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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 TOOIL
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.)

Brenda J. Pardun, RPR
Reporter, Notary Public

P R O C E E D I N G S

1
2 MAJORITY CHAIRMAN DIGIROLAMO: Nine
3 o'clock, we're going to get this hearing
4 underway.

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

9 (Whereupon, the Pledge of Allegiance
10 was recited.)

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

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

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

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

1 Allegheny County.

2 REPRESENTATIVE MIHALEK: Good
3 morning. I'm Natalie Mihalek. I represent at
4 40th District. It's parts of Allegheny County
5 and Washington County.

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

9 REPRESENTATIVE TOOHLIL: Good morning,
10 everyone. State Representative Tarah Toohil,
11 Luzerne County. White Haven Center is right
12 on the edge of my district, after
13 redistricting.

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

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

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

24 REPRESENTATIVE MADDEN: Good morning.
25 Representative Madden, representing Monroe

1 County.

2 REPRESENTATIVE STRUZZI: Good
3 morning. Jim Struzzi, 62nd District, Indiana
4 County.

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

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

11 And the way we're going to conduct
12 the hearing is we're going to let everybody
13 testify first, and then, with the time we have
14 remaining till 11 o'clock or a little before
15 11:00, we'll open it up for questions and
16 answers. So, when you testify, if you can
17 please stick around. We might have some
18 questions for you.

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

23 And with that, we'll have our first
24 testifier, Susan Jennings. And her topic is
25 going to be keeping intellectual disabilities

1 safe.

2 Susan, you can begin whenever you'd
3 like. And I would ask you to try to talk as
4 close into the microphone as possible so
5 everybody can hear. Thank you.

6 MS. JENNINGS: Thank you, Chairman
7 DiGirolamo.

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

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

20 And I'm proud to announce that we
21 held a petition drive. We pounded the
22 pavement. We gathered ten thousand one
23 hundred twenty-three signatures in the space
24 of about two months, which we will present to
25 you later today in this hearing.

1 I am the mother of an autistic child
2 named Joey, who found a wonderful quality of
3 life and safety in one of our treasured state
4 developmental centers, White Haven state
5 center, after three years of suffering in the
6 community.

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

15 Group houses in the community were
16 the only services offered to my son. His
17 behaviors are severe. He could not be managed
18 safely in the community. He was discharged
19 from six different group homes. They section
20 302'd him into five different psychiatric
21 wards. They tried to put him in a chemical
22 straight jacket with powerful psychotropics,
23 which backfired, and his life became a living
24 hell.

25 Then we discovered the existence of

1 the intermediate care facilities, the state --
2 the Pennsylvania state developmental centers.
3 But we ran into a brick wall. And that brick
4 wall was the policy of closed admissions. In
5 order to enter a Pennsylvania state
6 developmental center, a -- [inaudible] --
7 developmental programs.

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

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

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

23 The deinstitutionalization advocates
24 with advanced degrees who do not have the same
25 challenges as our parents with severe autism

1 and with medically fragile conditions are
2 vexing because they would deny our children
3 the right living situation for them, even if
4 it's not something they would chose for
5 themselves or their loved ones.

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

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

22 Breaking up the institutions was done
23 without -- without considering the
24 ramifications of separating vulnerable people
25 from specialized care and without considering

1 that you are eliminating a critical safety net
2 for those people.

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

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

23 And here's just a small sampling
24 of -- for example, Nowhere to Go series.
25 Young people with severe autism languish weeks

1 or longer in hospitals. And that's what
2 happened to my son.

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

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

24 The closure advocates play a shell
25 game with the legislature and with taxpayers.

1 It's called cost sharing. The community group
2 homes are not all-inclusive. They rely upon
3 other bureaucracies to pick up the costs that
4 they don't. And when they cannot manage
5 severe and challenging cases, they turn to
6 police, the courts, the jails, the hospitals.
7 So, while the cost for the Office of
8 Developmental Programs looks like it's going
9 down, the cost to the taxpayer and to you
10 legislatures is going up for police, for
11 courts, for jails, for hospitals, for
12 psychiatric wards, and for emergency services.

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

24 The deinstitutionalization advocates
25 also tell you that, if you take -- if you rob

1 the money from the institution for the
2 community waiver services, you will eliminate
3 the waiting list. This is demonstrably false.
4 Eliminating the state centers will not
5 eliminate the waiting list. Opening the state
6 centers will eliminate the waiting list.

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

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

21 Here are the systemic shortcomes.
22 Group home businesses have to make a profit,
23 so they delegate front-line care to
24 inexperienced caregivers with negligible
25 training and minimal supervision. This is a

1 cost-cutting combination that leads to harm.

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

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

11 Additionally, the noncontiguous rule,
12 in order to meet community group home
13 regulations, group homes must be located a
14 certain distance from one another.

15 Consequently -- and I have ridden in the car
16 with supervisors of group homes -- they spend
17 the entire day driving from one group home to
18 another. What do they not do? They don't
19 interact with the staff. They don't interact
20 with the residents. And the rest of their day
21 they fill out paperwork. So, there is minimal
22 supervision.

23 Front-line caregivers are expected to
24 handle life and death situations on a
25 fast-food budget -- on a fast-food wage. This

1 is why you have staff shortages. This is why
2 you have 30 to 70 percent staff turnovers,
3 because you're asking too much for too little.
4 In addition, because you are unwilling to
5 provide a therapeutic environmental or skilled
6 training for the aides, you have -- you have
7 to rely upon psychotropics as a chemical
8 straight jacket, which is brutal and inhumane
9 to the patients.

10 So, what we're asking for is that --
11 that the legislature -- that you pass
12 legislation opening the Pennsylvania state
13 developmental centers to admission; you
14 reverse the closed admissions policy; you
15 invest and promote a wide range of residential
16 service options, to include farmstead,
17 homesteads, villages, campuses, and ICFs; and
18 that you sponsor an objective, independent
19 cost study on what will happen if this
20 deinstitutionalization is carried out; and to
21 stand with us, the voters and the families
22 who are battling for the safety, health, and
23 welfare of our loved one against powerful
24 organizations who are promoting an unrealistic
25 ideology.

1 The answer to this problem was
2 codified in the supreme court decision
3 Olmstead, when they said, quote, But we
4 recognize as well the state's need to maintain
5 a range of facilities for the care and
6 treatment of persons with diverse mental
7 disabilities and the state's obligation to
8 administer services with an even hand.

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

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

20 Thank you.

21 CHAIRMAN DIGIROLAMO: Susan, thank
22 you for your testimony.

23 And, next, we have of panel of four
24 people who are going to testify. I'd ask them
25 to come up. I think we have the chairs up

1 front. Dr. Lee Wachtel, who's a psychiatrist
2 at the Kennedy-Krieger Center; Hugo Dwyer,
3 executive director of Voice of Reason; Amy
4 Lutz, who's the president of EASI, National
5 Council of Severe Autism. And I believe we
6 have one testifier who's going to testify via
7 Skype, and that's Dan Torisky, who is the past
8 president of the Autism Society of America.

9 Is that all set up to Skype now?
10 Okay. It's all ready to go.

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

15 Joe.

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

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

22 REPRESENTATIVE POLINCHOCK:
23 Representative Todd Polinchock from the 144th,
24 central Bucks County.

25 REPRESENTATIVE HOWARD: Hi. Kristine

1 Howard, from the 167th, Chester County.

2 MAJORITY CHAIRMAN DIGIROLAMO: Okay.
3 I think we are ready. So, Lee, I guess when
4 you get started.

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

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

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

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

22 So, I'm a psychiatrist. And I
23 specialize in the care of youth and young
24 adults with autism and other neuro
25 developmental disabilities, often in tandem

1 with intellectual disability, ranging from
2 mild to profound.

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

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

24 My patients, if you will, are the
25 ones who have hit themselves in the head so

1 many times that they've caused retinal
2 detachment, traumatic cataracts, and
3 concussions, whose bodies may be covered in
4 open wounds or wounds that are various stages
5 of healing and scarring, who have sent
6 caregivers to the emergency department in the
7 aftermath of assaultive behaviors, who live in
8 full-body protective equipment with large
9 in-home workers or exhausted parents
10 attempting to simply block their most
11 dangerous behaviors and live to see the next
12 day without another medical crisis, a
13 fruitless call to help -- for help to the
14 police or ambulance or emergency service or a
15 useless trip to the emergency room to only be
16 told that nothing can be done to help them.

17 These kids and their families are
18 really the black sheep of the autism and
19 disability community, and often don't have a
20 place at the table in autism advocacy circles
21 as they don't really represent the currently
22 popular neuro diversity movement where
23 everybody is just a little bit autistic and
24 autism or developmental disability are
25 presented as gifts to be cherished and

1 embraced, rather than major health concerns
2 that no parent in his right mind would choose
3 for his child anymore than he would choose for
4 his child to have cancer or organ failure.

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

18 The fact of the matter is, in the
19 real world, that people exist on the entire
20 range of the autism and neuro developmental
21 disability spectrum, including those who
22 aren't nice to see and who don't represent
23 what every parent with a toddler who's just
24 received an autism, Down syndrome, or other
25 development disability diagnosis is hoping to

1 have twenty years down the road.

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

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

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

22 A lot of resources are focused on
23 children with disability, but at the end of
24 the day, these children are going to spend a
25 much greater percentage of their lives as

1 adults with disability, and most likely are
2 going to have the same degree of impairment
3 and associated needs as during their
4 childhoods. Only, as adults, now they are
5 faced with aging parents, diminished
6 resources, and programming options, as they no
7 longer qualify for school services, diminished
8 safeguards such as substituted decision-making
9 from parents or appointed proxies, and often
10 most importantly, an all-too-frequent lack of
11 quality, safe, and meaningful living options.

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

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

1 an informed choice.

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

16 These might not represent politically
17 correct statements, but they do represent the
18 hard truth, and PC behavior and fantasy
19 thinking can't change biology. Regardless of
20 the severity of said biology, every one of
21 these individuals should still have access to
22 safe and dignified adult living solutions, as
23 they transition away from the primary
24 childhood home -- because truly, no one can
25 live at home forever -- solutions that allow

1 for meaning and joy according to each person's
2 unique attributes, challenges, and potential.

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

10 Thank you.

11 CHAIRMAN DIGIROLAMO: Okay, Doctor.

12 Thank you.

13 And, Hugo, whenever you're ready.

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

25 I need to talk louder? I'm trying.

1 I'm not a loud talker. It's probably -- is
2 that better? There we go. I was going to
3 say, it's probably not the microphone. It's
4 probably me. I'm not a loud talker.

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

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

24 Our opponents still like to refer to
25 us as institutions. They like the idea that

1 if they call us an institution, it brings --
2 it evokes the memory of warehousing
3 facilities. A modernize ICF is nothing like
4 the old Pennhurst, the old Willowbrook. It is
5 much more like a treatment center.

6 But starting, I guess, about twenty,
7 thirty years ago, we sort of overshot.

8 Instead of treating everybody like they
9 belonged in a warehouse and then moving
10 towards let's try these other things, we took
11 the success of the higher-functioning people
12 in group homes and said, Hey, this is working
13 for them. Let's do it for everybody.

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

22 We need more money for services,
23 because at the time being, we've got people on
24 one end of the spectrum fighting for the same
25 piece of the pie that other people on the

1 other end of the spectrum are trying to get.
2 We've got people who are left out of the
3 kitchen and can't get a piece of the pie. We
4 have to figure out a way to help everybody.
5 And the way you do that is you make a more
6 efficient, more effective system.

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

16 I have a brother who's sixty-two
17 years old. Dr. Wachtel described him fairly
18 well. He had self-injurious behaviors. He
19 banged his head all the time, detached a
20 retina. He's got pica. So, if you have
21 anything loose, he will pick it up and put it
22 in his mouth. He is in a special cottage for
23 people with pica. They can't wear clothing
24 with buttons on them, because buttons might
25 fall off and get picked up.

1 And he had a roommate at one time,
2 who left and went into a community, a special
3 pica group home, with four people and two
4 caregivers. One caregiver was late for his
5 shift. One of the residents was acting out.
6 The caregiver looked after the resident who
7 was acting out, and my brother's ex-roommate,
8 Larry, swallowed a hot dog and choked to death
9 three weeks after starting at this home.

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

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

21 He has -- over the years, he's had
22 one or two caregivers who really can get
23 through to him and ask him to do things and he
24 will do them. You know, whether it's trying
25 to brush his teeth -- which he still doesn't

1 do very well -- or pulling up his pants after
2 toileting. One or two people can get through
3 to him and get him to do that, and others have
4 a harder time. This is Tom. This is what it
5 is.

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

16 You know, in the deaf community,
17 there was an effort to integrate people in
18 with hearing people. And they'd put them into
19 classrooms with hearing people and so on. And
20 they found right away that what they called
21 the lease restrictive environment wasn't
22 working because these were people who couldn't
23 communicate by anything except American Sign
24 Language. So, they stopped doing that. They
25 put them in what they called the language rich

1 environment, put them with others like them
2 who they could communicate with, and they all
3 thrived.

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

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

18 When your kids go to -- finish high
19 school and go off to college, you're probably
20 going to put them all into a dormitory. And
21 these are not the least restrictive
22 environments. And God knows, you don't
23 necessarily want your kids to leave high
24 school, go into college and be in the least
25 restrictive environment. You want

1 protections. You want to know that somebody's
2 looking after them, that they're in an
3 environment that's geared towards their needs.

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

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

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

25 Supreme court recognized the need for

1 states to maintain a range of facilities for
2 the diverse needs of people with developmental
3 disabilities. They wrote: Unjustified
4 isolation, we hold, is properly regarded as
5 discrimination based on disability. But we
6 recognize, as well, the states need to
7 maintain a range of facilities with the care
8 and treatment of persons with diverse mental
9 disabilities and the state's obligation to
10 administer these services with an even hand.

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

20 So, in these two paragraphs, they
21 recognize the need for both types of
22 facilities and they maintained that. They
23 went on to say that they have a need for
24 standards, determining the appropriate level
25 of care: Consistent with these provisions,

1 the state generally may rely on the reasonable
2 assessments of its own professionals in
3 determining whether an individual meets the
4 essential eligibility requirements for
5 habilitation in a community-based program.
6 Absent such qualification, it would be
7 inappropriate to remove a patient from the
8 more restrictive setting.

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

18 Under Title II of the ADA, states are
19 required to provide community-based treatment
20 for persons with mental disabilities, one,
21 with the state's treatment professionals
22 determine that such a place is appropriate;
23 two, the affected persons do not oppose such
24 treatment, and that includes parents and
25 guardians as well as the affected person;

1 three, that the placement can be reasonably
2 accommodated, taking into account the
3 resources available to the state and the needs
4 of others with mental disabilities.

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

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

18 Here we go.

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

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

25 They went on to say it would be --

1 Justice Kennedy went on to warn about the
2 possibility of tragic consequences for ICF
3 residents if this is misinterpreted. He said:
4 It would be unreasonable, it would a tragic
5 event then, were the Americans with
6 Disabilities Act of 1990 to be interpreted so
7 that states have some incentive, for fear of
8 litigation, to drive those in need of medical
9 care and treatment out of appropriate care and
10 into settings with too little assistance and
11 supervision. In light of these concerns, if
12 the principle of liability announced by the
13 Court is not applied with caution and
14 circumspection, states may be pressured into
15 attempting compliance on the cheap, placing
16 marginal patients into integrated settings
17 devoid of the services and attention necessary
18 for their condition.

19 So, again this is the federal law.
20 This is one of the things you've got to keep
21 in the back of your mind as you determine how
22 best to treat the population of individuals
23 with intellectual disabilities in
24 Pennsylvania.

25 So, in spite of the supreme court's

1 ruling in Olmstead, several states have closed
2 their intermediate care facilities. What
3 happens to those who do not transition
4 successfully? Does anybody know?

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

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

23 In 2014 -- because they stopped the
24 program and restarted it -- so, in 2014, an
25 additional four hundred ninety-eight people

1 who were receiving community care died,
2 including a hundred forty-one who were
3 considered unexpected deaths.

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

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

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

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

1 for extended stays.

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

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

22 A better solution would be to
23 preserve your intermediate care facilities in
24 Pennsylvania. Invest in them. Make them
25 better. Improve the scope of their offerings

1 so that they meet the needs of those not
2 served in the group home system.

3 Thank you for your time.

4 MAJORITY CHAIRMAN DIGIROLAMO: Good.
5 Thank you.

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

9 Doyle.

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

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

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

20 Thank you for being here today.

21 CHAIRMAN DIGIROLAMO: Thank you.

22 Amy, you can begin when you're ready.

23 MS. LUTZ: Thank you. My name is Amy
24 Lutz, and I'm president of EASI Foundation,
25 Ending Aggression and Self-Injury in the

1 developmentally disabled, and a founding board
2 member of the National Council on Severe
3 Autism, which just launched in January.

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

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

18 I'm really happy to be back. And I'm
19 grateful to the committee for hosting this
20 ongoing conversation about the commonwealth's
21 most vulnerable citizens. Today, I'd like to
22 talk to you about residential policy. I'm
23 sure it's not news to you that nothing keeps
24 parents like me up at night more than panic
25 over where our severely intellectually and

1 disabled children will live when they leave
2 home. I'm thrilled to report that some of the
3 most exciting projects unfolding all over the
4 country are responding to this critical
5 concern.

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

20 In fact, just last month, Kristin
21 Biddle, the mother of a twenty-two-year-old
22 son, Will, who is severely autistic and
23 suffers from aggressive and self-injurious
24 episodes that require five trained staff
25 members to safely manage, sent a proposal to

1 ODP to build such a community. And I would
2 say Kristin wanted to be here to participate
3 in this hearing, but she just couldn't leave
4 her son.

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

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

20 Keep in mind that Kristin was not
21 asking the commonwealth to build these
22 communities. The Lotus Mission would raise
23 the funds for purchasing the property and
24 constructing the buildings. She was just
25 asking that residents be allowed to use their

1 houses sixteen people. This is how far we
2 have shifted the definition of institution
3 today.

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

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

16 Well, you might be thinking, surely
17 inclusion advocates must have studies to back
18 up such a draconian position. They claim they
19 do, but the studies they point to are so
20 flawed, so biased, that, in a review of the
21 literature, David Mandell, who made an earlier
22 appearance in this hearing, director of the
23 Center for Mental Health Policy and Services
24 Research at the University of Pennsylvania,
25 concluded, quote, Right now, our

1 decision-making regarding which types of
2 placements to pay for and prioritize is based
3 on values rather than data. Which is
4 undoubtedly why CMS issued new guidance in
5 January designed to ensure that adults with
6 I/DD enjoy the same right to choose where and
7 with whom they live that those of us without
8 disabilities take for granted.

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

17 Gone from the guidance were the
18 warnings that farmsteads, gated communities,
19 and clustered group homes might be, quote,
20 isolating or segregating. Instead of the
21 physical characteristics of settings, CMS has
22 adopted an outcome-oriented approach,
23 recognizing that, as those of us who follow
24 the 2017 Blossom scandal, in which the
25 Philadelphia-based service provide of over

1 thirty community-based group homes was
2 stripped of its license due to, quote, gross
3 incompetence, know all too well, abuse and
4 neglect can and do happen anywhere.

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

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

20 There are parents in this room today
21 whose children bounced from group homes to
22 emergency rooms to group homes to psych wards
23 and back to group homes, paying with their
24 unspeakable trauma for ODP's ideological
25 intransigence. They know that allegedly

1 inclusive settings like small group homes and
2 individual apartments can be the most isolated
3 and segregated of all for those with
4 challenging behaviors that require more
5 structure and more support than can be
6 provided in those environments.

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

16 Thank you.

17 MAJORITY CHAIRMAN DIGIROLAMO: Okay.
18 Amy, thank you.

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

25 John, want to say hello to everybody

1 and let everybody know where you're from?

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

5 CHAIRMAN DIGIROLAMO: Dan.

6 REPRESENTATIVE MILLER: Dan Miller,
7 Allegheny County.

8 REPRESENTATIVE JONES: Mike Jones,
9 York County.

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

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

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

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

22 MAJORITY CHAIRMAN DIGIROLAMO: I
23 think we're going to bring our next panel up.
24 And that's Tom Kashatus, who is president of
25 White Haven Friends and Families; Irene

1 McCabe, President, Polk Center Friends and
2 Families; and Trudy Sheetz, from Selinsgrove
3 Center family member and KIIDS representative.

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

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

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

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

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

24 I remember the story that you told us
25 about your grandson.

1 Maria was our first. She is special,
2 and she is my hero. Her story is attached to
3 this testimony. It's in your folders.

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

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

20 To really appreciate her story, put
21 yourself in the place of Mrs. Nauman. To the
22 left is a photo of Mrs. Nauman. She's
23 seventy-seven years old, same age as my wife,
24 with her seven children. Jimmy is on her
25 right, Danny is on her left. Standing from

1 left to right are Lisa, Marie, Billy, Beth,
2 and Elsie.

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

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

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

24 Mrs. Nauman also had experience with
25 I/DD self-advocates who lived in the

1 community-based living arrangement because she
2 worked at REDCO day program in Hazleton. She
3 was employed as a therapeutic service aide for
4 fifteen years. She felt that their living
5 standards, personal hygiene, diet, et cetera,
6 was substandard, and she wanted better for
7 Danny.

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

22 A judge was appointed. Counsels were
23 set. Necessary data was collected, et cetera.
24 In the meantime, Danny fell and broke an arm
25 at Keystone and ended up in the hospital. For

1 recovery, Danny was sent to Weatherwood
2 Nursing Home in Weatherly, a place not
3 appropriate for anyone with I/DD.

4 This became a nightmare for Danny, as
5 he deteriorated physically and emotionally.
6 If Danny was a resident at White Haven Center,
7 recovery could have taken place there with
8 full-time staff close by, twenty-four/seven
9 close nursing care, one-on-one staffing if it
10 was necessary, and a full-time doctor on duty
11 five days a week.

12 Can everybody hear me? Thank you.

13 In the meantime, continued
14 negotiations were pursued by the state to have
15 Mrs. Nauman select a group home for Danny.
16 One thing for sure, the state of Pennsylvania
17 has smart lawyers, who know every trick in the
18 book to prolong a court case.

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

24 After visual inspections, Mrs. Nauman
25 saw none that suited her satisfaction for

1 Danny. For a number of reasons, postponements
2 continued to surface, bills kept piling up,
3 and finally Mrs. Nauman had to make a choice
4 on whether to continue the White Haven journey
5 for Danny.

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

17 Because of an unfortunate policy of
18 leadership in the ODP and with the county
19 human services, influenced by the Pennsylvania
20 ARC and the DRP, Disability Rights of
21 Pennsylvania, et cetera, advocacy
22 organizations who receive tax dollars from all
23 Pennsylvanians, I/DD citizens who are in need
24 of services are told that ICFs are available
25 for their benefit, but they are private ICFs,

1 such as Saint Joseph's and Allied Services of
2 Scranton.

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

9 I'm almost done, guys.

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

22 Individuals and those who have
23 guardians should be given the opportunity to
24 select a venue of their choice, after a
25 complete review of providers of services is

1 experienced, to include that of state centers.

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

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

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

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

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

23 CHAIRMAN DIGIROLAMO: Thank you, Tom.
24 And God bless you, too.

25 Irene.

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

3 I wanted to say, I go back way far,
4 Pinehurst -- Pennhurst. Pennhurst, I'm sorry.
5 At Pennhurst, I remember Pennhurst. And I
6 remember the news anchor who was called in to
7 see it, and then they called the governor's
8 mansion. And they said, You've got to come
9 and see this. And they got Ray Broderick.
10 And he went over there in the middle of the
11 night. And he said, This has got to change.

12 And that was where he started. And
13 then a lot of good stuff happened at
14 Pennhurst. But, in the meantime, the
15 legislators said, We'll give you money to fix
16 up Pennhurst.

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

19 And that was a better idea. We're
20 talking back in the '60s. ARC was mainly -- a
21 lot of fellows who came back from the second
22 World War, they had the same amount of
23 retarded kids as anybody else, but those kids
24 were not allowed to go to school. They didn't
25 go to school.

1 And so, they came to the legislators
2 and said, What can we do about this? So, what
3 happened is, Ray Broderick then was a district
4 justice, and he said, I know what I'm going to
5 do. We're going to give the money to ARC.

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

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

23 So, if somebody's taking care of
24 eleven thousand, and they do a great job and
25 they're having a dinner, and you might be

1 invited and they're great, I have no argument.
2 Thank you. God, thank you, thank you. But my
3 sister is very happy at Polk. Let her alone.
4 Let her alone.

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

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

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

22 And Tom Gilhool -- if you don't know
23 him, he was a saint and an amazing guy in your
24 history. And he said, Let's sue the state,
25 saying that they have to be able to go to

1 school. And he was good friends with the guy
2 who did Brown versus Board of Education. And
3 so they got this brilliant strategy and they
4 went to court, and they were only in there for
5 two days, and the judge said, Done. These
6 kids have to be able to go to school.

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

14 That case that started right here
15 resulted in the land rock -- the legislation
16 that said all kids could go to school. So,
17 there is a rich, deep, profound history. And
18 there are people at the department and --
19 and -- and alive now that have formed policy
20 preference based on what they saw at
21 Pennhurst, which is to say, when you're in
22 part of something that's really important --
23 like, if you went to Woodstock, you just say
24 you remember you were there and you say it.
25 I'd say I was there, but it rained and we

1 didn't get there. But when you're part of
2 something that important, it tends to infuse
3 you.

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

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

24 I will give you a -- Tom was talking
25 about Allied. There was -- at one point, the

1 director said to Allied, You can't do that,
2 whatever you're doing.

3 And they said, Yeah, we can do it.

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

7 And she said, That is my preference.

8 And they said, But is it policy?

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

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

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

21 Okay. Olmstead, the only thing you
22 don't know about Olmstead, when it was passed,
23 those of us who had loved ones in
24 institutions, centers -- I call them
25 institutions. I don't have any problem with

1 that. I have -- there's institutional
2 awareness. There's institutional memory.
3 There's a lot of good stuff to be said about
4 institutions. You guys are an institution.
5 You know, it's all right.

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

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

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

18 And the judge on appeal said, No, you
19 don't have to go. But that was -- and the
20 state attorneys from the department were
21 there, so the cost -- cost you guys a hundred
22 thousand, cost us. At the end of it, we came
23 up with something called a Benjamin
24 settlement. Everybody in the department knows
25 about the Benjamin Settlement. They know what

1 we believe. We spent five years, a hundred
2 thousand dollars telling you what we want, and
3 our opinions are dismissed like this. Just
4 like this, like we're not even there.

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

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

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

25 So, in any event, I sent him a little

1 picture. It was like through the looking
2 glass. I had to stretch. I'm going to stop
3 now. That's why I'm kind of hot. I just
4 wanted to say it so badly.

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

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

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

20 And my sister -- my sister is on her
21 third generation of family at Polk. They'll
22 say, Oh, Grandma had Karen over at North Side.
23 Okay? I'm just saying, I'm kind of a
24 psychologist kind of person or psychologist,
25 and you really value when people learn the

1 right thing to do. I call that institutional
2 awareness. You guys have got, like, maybe
3 four, five hundred years of institutional
4 awareness.

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

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

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

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

18 MS. MCCABE: It rained.

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

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

24 CHAIRMAN DIGIROLAMO: Okay. Thank
25 you, Irene, for your very passionate

1 testimony. Appreciate that.

2 Trudy, begin when you're ready.

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

9 Is that better? Okay. Thank you.

10 Thank you for allowing me to speak.
11 I'm sister and co-guardian of a brother living
12 at Selinsgrove Center and a retired nurse in
13 the commonwealth.

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

22 Today, residents ages twenty-three to
23 ninety-five years there, many calling
24 Selinsgrove home for more than forty years.
25 They employ roughly nine hundred union

1 included there.

2 Residents living at Selinsgrove have
3 varying levels of intellectual disabilities
4 requiring extensive supports with daily
5 living, social skills, medical care, and
6 vocational training. The center provides
7 twenty-four-hour-a-day medical services,
8 on-site nursing, occupational and physical
9 therapy, psychiatric, speech and hearing,
10 recreational, and social work services.

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

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

25 My brother is sixty-five years old,

1 was born with cleft palate, which is an
2 opening in the roof of his mouth. It was
3 repaired at age four. He was admitted to
4 Allentown State Mental Hospital mental
5 retardation unit at age five, unable to
6 toilet, feed himself, or communicate verbally.
7 His behaviors became exceedingly overactive
8 between ages four to five, showing amazing
9 strength, able to upset things like TVs -- in
10 1950, they weren't light like today --
11 furniture, and attempts at trying to jump from
12 second-story windows.

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

23 Some of his diagnoses. He's
24 schizophrenic, reaction to childhood
25 mentality, two to four years. He's

1 sixty-five; mentality, two to four years, with
2 profound mental retardation. Mood disorder
3 NOS. NOS meaning "not otherwise specified",
4 impairing but not fitting with any other
5 specific diagnosis. Nonverbal verbalization,
6 basically unintelligible. He does not express
7 pain or discomfort but has a fear of
8 unfamiliar surroundings. He has epilepsy
9 seizure disorder and auditory processing
10 disorder affecting his hearing ability.

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

22 Selinsgrove has been prayers
23 answered. Staff has reduced his self-abusive
24 incidents, when he begins these things, from
25 twenty-four to four or less per month with the

1 teaching skills and the professional care on
2 site, the love that Selinsgrove has provided
3 for the fifty-two years he's been there. He
4 leads a healthy, active, enjoyable life. He's
5 normal body weight. He had programing skills
6 Monday through Friday to keep his skills up to
7 date. He attends in-house and off-site
8 events, church weekly van rides. And he's
9 been able to live and progress with his
10 skills. We would not have been able to do
11 that at home.

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

20 State ICF provide hallways between
21 living areas, allowing space to run the
22 frustration energy off. And if you're
23 familiar with severe profound autistic or
24 mentally challenged, many times they just --
25 they'll pop up out of a chair and they'll take

1 off. And they'll just want to run or do
2 whatever. And they can at least take them to
3 the back hall, where they have space to run.
4 You can't do that in a small house or smaller
5 setting.

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

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

20 Overmedication for extreme behaviors
21 is on the rise in community. And due to the
22 brain deformity trauma of these residents,
23 this may actually add to the increased
24 behaviors because sometimes they don't work
25 right. Okay. Physicians in state ICFs

1 specialize and know this. Medical services in
2 community settings are on an on-call or
3 as-needed basis.

4 With shortages in the communities of
5 physicians trending, nurse practitioners and
6 physician assistants are who many residents
7 now see, hence lack of knowledge with the
8 patient base. The poorest of the poor will
9 never be able to take care of their physical,
10 medical, daily living needs or finances
11 without twenty-four/seven professional care,
12 are being sentenced to a life of neglect,
13 abuse, and death.

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

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

1 work program.

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

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

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

1 hospital with a fractured pelvis and extensive
2 bladder damage.

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

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

23 Abuse in Pennsylvania, I wish to
24 educate on increasing abuse of our mentally
25 challenged in Pennsylvania. Time doesn't

1 permit going into all the allegations and
2 abuses, and, therefore, I will hit just a few.

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

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

19 A month prior, she was prescribed an
20 antiemetic medication and regular blood
21 sugar testing. Neither was received. On June
22 27, she had been told to stop lisinopril,
23 which is a blood pressure medication, because
24 her blood pressure was going too low. But
25 they gave that up to the day she died.

1 Another female laying on the floor in
2 a nightgown for four days, nurse practitioner
3 stated she couldn't help, called the
4 psychiatric nurse.

5 I need to wrap it up? Okay.

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

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

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

18 Thank you.

19 MAJORITY CHAIRMAN DIGIROLAMO: Thank
20 you, Trudy.

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

25 And, Dan, if you can hear me.

1 MR. TORISKY: Yes.

2 MAJORITY CHAIRMAN DIGIROLAMO: Okay.
3 You can begin your testimony. Welcome.

4 MR. TORISKY: I don't see a picture.
5 Is anybody else there besides you?

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

8 MR. TORISKY: Good morning, people.
9 I'm here to describe a scary situation called
10 CMS that threatens all of us. They're deeply
11 embedded in a misguided governmental scheme
12 who is, right now, stifling the rights of
13 developmentally disabled individuals and their
14 families. Simply put, the culprit is an
15 entrenched governmental agency of unelected
16 socialist reformers called Centers for
17 Medicare and Medicaid Services, CMS, which has
18 decreed -- decreed, mind you -- that our
19 medical assistance tax dollars may no longer
20 be provided. If the settings where delivery of
21 necessary services to our loved ones are not
22 community enough, the decree called the Final
23 Rule -- move over, boy, I thought you were the
24 only one that made final rules -- applies to
25 all citizens where services are provided from

1 institutions down through living in centers of
2 all types.

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

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

1 beginning.

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

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

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

23 Until recently, all states had to
24 submit a plan of compliance to CMS by a
25 certain date, so CMS decided to take us on

1 state by state, regardless, the community-only
2 criteria, and had to be adhered to without
3 exception. So, nothing's changed.

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

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

23 We are enraged that so very few
24 elected officials in our country perceive this
25 danger to our disabled loved ones in our

1 country. That's why we have to undertake a
2 campaign with other parents, groups, and
3 advocates, to enlighten our elected government
4 to crush the so-called final rule and its
5 crippling mandates.

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

17 Thank you. And God bless you all.
18 Pray for us.

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

21 MR. TORISKY: All right. The full
22 extent of my speech is with the press table
23 out front. And if anybody wants to talk to me
24 or any of our representatives in this
25 campaign, we'll stay on Skype here long enough

1 to answer any questions that press might have
2 or anybody of you might have. Thank you.

3 CHAIRMAN DIGIROLAMO: Thank you, Dan.

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

9 Thank you both for being here. We
10 are a little bit pressed for time, so we have
11 about twenty minutes left for testimony. We
12 are going to have to forgo the
13 question-and-answer part, but if I could ask
14 each of you to try to keep it within ten
15 minutes each so -- we have to be done before
16 11 o'clock.

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

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

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

24 My name is Mary Wills. My
25 sister-in-law, Sandy Wills, is sixty-seven

1 years old and lives in a state center since
2 she was ten. I'm also the president of the
3 ACE association, which is a family and friends
4 association from Ebensburg.

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

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

25 The state centers can provide care

1 for many more without much cost, because the
2 buildings and the services are already set up
3 and able to serve many more. We have so many
4 more life stories and reasons for why we are
5 all here today. And we have only touched upon
6 a few of the reasons in this limited time.

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

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

18 Thank you.

19 MAJORITY CHAIRMAN DIGIROLAMO: Thank
20 you very much.

21 And I just want to let everybody
22 know, Mary, about the signatures. I think you
23 have ten thousand one hundred twenty-three
24 signatures in the box that you delivered to
25 me. And we're going to try to figure out what

1 is the best way to get these to the members of
2 the general assembly or where they need to go.
3 And I just want to read what they -- everybody
4 signed.

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

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

1 the centers out of the service system.

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

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

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

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

16 And last, we have Patty Degen.

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

25 My name is Patricia Degen, and I'm a

1 retired I.T. specialist from the U.S.
2 Department of Agriculture, a representative of
3 KIIDS, Keeping kids -- Keeping Individuals and
4 Intellectual Disabilities Safe -- and
5 volunteer with PAWS, People and Animals Who
6 Serve.

7 I visit White Haven Center regularly
8 with Bella Mia (phonetic), a therapy dog. In
9 the late summer and fall of 2017 and August of
10 2018, I secured a vender spot for an
11 information booth at five festivals in
12 northeastern Pennsylvania for petition signing
13 to vote no on HB 1650 to stop closure of
14 intermediate care facilities in Pennsylvania
15 and care for profoundly disable. We are proud
16 to say ten thousand one hundred twenty-three
17 signatures were obtained throughout
18 Pennsylvania in a short time frame.

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

25 While myself and others manned this

1 both, we encountered the following responses
2 from festival patrons. Now, I have
3 twenty-five responses listed, but I'm only
4 going to go through a few because of time.

5 White Haven Center gives excellent
6 care.

7 White Haven Center has been there for
8 a long time.

9 Where would the individuals be moved?

10 Who wants to close White Haven
11 Center?

12 I work or worked at White Haven
13 Center.

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

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

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

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

24 What can I do to help?

25 A few of the festivals have invited

1 us to return as an information vendor to
2 upcoming festivals to continue petition
3 signing. The profoundly disabled need to get
4 adequate care and be kept safe. All
5 facilities need strict guidelines, oversight,
6 and accountability. I repeat that. All
7 facilities need strict guidelines, oversight,
8 and accountability.

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

18 One size does not fit all. A tragedy
19 can occur in any family, resulting in a
20 disabled individual. No one, none us here,
21 are shielded from it. It can happen by
22 complication in pregnancy, problems during
23 labor and birth, accident, virus, fever,
24 insect bite, illness, disease, toxins,
25 poisons, genetics, alcohol and drugs, et

1 cetera. Human beings who cannot care for
2 themselves should be top priority over any
3 other expense.

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

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

10 Thank you for consideration in this
11 matter.

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

15 Could you pass that over to them?

16 MAJORITY CHAIRMAN DIGIROLAMO: Okay.
17 Thank you, Patty.

18 MS. DEGEN: Thank you.

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

23 I want to recognize Representative
24 Murt.

25 REPRESENTATIVE MURT: Quick question,

1 Mr. Chairman.

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

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

7 Okay. Is that ODP?

8 UNIDENTIFIED VOICE: Yes.

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

13 Taylor, thank you for being here.

14 And I will be brief, Mr. Chairman.

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

1 we have the duty and the responsibility to
2 provide that. That is our responsibility.

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

12 And, you know, we, of course,
13 interact with a lot of people on the other
14 side of this issue that care deeply about
15 adults with special needs, intellectual
16 disabilities who, you know, are exerting
17 pressure on us to close these centers, and
18 this is a delicate balance, but I can tell you
19 that this is a system that we need to -- the
20 real answer, of course, is to fund Human
21 Services in the magnitude that we need to.
22 We've caught up in the last years, but this is
23 a mission of state government that has been
24 underfunded literally for decades, maybe even
25 longer than that.

1 And we have -- we've made progress
2 the last several years, even during the
3 Corbett administration, when there were some
4 cuts. But this is a great system, and I would
5 encourage any of my colleagues -- I know Todd
6 and I know Representative Mike Jones have an
7 interest in visiting these centers, too, and
8 maybe this summer we can get to a couple of
9 them.

10 So, thank you, Mr. Chairman.

11 CHAIRMAN DIGIROLAMO: Representative
12 Jones.

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

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

24 I'm amazed how God can take anybody
25 with any disabilities or disfiguration, and

1 they are still beautiful.

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

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

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

25 So, in any event, I do support -- I

1 understand, I think, at least in a little way,
2 what you're talking about. And it seems to me
3 we need economies of scale to deal with this
4 in a cost effective and a manner that is in
5 their best interest.

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

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

25 So, this happens in business as well.

1 If you take 20 percent of the volume out of a
2 plant, their cost on the 80 percent of the
3 product goes up. And then you take 20 percent
4 more, and the cost goes up higher. It's a
5 death spiral. It's a self-fulfilling
6 prophesy.

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

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

22 The beds that are available and
23 filled in these facilities -- for instance, in
24 Selinsgrove, there are two hundred ninety beds
25 filled with two hundred seventy-four empty

1 that are available. And Ebensburg, two
2 hundred eight are filled but a hundred
3 ninety-four are available. In Polk, two
4 hundred filled and three hundred twenty-one
5 are available.

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

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

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

19 REPRESENTATIVE JONES: Okay. Yeah.
20 I'd be happy to do that, because I think if
21 we're going to look at cost -- and we have to
22 look at cost. You know, we do. I mean,
23 there's only so much money. Our population's
24 aging. Our young folks are -- I mean, we have
25 to be. But, I think, to be fair, we should

1 look at them at capacity or various levels of
2 capacity, you know, to make it apples to
3 apples.

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

6 MAJORITY CHAIRMAN DIGIROLAMO: Todd,
7 a question?

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

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

22 And that's what I believe in, and
23 that's what I think we ought to be doing.
24 Should come down to the families to make these
25 decisions and not somebody sitting in an

1 office somewhere in Harrisburg or somewhere else
2 looking at paper, paperwork, and saying this is
3 what's best for somebody. The family should make
4 the decisions themselves.

5 One comment -- one last comment?

6 (Whereupon, a comment was made off
7 microphone.)

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

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

14 (Whereupon, the hearing concluded at
15 10:54 a.m.)

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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
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