a state closes all its ICFs, the
state is sometimes forced to move people into
other states and use their ICFs. This has
happened in New York, New Jersey, Indiana,
Oregon. You're moving people away from their
families, from their caregivers. You're
moving them away from the state being able to
look after them and have any monitoring of
them. The monitoring decreases. You're
saying, Okay. We'll let the recipient state
do the monitoring. And they may; they may
not. In many cases, they haven't.

Other times, people wind up in
nursing facilities that offer no treatment,
and they're not really equipped for people
with I/DD. Or they wind up in emergency rooms
for extended stays.

There was a case of somebody in Connecticut who was there for six months because no group home could take him. The ICF was closed to admission. They didn't have a plan for this person. And, of course, they wind up in prison, because they're in an inappropriate care, and they escape, they act out against police. Sometimes people have been killed. There was a child killed for acting out in a movie theater recently, about a year ago. This is most common with people who have severe autism with tendencies towards violent behaviors.

So, among those who failed to adapt to a group home environment, we see that the results are either death or moving from an appropriate institution, an ICF, to an inappropriate institution, an out-of-state facility, a nursing facility, an emergency room, or a prison.

A better solution would be to preserve your intermediate care facilities in Pennsylvania. Invest in them. Make them better. Improve the scope of their offerings
so that they meet the needs of those not
served in the group home system.

Thank you for your time.

MAJORITY CHAIRMAN DIGIROLAMO: Good.

Thank you.

Some other members have come in, so
I'd like to give them an opportunity to say
hello.

Doyle.

REPRESENTATIVE HEFFLEY: Thank you,
Mr. Chairman. Doyle Heffley, state
representative, 122nd District, Carbon County.

REPRESENTATIVE NELSON: Thank you,
Mr. Chairman. Eric Nelson, 57th District,
Westmoreland County.

REPRESENTATIVE GREGORY: And thank
you. Good morning, Mr. Chairman. My name is
Jim Gregory. I represent the 80th District in
Blair County.

Thank you for being here today.

CHAIRMAN DIGIROLAMO: Thank you.

Amy, you can begin when you're ready.

MS. LUTZ: Thank you. My name is Amy
Lutz, and I'm president of EASI Foundation,
Ending Aggression and Self-Injury in the
developmentally disabled, and a founding board
member of the National Council on Severe
Autism, which just launched in January.

Most importantly, I'm mom of a
twenty-year-old son, Jonah, who suffers from
severe autism, intellectual disability, and
epilepsy and was one of Dr. Wachtel's black
sheep that she references. And he spent a
year in -- almost a year inpatient at
Kennedy-Krieger when he was nine years old.

This is my second time actually
testifying before you. I was also here two
years ago to oppose the proposed change that
would have forced waiver recipients in day
programs to spend 75 percent of their time in
fully integrated settings, effectively closing
sheltered workshops.

I'm really happy to be back. And I'm
grateful to the committee for hosting this
ongoing conversation about the commonwealth's
most vulnerable citizens. Today, I'd like to
talk to you about residential policy. I'm
sure it's not news to you that nothing keeps
parents like me up at night more than panic
over where our severely intellectually and
disabled children will live when they leave home. I'm thrilled to report that some of the most exciting projects unfolding all over the country are responding to this critical concern.

In New Jersey, Arizona, Florida, even Arkansas and elsewhere, families are collaborating with providers, medical professionals, universities, and local businesses to build beautiful communities designed to meet the particular needs of individuals with severe intellectual and developmental disabilities and challenging behaviors like self-injury, aggression, elopement, and property destruction while, at the same time, ensuring that those behaviors don't preclude residents from enjoying a joyous and meaningful life. But that isn't happening here in Pennsylvania.

In fact, just last month, Kristin Biddle, the mother of a twenty-two-year-old son, Will, who is severely autistic and suffers from aggressive and self-injurious episodes that require five trained staff members to safely manage, sent a proposal to
ODP to build such a community. And I would say Kristin wanted to be here to participate in this hearing, but she just couldn't leave her son.

Her project, called the Lotus Mission, seeks to, quote, create integrated, sustainable, walkable communities of sixteen residents each that would serve the entire spectrum of adults with I/DD but were designed specifically for those with dangerous behaviors who require, as she writes in her proposal, quote, a more secure, autism-friendly environment in order to maximize their opportunities for community engagement.

These developments would feature a community center and a hydroponic greenhouse that would provide minimum wage jobs to those residents that chose to live there.

Keep in mind that Kristin was not asking the commonwealth to build these communities. The Lotus Mission would raise the funds for purchasing the property and constructing the buildings. She was just asking that residents be allowed to use their
waivers to live there.

    This is a perfect example of the kind of public-private partnerships that our overstretched system, with a waiting list of almost fifteen thousand, should be eagerly pursuing. Instead, ODP officials flatly rejected her proposal, noting that they would not approve any new residential setting larger than four people, unless the percentage of waiver recipients was restricted to 25 percent. Despite the fact that, as some of the other speakers have noted, no obstacles exist to building peer-specific communities for virtually any other population, such as seniors, veterans, college students, religious orders, et cetera.

    It's worth considering the reasons behind these standards. Doubtlessly, they are well intentioned, reflecting the horror we all felt following exposes of abuse and neglect at megasylums like Willowbrook and Pennhurst. But let's remember that Willowbrook had six thousand kids and a resident-to-staff ratio of forty to one.

    Kristin wants to build something that
houses sixteen people. This is how far we have shifted the definition of institution today.

So, today, inclusion advocates have, in a truly dazzling display of discursive slight of hand, re-defined "institution" to mean "any setting larger than four people."
From six thousand to four.

This not only defies common sense, but, as the National Council on Severe Autism argues in its position paper on residential settings, it, quote, imperils existing quality programs and sharply restricts the development of safe, robust, and clinically necessary programs and models.

Well, you might be thinking, surely inclusion advocates must have studies to back up such a draconian position. They claim they do, but the studies they point to are so flawed, so biased, that, in a review of the literature, David Mandell, who made an earlier appearance in this hearing, director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania, concluded, quote, Right now, our
decision-making regarding which types of placements to pay for and prioritize is based on values rather than data. Which is undoubtedly why CMS issued new guidance in January designed to ensure that adults with I/DD enjoy the same right to choose where and with whom they live that those of us without disabilities take for granted.

I used to say that adults with I/DD represented the only population that can't choose where and with whom they live until someone pointed out to me, actually, in some townships, convicted sex offenders also don't -- can't choose where and with whom they live, so -- but, still, I think my point is valid.

Gone from the guidance were the warnings that farmsteads, gated communities, and clustered group homes might be, quote, isolating or segregating. Instead of the physical characteristics of settings, CMS has adopted an outcome-oriented approach, recognizing that, as those of us who follow the 2017 Blossom scandal, in which the Philadelphia-based service provider of over
thirty community-based group homes was
stripped of its license due to, quote, gross
incompetence, know all too well, abuse and
neglect can and do happen anywhere.

Despite the fact that the data don't
support restrictive residential policies and
CMS no longer encourages that, ODP has refused
to budge, resulting in a residential policy
that is among the strictest in the nation. As
far as I'm concerned, when Arkansas has a more
flexible liberal policy about these things
than you do, you need to take a closer look.

We are asking you, our legislators,
to intervene. The I/DD population is
extraordinarily diverse, representing a broad
range of needs, impairments, and preferences.
A one-size-fits-all model of service provision
is not only absurd, but it is bound to fail.
And it has failed many times.

There are parents in this room today
whose children bounced from group homes to
emergency rooms to group homes to psych wards
and back to group homes, paying with their
unspeakable trauma for ODP's ideological
intransigence. They know that allegedly
inclusive settings like small group homes and
individual apartments can be the most isolated
and segregated of all for those with
challenging behaviors that require more
structure and more support than can be
provided in those environments.

We need to support a range of
residential options, from ICFs to intentional
communities to group homes to supported
apartments. This is the only way to honor
individual choice and person-centered
planning, principles that are supposed to be
at the core of disability service provisions
today. Choice is only meaningful if there are
options to choose from.

Thank you.

MAJORITY CHAIRMAN DIGIROLAMO: Okay.

Amy, thank you.

John, I know you need a couple
minutes to get set up, so we're going to pause
for a couple minutes so we can get the Skype
set up, but I know a couple other members have
come in, so if you want to say hello in the
interim.

John, want to say hello to everybody
and let everybody know where you're from?

REPRESENTATIVE HERSHEY: Sure. I'm
John Hershey, from Juniata, Mifflin, and
Franklin counties.

CHAIRMAN DIGIROLAMO: Dan.

REPRESENTATIVE MILLER: Dan Miller,
Allegheny County.

REPRESENTATIVE JONES: Mike Jones,
York County.

MAJORITY CHAIRMAN DIGIROLAMO: Barb,
good morning. Want to say hello to everybody
and let everybody know where you're from?

REPRESENTATIVE GLEIM: Hi. I'm
Representative Barb Gleim, from the 199th in
Cumberland County.

MAJORITY CHAIRMAN DIGIROLAMO: Okay.
I think we're ready. And we are going to have
Dan Torisky, who is the past president of
Autism Society of America.

(Whereupon, the attempted testimony
by Skype was unsuccessful.)

MAJORITY CHAIRMAN DIGIROLAMO: I
think we're going to bring our next panel up.
And that's Tom Kashatus, who is president of
White Haven Friends and Families; Irene
McCabe, President, Polk Center Friends and Families; and Trudy Sheetz, from Selinsgrove Center family member and KIIDS representative.

(Whereupon, a brief comment was made from the audience without the microphone.)

MAJORITY CHAIRMAN DIGIROLAMO: Thank you very much. We appreciate it. And I don't think we'll have to report them on our ethics statement when we fill it out.

Tom, if you want to get started, whenever you're ready. And try to talk as close to the mic as possible so everybody can hear.

MR. KASHATUS: I'm trying to relax a little bit, and I think I am because there's two of yous that I know. That's you and Representative Murt.

My wife and I are retired, and we're in our seventies. We had a good life, me a retired prison guard, she a homemaker. No regrets. Never took a two-week vacation. But we raised five kids, and we love every one of them.

I remember the story that you told us about your grandson.
Maria was our first. She is special, and she is my hero. Her story is attached to this testimony. It's in your folders.

Thirty Thousand Dollars, that's the title of my testimony. Why thirty thousand dollars? Because if most people, in their golden years, have to spend thirty thousand dollars, give or take a few bucks, within a short period of time on behalf of a loved one for disability services, they would probably be wiped out of their long-term and short-term savings, maybe even go into debt and be saddled with a payment for the rest of their lives.

However, I am here today to talk about a friend. And her name is Celine Nauman, of White Haven, PA. Whatever I have to say about Celine here, she read this and she approved of it.

To really appreciate her story, put yourself in the place of Mrs. Nauman. To the left is a photo of Mrs. Nauman. She's seventy-seven years old, same age as my wife, with her seven children. Jimmy is on her right, Danny is on her left. Standing from
left to right are Lisa, Marie, Billy, Beth, and Elsie.

Jimmy, a resident of White Haven Center, recently passed away at age fifty-four from complications, and so did Lisa, tragically, from cancer. That's all within the last couple months.

Danny, age fifty-six, and now a resident of Allied Services in Scranton, also suffers from I/DD and was being taken care of by Mrs. Nauman until that became impossible due to her health and physical limitations. Mrs. Nauman needs a wheelchair for mobility.

In January 2016, it became necessary that she needed help with Danny, and she began to pursue long-term care for him. From hers and Jimmy's experience with White Haven Center -- forty-seven years Jimmy was there -- she felt that White Haven Center would be the most appropriate placement for Danny. Her two boys would be close, and she could visit regularly -- she lives in White Haven -- and keep an eye on them.

Mrs. Nauman also had experience with I/DD self-advocates who lived in the
community-based living arrangement because she worked at REDCO day program in Hazleton. She was employed as a therapeutic service aide for fifteen years. She felt that their living standards, personal hygiene, diet, et cetera, was substandard, and she wanted better for Danny.

Unfortunately, upon onset of her new journey, Mrs. Nauman was pressured into accepting a group home called Keystone, in West Hazleton. There she witnessed -- she witnessed the verbal abuse, diet abuse, lack of active treatment, et cetera. Subsequently, she hired an attorney. At first, it was a difficult task to find an attorney to handle her case. Eventually, a 406 petition was filed in Luzerne County Court, because that was Danny's home of residence, Luzerne County, to start the process for court placement of her own choice, her own choice, at White Haven Center.

A judge was appointed. Counsels were set. Necessary data was collected, et cetera. In the meantime, Danny fell and broke an arm at Keystone and ended up in the hospital. For
recovery, Danny was sent to Weatherwood Nursing Home in Weatherly, a place not appropriate for anyone with I/DD.

This became a nightmare for Danny, as he deteriorated physically and emotionally.

If Danny was a resident at White Haven Center, recovery could have taken place there with full-time staff close by, twenty-four/seven close nursing care, one-on-one staffing if it was necessary, and a full-time doctor on duty five days a week.

Can everybody hear me? Thank you.

In the meantime, continued negotiations were pursued by the state to have Mrs. Nauman select a group home for Danny.

One thing for sure, the state of Pennsylvania has smart lawyers, who know every trick in the book to prolong a court case.

This became a long, drawn-out process, as the state and county caseworkers continued to insist that there were group homes available, and they were appropriate for the services that Danny needed.

After visual inspections, Mrs. Nauman saw none that suited her satisfaction for
Danny. For a number of reasons, postponements continued to surface, bills kept piling up, and finally Mrs. Nauman had to make a choice on whether to continue the White Haven journey for Danny.

In the end, due to financial restraints, Mrs. Nauman had to make a forced choice to have -- a forced choice to have Danny placed at Allied Service in Scranton. Now, regular face-to-face visits with Danny are, unfortunately and tragically, limited for a mother who was always there and close to her son since he was born, limited to telephone conversations, while a hundred fifty-seven certified empty beds for services, give or take, at White Haven Center remain empty.

Because of an unfortunate policy of leadership in the ODP and with the county human services, influenced by the Pennsylvania ARC and the DRP, Disability Rights of Pennsylvania, et cetera, advocacy organizations who receive tax dollars from all Pennsylvanians, I/DD citizens who are in need of services are told that ICFs are available for their benefit, but they are private ICFs,
such as Saint Joseph's and Allied Services of Scranton.

If someone knows that state centers exist and ask if they are available, they are strongly urged to look to a private facility, even the chance for a tour of a state center is frowned upon and very unlikely about to take place.

I'm almost done, guys.

Policy can be changed at the top, but that is unlikely if leadership could not see the light. It may have to take legislation to ensure that our most fragile citizens of Pennsylvania, whether in community-based living situations or institutions, to include state centers, are entitled to the Cadillac -- Cadillac of services, to have a quality of life that they deserve. "Cadillac of services," that came from a former facility director at White Haven Center. It made me cry when he said that.

Individuals and those who have guardians should be given the opportunity to select a venue of their choice, after a complete review of providers of services is
experienced, to include that of state centers.

I'm done. But I want to tell you something. Representative DiGirolamo, thank you. Two years ago, when you invited us into your quarters over there, you were respectful. You showed dignity for us and all. And we appreciate that.

Representative Murt, you wanted to come to White Haven Center after hearing -- I talked to him once before. You said you wanted to go there. You came there. You seen for yourself what White Haven Center is. I hope you were satisfied with your trip.

Tarah Toohil, she's always there, fighting for White Haven Center. We appreciate that. I see she left here.

After the last census, Tarah lost, lost the township, got moved someplace else, but she still fights for our facility up there. And we also appreciate that, too.

Thank you for your time. And God bless yous all.

CHAIRMAN DIGIROLAMO: Thank you, Tom.

And God bless you, too.

Irene.
MS. MCCABE: I'd rather do it without
a mic, if -- it's not too loud?

I wanted to say, I go back way far,
Pinehurst -- Pennhurst. Pennhurst, I'm sorry.
At Pennhurst, I remember Pennhurst. And I
remember the news anchor who was called in to
see it, and then they called the governor's
mansion. And they said, You've got to come
and see this. And they got Ray Broderick.
And he went over there in the middle of the
night. And he said, This has got to change.
And that was where he started. And
then a lot of good stuff happened at
Pennhurst. But, in the meantime, the
legislators said, We'll give you money to fix
up Pennhurst.

And then ARC said, We have a better
idea. Give us the money.

And that was a better idea. We're
talking back in the '60s. ARC was mainly -- a
lot of fellows who came back from the second
World War, they had the same amount of
retarded kids as anybody else, but those kids
were not allowed to go to school. They didn't
go to school.
And so, they came to the legislators and said, What can we do about this? So, what happened is, Ray Broderick then was a district justice, and he said, I know what I'm going to do. We're going to give the money to ARC.

And that happened fifty years ago, and that was the beginning of PAR, Pennsylvania Advocacy Resources. I think they're here in the room today, and they did present testimony. But what happened is, the legislators gave the twenty thousand dollars to ARC, and that started the public-private partnership. It's the oldest one in the state. It's the oldest one in the state.

And what we have now is we have with children -- children like my sister, who lives in a center happily -- she's been there for sixty-seven years. Here's her picture. She's as happy as she can be. But PAR, PAR takes care of eleven thousand residents. They take care of eleven thousand. And the centers take care of eight hundred.

So, if somebody's taking care of eleven thousand, and they do a great job and they're having a dinner, and you might be
invited and they're great, I have no argument.

Thank you. God, thank you, thank you. But my sister is very happy at Polk. Let her alone. Let her alone.

But you've got a market force thing happening, when eleven thousand people over here and nine hundred people over here, then, you know it's a market. They're a giant eagle; we're mom and pop. And they seem to not have anything nice to say about us. I can tell good things about us all day. But that's what the setup is. So, it's market forces.

One of the reasons why you hear that the institutions are not good is, that's coming from not the people in the institutions, not us. It's not coming from us.

I also wanted to remind you that at the same time that this was going on, the children couldn't go to school, ARC said, Let's sue the state.

And Tom Gilhool -- if you don't know him, he was a saint and an amazing guy in your history. And he said, Let's sue the state, saying that they have to be able to go to
school. And he was good friends with the guy who did Brown versus Board of Education. And so they got this brilliant strategy and they went to court, and they were only in there for two days, and the judge said, Done. These kids have to be able to go to school.

Life is funny. One of the ARC members had a job at the New York Times, and he told them what was happening, and two days, three days after the settlement, they ran an editorial in the New York Times, and two or three weeks after that every other state said, We're going to do that.

That case that started right here resulted in the land rock -- the legislation that said all kids could go to school. So, there is a rich, deep, profound history. And there are people at the department and -- and -- and alive now that have formed policy preference based on what they saw at Pennhurst, which is to say, when you're in part of something that's really important -- like, if you went to Woodstock, you just say you remember you were there and you say it. I'd say I was there, but it rained and we
didn't get there. But when you're part of something that important, it tends to infuse you.

So, what happens is, Nancy Thayer (phonetic), who ran the department for a long time, she even brought a young man home with her. A beautiful -- he's an older fellow now -- wonderful. She was there. She saw it. She believed it. You couldn't tell her she didn't see what she saw. She saw it. But it made her real doctrinaire. It made her real brittle. Made her, like, I know the better thing to do. So, I'm going to do the better thing. And she did do the better thing for a lot of people, but not for my sister. It was not meant for my sister.

So, as we have -- we have a -- kind of an inability to talk to ODP. You know, they talk about mission creep. So, you started out doing something, but now you want to do everything for everybody. So, we have kind of a mission creep issue there, that makes it hard for us to get recognized.

I will give you a -- Tom was talking about Allied. There was -- at one point, the
director said to Allied, You can't do that, whatever you're doing.

   And they said, Yeah, we can do it.

   They said, No, you can't do it. So, they went to court. And they said, Why are you doing this?

   And she said, That is my preference.

   And they said, But is it policy?

   And she said -- God love her -- she said, No, it's my preference. Which now has become the preference of ODP. Her preference is their preference in my opinion. In my humble opinion. Okay?

   So, the judge said, Preference is not the same thing as policy.

   So, sometimes when you're head of everything, you do what you think is the best thing. And I'm not saying it's not the best thing in some cases, but it was never the best case for what we wanted.

   Okay. Olmstead, the only thing you don't know about Olmstead, when it was passed, those of us who had loved ones in institutions, centers -- I call them institutions. I don't have any problem with
that. I have -- there's institutional awareness. There's institutional memory. There's a lot of good stuff to be said about institutions. You guys are an institution. You know, it's all right.

In any event, what happened is, those of us said, don't take my kids out of the shelter, and the judge said, Well, you have to go.

And we said no. And then we went to court. So, it took five years, a hundred thousand dollars. We were fortunate in that he got pro bono. It was very expensive. And the judge said, No, whatever. You have to leave.

And we said, We don't want to leave. We want to appeal.

And the judge on appeal said, No, you don't have to go. But that was -- and the state attorneys from the department were there, so the cost -- cost you guys a hundred thousand, cost us. At the end of it, we came up with something called a Benjamin settlement. Everybody in the department knows about the Benjamin Settlement. They know what
we believe. We spent five years, a hundred thousand dollars telling you what we want, and our opinions are dismissed like this. Just like this, like we're not even there.

I was just teasing Kevin. I saw him in the back. I said, How come you never answered any of my questions? They don't.

All right. In any event -- oh, when I became my sister's guardian, I was amazed the number of people who you have -- have as their mission the closing of Polk and White Haven and Selinsgrove and Ebensburg.

PAR has as their mission the closing of the centers, but that's market things. Disability Rights of Pennsylvania has as their second mission the closing of us. So, they're big. They're big. There's a lot of them. They have lobbyist. They're very important. We're just here to tell you now that -- that -- what we've been through and also warn you that it would be better if the department was a little bit more receptive to the individuals with severe autism. That's coming down the road.

So, in any event, I sent him a little
picture. It was like through the looking
glass. I had to stretch. I'm going to stop
now. That's why I'm kind of hot. I just
wanted to say it so badly.

I don't understand -- I honest to God
don't understand why they won't let us
function as caring people. I mean, this is my
sister. These are my family. And when I tell
you that I know what's good for her, I know
what's good for her.

I don't want the book about everyday
lives or whatever.

Okay. Then the last thing is, in --
the really last thing that I wanted to say is,
don't forget about that workforce. We have
eight hundred clients in the centers, but you
have got two, three thousand state employees.
They are the best people you've ever wanted to
run into. They are so good.

And my sister -- my sister is on her
third generation of family at Polk. They'll
say, Oh, Grandma had Karen over at North Side.
Okay? I'm just saying, I'm kind of a
psychologist kind of person or psychologist,
and you really value when people learn the
right thing to do. I call that institutional awareness. You guys have got, like, maybe four, five hundred years of institutional awareness.

Those who -- the Polk people have been there for more than a hundred years. So, that is -- that's resource. That really is a resource.

Whether you want to hold on to them and do something for autism, whether you want to hold on to them and do something, you know, for the I/DD population, that is enormous, enormous. And I value them very much.

And thank you. Thank you, thank you, thank you. Thank you very much.

MAJORITY CHAIRMAN DIGIROLAMO: Thank you, Irene. I also missed Woodstock.

MS. MCCABE: It rained.

MAJORITY CHAIRMAN DIGIROLAMO: But I hear they're going to have a second one, so maybe me and you can make the second one.

MS. MCCABE: I don't -- I don't -- it was testimony, so I wanted to tell the truth.

CHAIRMAN DIGIROLAMO: Okay. Thank you, Irene, for your very passionate
testimony. Appreciate that.

Trudy, begin when you're ready.

MS. SHEETZ: Thank you for allowing me to speak today. As sister and co-guardian of my brother at Selinsgrove Center and retired nurse in this commonwealth, I hope to educate the importance of the need to maintain our state regulated --

Is that better? Okay. Thank you.

Thank you for allowing me to speak.

I'm sister and co-guardian of a brother living at Selinsgrove Center and a retired nurse in the commonwealth.

I just would like to make you aware of the importance and need to maintain our centers. Selinsgrove is located in Snyder County. Initially, they purchased up to thirteen hundred acres. Today, it is only two hundred fifty-four acres and a population of two hundred twelve. In 1965, population was twenty-one hundred.

Today, residents ages twenty-three to ninety-five years there, many calling Selinsgrove home for more than forty years. They employ roughly nine hundred union
Residents living at Selinsgrove have varying levels of intellectual disabilities requiring extensive supports with daily living, social skills, medical care, and vocational training. The center provides twenty-four-hour-a-day medical services, on-site nursing, occupational and physical therapy, psychiatric, speech and hearing, recreational, and social work services.

They're actively involved in the community, and they make every effort to see that the people at Selinsgrove are in an environment maximizing the individual potential, ensuring their personal needs are met and regularly and thoroughly assessed.

Staff at Selinsgrove retire after twenty-plus years. It's the dedication, the work environment, and residents that keep them. They're not making big bucks, we know that. These are adult bodies with child-like mentalities. And what happens to the livelihood and businesses in the towns of nine hundred jobs if that closes?

My brother is sixty-five years old,
was born with cleft palate, which is an opening in the roof of his mouth. It was repaired at age four. He was admitted to Allentown State Mental Hospital mental retardation unit at age five, unable to toilet, feed himself, or communicate verbally. His behaviors became exceedingly overactive between ages four to five, showing amazing strength, able to upset things like TVs -- in 1950, they weren't light like today -- furniture, and attempts at trying to jump from second-story windows.

He was at Allentown until 1967, at age thirteen. They recommended that we put him in Selinsgrove in the ICF because they were geared more to the I/DD and the mentally challenged, so that they felt they could take him further than their MR unit was capable of doing. They were more advanced to handle the mentally challenged, some bodily deformed since birth, bringing them to the most potential on all levels.

Some of his diagnoses. He's schizophrenic, reaction to childhood mentality, two to four years. He's
sixty-five; mentality, two to four years, with profound mental retardation. Mood disorder NOS. NOS meaning "not otherwise specified", impairing but not fitting with any other specific diagnosis. Nonverbal verbalization, basically unintelligible. He does not express pain or discomfort but has a fear of unfamiliar surroundings. He has epilepsy seizure disorder and auditory processing disorder affecting his hearing ability.

Still today, when he gets upset and acts out, he begins to shake hands, bites himself, scratches, intentionally head bangs, throws himself into things with the intent of self-harm, property destruction, taking/hoarding others' belongings, or breaking/tearing his own and flushing it in the toilet. This may require at least two persons to intervene and redirect. He is not permitted to ride in a vehicle without at least two people present.

Selinsgrove has been prayers answered. Staff has reduced his self-abusive incidents, when he begins these things, from twenty-four to four or less per month with the
teaching skills and the professional care on
site, the love that Selinsgrove has provided
for the fifty-two years he's been there. He
leads a healthy, active, enjoyable life. He's
normal body weight. He had programing skills
Monday through Friday to keep his skills up to
date. He attends in-house and off-site
events, church weekly van rides. And he's
been able to live and progress with his
skills. We would not have been able to do
that at home.

Severe and profound mentally
challenged individuals are children in their
mental development, but they're grown adults,
with strength and determination of such when
upset and acting out, happening at any time,
without any known reason. They're like a big
kid having a temper tantrum for whatever
reason. Some times we don't know.

State ICF provide hallways between
living areas, allowing space to run the
frustration energy off. And if you're
familiar with severe profound autistic or
mentally challenged, many times they just --
they'll pop up out of a chair and they'll take
off. And they'll just want to run or do whatever. And they can at least take them to the back hall, where they have space to run. You can't do that in a small house or smaller setting.

Staff is there to provide individual interventions, walking, showering. Sometimes showering helps to calm them, redirecting, one-to-one needed at that moment, all of which is diversionary, helping to quell the behaviors, frustrations, or the temper tantrums while keeping them safe.

All right. For severe and profound, a lifetime of care is needed, programming weekly to maintain their skills, nurses and doctors trained with working with the residents twenty-four/seven, and monitoring their many medical issues. And most of them have more than one or two.

Overmedication for extreme behaviors is on the rise in community. And due to the brain deformity trauma of these residents, this may actually add to the increased behaviors because sometimes they don't work right. Okay. Physicians in state ICFs
specialize and know this. Medical services in 
community settings are on an on-call or 
as-needed basis.

With shortages in the communities of 
physicians trending, nurse practitioners and 
physician assistants are who many residents 
now see, hence lack of knowledge with the 
patient base. The poorest of the poor will 
ever be able to take care of their physical, 
medical, daily living needs or finances 
without twenty-four/seven professional care, 
are being sentenced to a life of neglect, 
abuse, and death.

Families with severe and profound 
mentally challenged over age seventeen are not 
being made aware of the state ICF centers, 
remaining on waiting list. Why?

Seven years I did home health 
nursing. I went into the community. One time 
I was administering insulin to a newly 
diagnosed diabetic. I told the staff, one 
staff person in a house of six, that that 
person needed to eat breakfast within the half 
hour. And they informed me that they needed 
to be on the bus in five minutes to go to the
work program.

And I said, well, they have to have breakfast. They can't do that. And you can't feed them for, like, twenty minutes to half an hour.

So, I called their management, told them the story. They allowed the person to get breakfast. But had I not instructed that and left, they would have put them on the bus, he'd have passed out on the way to the work program. He'd have required an ambulance to the hospital, all incurring more cost to the state for low blood sugar.

The flip side, I took care in hospital of twenty-two-year-old female patient that had been injured by a resident acting out. The ratio was two females to four male residents. And these were mild to moderately in a group home situation. The male resident acted out, the other staff person calling via phone, afraid to intervene for her own safety, awaiting help. The victim staff are punched and kicked, unable to get away. She stated, taking a fetal sitting position on the floor, attempting to protect herself, ended up in the
hospital with a fractured pelvis and extensive bladder damage.

Three urological consults later, told having children would probably never happen. And she also could be looking to have a suprapubic catheter, one coming through the front pelvic wall, for the rest of her life. Twenty-two years old. All pending questionable, inoperable damage sustained.
The patient did not wish to sue this resident. He didn't belong in jail. But did her employer provide a safe working environment?

Community placement requires the on-call person or emergency personnel to decide what to do, and that's allowing too much for physical injury, property damage, potential jail times, and sometime death, increasing costs incurred to the state because they couldn't sufficiently handle the behaviors that our ICFs know how to do. Remember, most have severe and profound mental deficits at state ICFs.

Abuse in Pennsylvania, I wish to educate on increasing abuse of our mentally challenged in Pennsylvania. Time doesn't
permit going into all the allegations and abuses, and, therefore, I will hit just a few.

Death of a female, 2016. They waited twelve hours to call an ambulance. Started on the evening of July 8th, at 7:30. She had trouble walking, nausea, vomiting. The program specialist said, Give her some water. Continued through the night with the poor ambulation, nausea, vomiting, and at 9 o'clock the next a.m., the program specialist or their supervisor instructed administration of medication instead of hospitalization.

Staff thought she fell asleep on the couch at 1:00 p.m. The program specialist or supervisor had not arrived yet to check, so they called 911 at 1:30. Emergency workers administered CPR upon arrival, and she passed away in the ER soon after.

A month prior, she was prescribed an antivomiting medication and regular blood sugar testing. Neither was received. On June 27, she had been told to stop lisinopril, which is a blood pressure medication, because her blood pressure was going too low. But they gave that up to the day she died.
Another female laying on the floor in a nightgown for four days, nurse practitioner stated she couldn't help, called the psychiatric nurse.

I need to wrap it up? Okay.

All right. Anyway, when the psychiatric nurse came, she was found that she was having flashbacks from rape. So, she was taken to the hospital, with pressure ulcers and bruises on her backside.

And since I need to wrap it up, the rest of it is in your notes so that you can read.

And I would like to say that I assure you, as often as you neglected to do it to one of these least ones, you neglected to do it to me. Matthew 25:45.

Thank you.

MAJORITY CHAIRMAN DIGIROLAMO: Thank you, Trudy.

John, do we have Dan? We're going to go to Skype now and hear Dan Torisky's testimony, who's the past president of Autism Society of America.

And, Dan, if you can hear me.
MAJORITY CHAIRMAN DIGIROLAMO: Okay.

You can begin your testimony. Welcome.

MR. TORISKY: I don't see a picture.

Is anybody else there besides you?

CHAIRMAN DIGIROLAMO: We have got a large group here, Dan.

MR. TORISKY: Good morning, people.

I'm here to describe a scary situation called CMS that threatens all of us. They're deeply embedded in a misguided governmental scheme who is, right now, stifling the rights of developmentally disabled individuals and their families. Simply put, the culprit is an entrenched governmental agency of unelected socialist reformers called Centers for Medicare and Medicaid Services, CMS, which has decreed -- decreed, mind you -- that our medical assistance tax dollars may no longer be provided. If the settings were delivery of necessary services to our loved ones are not community enough, the decree called the Final Rule -- move over, boy, I thought you were the only one that made final rules -- applies to all citizens where services are provided from
institutions down through living in centers of all types.

The most severely punished under this decree are the profoundly autistic and/or ID, once called mentally retarded, and their parents and family. These unelected CMS policy makers in Washington, through decree, intend to take away all service options available except the one they want us to have. Take away all the options and leave only one choice. This is totally antifamily and antifamily values, are the core underpinnings of our represented republic.

The outcome is the disastrous and can only get worse. These services and worker wages are already being cut, and this is totally across the board. CMS cohorts in Pennsylvania have already sent in Pennsylvania's plan to comply, for God sake. The final rule decree has the force of law. Our own analysis are the results that proves that necessary services for our people will become so costly in money and human suffering that would cause ultimate collapse of our entire health care system. It's thus
beginning.

Institutions were the primary cause of the CMS policy makers who fail to comprehend that unless all necessary services are available to our people under one roof, such as properly staffed and monitored institutions provide, very few of our differently abled -- got that? Differently abled -- loved ones can survive and thrive.

Further, unless in close proximity to one another so that services can be shared, not even group homes, the best group homes, and community-living settings of lessor intensity can survive.

Further exacerbating the situation are poor wages for those individuals providing care in this field. Proper services require properly trained individuals paid a living wage. Appropriate services, hence, overwhelm the tax dollars available to pay for them. Fewer and fewer people can be served, despite burgeoning budgets.

Until recently, all states had to submit a plan of compliance to CMS by a certain date, so CMS decided to take us on
state by state, regardless, the community-only
criteria, and had to be adhered to without
exception. So, nothing's changed.

Realistically, a community is not the
utopian environment that these socialist
reformers try to shove down our throats.
"Community" is a broad term itself, meaning a
combination of settings which we occupy
throughout life, job site, employed, living
with parent, self, family, or singly, three,
five, eight, and so on and so on. They're all
various communities in which we are living and
which we adapt ourselves and are supported and
adapting every day, sometimes several times a
day. These are communities.

The support mechanism is friends,
family, and providers. That's us. Because
the government's role really is to protect and
support us in this universal right to thrive,
which every human being has in the United
States, and it starts by cutting off the head
of this pervasive snake, namely CMS.

We are enraged that so very few
elected officials in our country perceive this
danger to our disabled loved ones in our
country. That's why we have to undertake a
campaign with other parents, groups, and
advocates, to enlighten our elected government
to crush the so-called final rule and its
crippling mandates.

This is the United States. The first
step, we hope, will be Pennsylvania
legislation stating that our commonwealth is
withdrawing its compliance to the CMS final
rule, pending further study. We urge your
assistance and support for us in this effort,
more to come, until one day, we pray, our
state will be able to join the other states in
our wonderful country in one voice to declare
that no developmentally disabled person left
behind.

Thank you. And God bless you all.

Pray for us.

CHAIRMAN DIGIROLAMO: Okay. Dan,
thank you very much for your testimony.

MR. TORISKY: All right. The full
extent of my speech is with the press table
out front. And if anybody wants to talk to me
or any of our representatives in this
campaign, we'll stay on Skype here long enough
to answer any questions that press might have
or anybody of you might have. Thank you.

CHAIRMAN DIGIROLAMO: Thank you, Dan.

And I'm going to call up our last
panel to testify, Mary Wills, who is ACE
president of the Ebensburg Center, and Patty
Degen, family member, with White Haven state
center.

Thank you both for being here. We
are a little bit pressed for time, so we have
about twenty minutes left for testimony. We
are going to have to forgo the
question-and-answer part, but if I could ask
each of you to try to keep it within ten
minutes each so -- we have to be done before
11 o'clock.

MS. WILLS: I'm going to make mine
very short.

MS. DEGEN: I'll cut mine down a
little bit.

MS. WILLS: I'm going to make mine
very short, because I'm not a speaker and you
have my whole story.

My name is Mary Wills. My
sister-in-law, Sandy Wills, is sixty-seven
years old and lives in a state center since she was ten. I'm also the president of the ACE association, which is a family and friends association from Ebensburg.

We are going to present the petitions to you today that we've collected. As we spoke to Pennsylvania voters at churches, festivals, businesses, and community gatherings to collect over ten thousand signatures on the petitions, which we have here today for you, and we can get more if you need to hear from more voters. We can go to the Internet. But these were all in person, one on one.

As we -- as the voters signed the petitions, they would often say, These state centers are needed because some of these people can -- cannot be taken care of properly in group homes. Most of the clients at the centers have lived there most of their lives. This is their home. It's not an institution. It is community living for the disable, the same as senior citizens community living to serve the needs of elderly.

The state centers can provide care
for many more without much cost, because the 
buildings and the services are already set up 
and able to serve many more. We have so many 
more life stories and reasons for why we are 
all here today. And we have only touched upon 
a few of the reasons in this limited time. 

So, we ask you to please take the 
time to visit an ICF, IID state center and see 
what we have to offer. It's going to be the 
only way you know what we're taking about and 
why.

We ask you to please let us have more 
input into this very important decision 
concerning the state centers' future and come 
see why we are fighting so hard to keep the 
state centers open and to guarantee this 
option to choose ICF, IID state centers. 

Thank you.

MAJORITY CHAIRMAN DIGIROLAMO: Thank 
you very much.

And I just want to let everybody 
know, Mary, about the signatures. I think you 
have ten thousand one hundred twenty-three 
signatures in the box that you delivered to 
me. And we're going to try to figure out what
is the best way to get these to the members of
the general assembly or where they need to go.
And I just want to read what they -- everybody
signed.

(Reading) Do not close the state
centers for the seriously impaired individuals
with autism and all intellectual disabilities.
The state centers are home to them. Because
of their intensive need, there is no safe
place in the community for them. The centers
serve them well, and it is their right to have
the home that meets their needs. The families
say no one else was able to care for my son.
My sister has been there for seventy years.
My cousin would be dead without center care.
I give thanks every day for the state centers.
The centers saved my entire family.

(Reading) I, too, am an advocate for
the care and the safety the centers provide or
I am a family member or friend or I'm a
concerned citizen, and I oppose the closing of
the centers. If passed, House Bill 1650 will
close public, long-term facilities, the
centers for persons with severe and profound
life-long intellectual disabilities, and take
the centers out of the service system.

And you're asking for a "no" vote on
House Bill 1650.

So, that's what we have here. Over
ten thousand signatures. I just want to make
sure everybody knows. And thank you. Must
have taken a lot of work to get this many
signatures.

MS. WILLS: It didn't take that long.
It only took us, like, three months to get
that many signatures. And we can go to the
Internet for a lot more.

CHAIRMAN DIGIROLAMO: God bless you
all for your hard work. Very much
appreciated.

And last, we have Patty Degen.

MS. DEGEN: Good morning,
legislators. Thank you for allowing me to
speak on behalf of my sister, Lauren Loxley
phonetic). She resides at White Haven Center
in an intermediate care facility and others
who are profoundly intellectually and
physically disabled who cannot speak for
themselves.

My name is Patricia Degen, and I'm a
retired I.T. specialist from the U.S. Department of Agriculture, a representative of KIIDS, Keeping kids -- Keeping Individuals and Intellectual Disabilities Safe -- and volunteer with PAWS, People and Animals Who Serve.

I visit White Haven Center regularly with Bella Mia (phonetic), a therapy dog. In the late summer and fall of 2017 and August of 2018, I secured a vendor spot for an information booth at five festivals in northeastern Pennsylvania for petition signing to vote no on HB 1650 to stop closure of intermediate care facilities in Pennsylvania and care for profoundly disable. We are proud to say ten thousand one hundred twenty-three signatures were obtained throughout Pennsylvania in a short time frame.

We believe there are many, many more Pennsylvania residents willing to sign our petition than not. We believe if we had done an online petition, we would have obtained millions of signatures from Pennsylvania residents.

While myself and others manned this
both, we encountered the following responses from festival patrons. Now, I have twenty-five responses listed, but I'm only going to go through a few because of time.

White Haven Center gives excellent care.

White Haven Center has been there for a long time.

Where would the individuals be moved?

Who wants to close White Haven Center?

I work or worked at White Haven Center.

The pictures of White Haven Center are amazing. It looks like a great place.

Are they allowing admittance to the facility? I am struggling to get help for my disabled child.

My child is autistic. I am on the waiting list to get help for my disabled child.

I'm from New Jersey. Can I sign the petition?

What can I do to help?

A few of the festivals have invited
us to return as an information vendor to
upcoming festivals to continue petition
signing. The profoundly disabled need to get
adequate care and be kept safe. All
facilities need strict guidelines, oversight,
and accountability. I repeat that. All
facilities need strict guidelines, oversight,
and accountability.

Closing White Haven Center and other
state centers denies needed care to the most
vulnerable segment of the intellectually and
physical disabled community. Come visit White
Haven Center and other state centers to see
the level disability and the quality of care
provided and you will agree is a need to
continue to support state centers in
Pennsylvania and open them to others in need.

One size does not fit all. A tragedy
can occur in any family, resulting in a
disabled individual. No one, none us here,
are shielded from it. It can happen by
complication in pregnancy, problems during
labor and birth, accident, virus, fever,
insect bite, illness, disease, toxins,
poisons, genetics, alcohol and drugs, et
cetera. Human beings who cannot care for themselves should be top priority over any other expense.

It is our hope to keep White Haven Center open and other facilities of its kind and reopen its doors as a matter of choice.

With that said, we present to you the ten thousand one hundred twenty-three signatures.

Thank you for consideration in this matter.

And I have a visual with me of White Haven Center, if you would like to see the facility.

Could you pass that over to them?

MAJORITY CHAIRMAN DIGIROLAMO: Okay.

Thank you, Patty.

MS. DEGEN: Thank you.

MAJORITY CHAIRMAN DIGIROLAMO: We don't have much time for questions, but I do want to ask the members if they have maybe a little quick statement.

I want to recognize Representative Murt.

REPRESENTATIVE MURT: Quick question,
Mr. Chairman.

Who made the decision to shut down admissions into these centers? Human Services?

I'm sorry. Somebody's going to have to --

Okay. Is that ODP?

UNIDENTIFIED VOICE: Yes.

REPRESENTATIVE MURT: Okay. I also want to recognize my intern for the day, Taylor Thompson, from Seneca Valley Senior High School.

Taylor, thank you for being here.

And I will be brief, Mr. Chairman.

I've had the opportunity to visit every state center except Selinsgrove, and I will be there sometime this year. Of course, there's a debate about the future of these centers, but the fact is that, as we've heard, one size does not fit all. If many of these residents could function well in a group home, they would be there. Their loved ones, their family, and the individuals, the residents need this placement such as the state centers, and as elected officials in the commonwealth,
we have the duty and the responsibility to
provide that. That is our responsibility.

Having visited the state centers, I
can tell you, they're staffed by
compassionate, professional, caring people who
do a great job caring for the residents. And
I think it's accurate to say, I don't think
that the residents would want to be anywhere
else. Like I said, if they could be in a
group home, would want to be in a group home,
they would be there.

And, you know, we, of course,
interact with a lot of people on the other
side of this issue that care deeply about
adults with special needs, intellectual
disabilities who, you know, are exerting
pressure on us to close these centers, and
this is a delicate balance, but I can tell you
that this is a system that we need to -- the
real answer, of course, is to fund Human
Services in the magnitude that we need to.
We've caught up in the last years, but this is
a mission of state government that has been
underfunded literally for decades, maybe even
longer than that.
And we have -- we've made progress the last several years, even during the Corbett administration, when there were some cuts. But this is a great system, and I would encourage any of my colleagues -- I know Todd and I know Representative Mike Jones have an interest in visiting these centers, too, and maybe this summer we can get to a couple of them.

So, thank you, Mr. Chairman.

CHAIRMAN DIGIROLAMO: Representative Jones.

REPRESENTATIVE JONES: Thank you. I want to echo what Representative Murt said. I will definitely take you up on the offer to visit Selinsgrove, and we'll try to do a combined effort.

I have a question and -- I guess a comment and a question. I get a little emotional about this stuff. So, I'll qualify that I understand your -- these are all beautiful people. They're all God's creation, okay. Just to make clear, be 110 percent.

I'm amazed how God can take anybody with any disabilities or disfiguration, and
they are still beautiful.

And so, my experience is limited to volunteering for a couple of years at church for an hour on Sundays, mainly to give parents just a little bit of relief. And so, I've seen -- and through other youth ministry work that my wife and I used to volunteer with. So, I can appreciate at least -- I cannot appreciate how people do that day in and day out. I know it's a labor of love.

But there are clearly those that are suitable for a group home. And there are others that are not.

And one young lady, and this was a thirteen-year-old girl, beautiful girl, but my main job was that I can handle being hit in the head six or seven times over the course of an hour. And that was fine. That was my limited capability. I had no training, but I could at least take, you know, a modest blow to the head a few times on Sunday. And it was a little more than that, of course. You know, she was nonverbal. Tough, she was tough, really tough.

So, in any event, I do support -- I
understand, I think, at least in a little way, what you're talking about. And it seems to me we need economies of scale to deal with this in a cost effective and a manner that is in their best interest.

My question, and I'll stop, and I don't know if there's anybody here to answer, or we can just follow up, Mr. Chairman. But some of this becomes a self-fulfilling prophecy on the cost side. And what I mean by that, Ms. Sheetz, I believe you said that Selinsgrove has two hundred twelve residents, but, in 1965, they had about twenty-one hundred. Is that accurate?

I don't know the current status of Selinsgrove, and we're not going to get in the weeds here, but if you have nine hundred people taking care of two hundred twelve, your cost per resident is going to be a lot higher than if you had fifteen hundred or two thousand, which is probably what we should have, at a minimum. I would be shocked if there aren't at least eight or ten thousand in Pennsylvania that could use these facilities.

So, this happens in business as well.
If you take 20 percent of the volume out of a plant, their cost on the 80 percent of the product goes up. And then you take 20 percent more, and the cost goes up higher. It's a death spiral. It's a self-fulfilling prophesy.

So, I would just suggest maybe, Mr. Chairman, we follow up a little bit on that vein, because the cost per individual is, by definition, going to go up if we close admissions. It's a self-fulfilling prophesy. So, maybe we should look at it in the context of if they were fully utilized and the economies of scale we would get, even if it's just, you know, a directionally sound projection. So, that's my comment, I guess, more than a question.

CHAIRMAN DIGIROLAMO: Mike, just to try to answer your question. In these facilities -- and I think, well said, what you just said.

The beds that are available and filled in these facilities -- for instance, in Selinsgrove, there are two hundred ninety beds filled with two hundred seventy-four empty
that are available. And Ebensburg, two hundred eight are filled but a hundred ninety-four are available. In Polk, two hundred filled and three hundred twenty-one are available.

So, I mean, there are beds available in these facilities. And so, I mean that's -- that's a legitimate question to ask the department. I mean, why aren't -- why aren't --

UNIDENTIFIED VOICE: I'd also add, those are code-approved, ready-to-go beds. Those facilities, many of them -- I know White Haven does -- has capacity for eleven, thirteen hundred.

MAJORITY CHAIRMAN DIGIROLAMO: That's a good -- that might be a good question for you to work with the staff on and maybe --

REPRESENTATIVE JONES: Okay. Yeah. I'd be happy to do that, because I think if we're going to look at cost -- and we have to look at cost. You know, we do. I mean, there's only so much money. Our population's aging. Our young folks are -- I mean, we have to be. But, I think, to be fair, we should
look at them at capacity or various levels of capacity, you know, to make it apples to apples.

So, yeah, whatever you need me to do, Mr. Chairman, be happy to help on that.

MAJORITY CHAIRMAN DIGIROLAMO: Todd, a question?

And I'm just going to close. And really very compelling, powerful hearing today, really was. It's good for us to hear that. And I hope the program has been played maybe around the state, and -- so other people can hear this testimony.

And somebody mentioned, I think Amy, the sheltered workshop issue. And that issue just centered around letting families decide what's best for their loved ones. The families should be making the decision, as in the testimony today. Families should be making the decision on what's best for their loved one when it comes to these issues.

And that's what I believe in, and that's what I think we ought to be doing. Should come down to the families to make these decisions and not somebody sitting in an
office somewhere in Harrisburg or somewhere else looking at paper, paperwork, and saying this is what's best for somebody. The family should make the decisions themselves.

One comment -- one last comment?

(Whereupon, a comment was made off microphone.)

CHAIRMAN DIGIROLAMO: Okay. Well, thank you. We have to get back up to session. It was real good. Give yourself a round of applause. Really, really good testimony.

Thank you for being here. And this hearing is now closed. Thank you.

(Whereupon, the hearing concluded at 10:54 a.m.)

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REPORTER'S CERTIFICATE

I HEREBY CERTIFY that the foregoing is a true and accurate transcript, to the best of my ability, produced from audio on the said proceedings.

BRENDA J. PARDUN, RPR
Court Reporter
Notary Public