COMMONWEALTH OF PENNSYLVANIA
HOUSE OF REPRESENTATIVES

HUMAN SERVICES COMMITTEE
AND
HEALTH COMMITTEE
JOINT PUBLIC HEARING

STATE CAPITOL
HARRISBURG, PA

MAIN CAPITOL BUILDING
140 MAJORITY CAUCUS ROOM

MONDAY, OCTOBER 21, 2019
11:03 A.M.

PRESENTATION ON
CLOSURE OF WHITE HAVEN AND POLK
STATE CENTERS

BEFORE:
HONORABLE GENE DiGIROLAMO, MAJORITY CHAIRMAN,
HUMAN SERVICES COMMITTEE
HONORABLE JAMES GREGORY
HONORABLE DOYLE HEFFLEY
HONORABLE JOHNNATHAN D. HERSHEY
HONORABLE LORI A. MIZGORSKI
HONORABLE THOMAS P. MURT
HONORABLE MARCI MUSTELLO
HONORABLE ERIC R. NELSON
HONORABLE F. TODD POLINCHOCK
HONORABLE JAMES B. STRUZZI II
HONORABLE TARAH TOOHL

* * * * *
Debra B. Miller
dbmreporting@msn.com
BEFORE (continued):
HONORABLE MAUREEN E. MADDEN, ACTING DEMOCRATIC
CHAIRMAN, HUMAN SERVICES COMMITTEE
HONORABLE JOSEPH C. HOHENSTEIN
HONORABLE KRISTINE C. HOWARD
HONORABLE STEPHEN KINSEY
HONORABLE MICHAEL H. SCHLOSSBERG

HONORABLE KATHY L. RAPP, MAJORITY CHAIRMAN,
HEALTH COMMITTEE
HONORABLE DAVID H. ZIMMERMAN, ACTING MAJORITY
CHAIRMAN, HEALTH COMMITTEE
HONORABLE JIM COX
HONORABLE MARCIA M. HAHN
HONORABLE JOHNATHAN D. HERSHEY
HONORABLE AARON D. KAUFER
HONORABLE DAWN W. KEEFER
HONORABLE KATE A. KLUNK
HONORABLE BRAD ROAE
HONORABLE DAN FRANKEL, DEMOCRATIC CHAIRMAN,
HEALTH COMMITTEE
HONORABLE PAMELA A. DELISSIO
HONORABLE SARA INNAMORATO
HONORABLE STEPHEN KINSEY
HONORABLE MICHAEL H. SCHLOSSBERG
HONORABLE WENDY ULLMAN

ALSO IN ATTENDANCE:
HONORABLE KAREN BOBACK
HONORABLE R. LEE JAMES
HONORABLE GERALD J. MULLERY
HONORABLE DONNA OBERLANDER
HONORABLE PARKE WENTLING

ALSO PRESENT:
SENATOR SCOTT HUTCHINSON
SENATOR KATIE J. MUTH
COMMITTEE STAFF PRESENT:
ERIN RAUB
  MAJORITY EXECUTIVE DIRECTOR,
  HUMAN SERVICES COMMITTEE

WHITNEY METZLER
  MAJORITY EXECUTIVE DIRECTOR, HEALTH COMMITTEE

MAUREEN BEREZNAK
  MAJORITY RESEARCH ANALYST, HEALTH COMMITTEE

EMILY KENDALL
  MAJORITY RESEARCH ANALYST, HEALTH COMMITTEE

LORI CLARK
  MAJORITY LEGISLATIVE ADMINISTRATIVE ASSISTANT,
  HEALTH COMMITTEE

ERIKA FRICKE
  DEMOCRATIC EXECUTIVE DIRECTOR, HEALTH COMMITTEE
<table>
<thead>
<tr>
<th>NAME</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>KRISTIN AHRENS</td>
<td>14</td>
</tr>
<tr>
<td>DEPUTY SECRETARY,</td>
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<td>OFFICE OF DEVELOPMENTAL PROGRAMS,</td>
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<td>PA DEPARTMENT OF HUMAN SERVICES</td>
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<td>SHERRI LANDIS</td>
<td>23</td>
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<td>EXECUTIVE DIRECTOR,</td>
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<tr>
<td>THE ARC OF PENNSYLVANIA</td>
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<tr>
<td>JAMIE RAY-LEONETTI</td>
<td>28</td>
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<tr>
<td>ASSOCIATE DIRECTOR OF POLICY,</td>
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<td>INSTITUTE ON DISABILITIES,</td>
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<td>TEMPLE UNIVERSITY</td>
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<td>JACQUELINE BEILHARZ</td>
<td>32</td>
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<td>ADVOCATE,</td>
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<tr>
<td>DISABILITY RIGHTS PENNSYLVANIA</td>
<td></td>
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<td>MARIAN BALDINI</td>
<td>38</td>
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<tr>
<td>PRESIDENT/CEO, KENCREST</td>
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<tr>
<td>GARY H. BLUMENTHAL</td>
<td>43</td>
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<td>VICE PRESIDENT OF GOVERNMENTAL RELATIONS AND ADVOCACY, INVISION HUMAN SERVICES</td>
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<td>TOM KASHATUS</td>
<td>47</td>
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<td>PRESIDENT, WHITE HAVEN CENTER</td>
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<tr>
<td>RELATIVES &amp; FRIENDS ASSOCIATION</td>
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<td>SUSAN JENNINGS</td>
<td>51</td>
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<td>MOTHER/CO-GUARDIAN OF JOEY,</td>
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<td>IRENE McCABE</td>
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<td>PRESIDENT,</td>
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<td>POLK CENTER PARENTS, FRIENDS AND FAMILY</td>
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<td>BILL HILL</td>
<td>60</td>
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<td>MAINTENANCE REPAIRMAN, WHITE HAVEN CENTER; PRESIDENT, AFSCME LOCAL 2334</td>
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TESTIFIERS (continued):

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<thead>
<tr>
<th>NAME</th>
<th>PAGE</th>
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<tbody>
<tr>
<td>TAMMY LUCE</td>
<td>62</td>
</tr>
<tr>
<td>RESIDENTIAL SERVICES AIDE, POLK CENTER; PRESIDENT, AFSCME LOCAL 1050</td>
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<td>MARIA FERREY</td>
<td>64</td>
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<td>RESIDENTIAL SERVICES SUPERVISOR/ QUALIFIED INTELLECTUAL DISABILITIES PROFESSIONAL, WHITE HAVEN CENTER; SEIU LOCAL 668 CHIEF F5 STEWARD, WHITE HAVEN CENTER</td>
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<td>WILLIAM BAILEY</td>
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<td>PSYCHOLOGICAL SERVICES SPECIALIST, POLK CENTER; SEIU LOCAL 668 F4 SHOP STEWARD, POLK CENTER</td>
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SUBMITTED WRITTEN TESTIMONY

See submitted written testimony and handouts online under "Show:" at:

GOOD MORNING. IF I COULD HAVE EVERYBODY’S ATTENTION. I WOULD LIKE TO CALL THIS JOINT HEARING OF THE HUMAN SERVICES AND THE HEALTH COMMITTEE TO ORDER.

AND IF I MIGHT FIRST ASK EVERYONE TO RISE FOR THE PLEDGE OF ALLEGIANCE.

(The Pledge of Allegiance was recited.)

OKAY. THANK YOU.

WE’RE NOT GOING TO TAKE ATTENDANCE TODAY, BUT I THOUGHT WHAT I MIGHT DO IS GIVE THE MEMBERS THAT ARE PRESENT AN OPPORTUNITY TO SAY HELLO AND IDENTIFY THEMSELVES AND LET YOU KNOW WHERE THEY’RE FROM.

AND IF I MIGHT START OFF UP TOP WITH REPRESENTATIVE JAMES.

GOOD MORNING, EVERYONE.

MY NAME IS LEE JAMES. I REPRESENT ALL THE FOLKS IN VENANGO COUNTY, DISTRICT 64, PLUS A LITTLE BIT OF NORTHEAST BUTLER COUNTY.

GOOD MORNING, EVERYONE.

STATE REPRESENTATIVE TARAH TOOHL, LUZERNE
County, the 116th Legislative District.

Representative Mullery: Good morning. Gerry Mullery, Luzerne County, the 119th Legislative District.

Representative Ullman: Good morning. Wendy Ullman, the 143rd District, parts of Bucks County.

Representative Howard: Kristine Howard, the 167th District, which is in Chester County.

Representative Mizgorski: Good morning. Lori Mizgorski. That’s the 30th District in Allegheny County.

Representative DeLissio: Pam DeLissio. I represent the 194th, parts of Philadelphia and Montgomery County.

Majority Human Services Chairman DiGirolamo: Okay. John?

Representative Hershey: Go ahead.

Representative Hohenstein: Joe Hohenstein, the 177th, Philadelphia County.

Representative Hershey: John Hershey, the 82nd District, Juniata, Mifflin, and Franklin Counties.

Representative Kaufer: Hi. Good morning. Aaron Kaufer, the 120th District, Luzerne County.

Representative Gregory: Good morning.
Jim Gregory, the 80th District, Blair County.

REPRESENTATIVE ROAE: Hi.

Brad Roae, the 6th Legislative District, parts of Crawford and parts of Erie.

SENATOR HUTCHINSON: State Senator Scott Hutchinson, the 21st Senatorial District. And I want to thank the Chairman for accommodating Senate Members, and thank you for your invitation to participate today.

REPRESENTATIVE HAHN: Good morning.

Marcia Hahn, the 138th, Northampton County.

REPRESENTATIVE WENTLING: Good morning.

Parke Wentling, the State Representative in the 17th Legislative District. I’m honored to serve parts of western Erie County, western Crawford, over towards real close to Venango County, down to the middle of Mercer, and a part of Lawrence. Thank you.

REPRESENTATIVE ZIMMERMAN: Representative Dave Zimmerman. I serve northeast Lancaster County.

MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN:

Good morning.

Representative Madden, serving the 115th District in Monroe County.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Gene DiGirolamo. I’m the Chairman of the Human Services Committee from Bucks County.
MINORITY HEALTH CHAIRMAN FRANKEL: Representative Dan Frankel, Allegheny County. I’m the Minority Chair of the Health Committee.

MAJORITY HUMAN SERVICES CHAIRMAN DIGIROLAMO:
Okay. Terrific. Welcome, everyone. Good to see everybody here.

Just a few ground rules before we get started.

The agenda, we’re going to have to try to keep the time limits on the testifier as much as possible. We have to be done this hearing by 1 o’clock, because that’s when session starts. So I’m going to try to finish like about 10 of 1, 5 of 1. We are not allowed by our rules to go past the time when session is on.

So what I’m going to do is allow everyone to testify first to make sure everybody gets in, because I know you have come from, a lot of you, from a long distance to be here. So we want to make sure everybody has the opportunity to testify. And then I would ask, after you get done testifying, if you would stick around until the end, because then we’re going to open it up for questions and answers from the Members that are here today.

And I’m going to let right now, just very briefly, the Chairmen of the Committees, the two Committees, maybe just a few brief comments, if they would like. But from my end, I mean, this is a very passionate
and emotional issue. This really is. And it’s an important issue to many of you here and many of you across the State of Pennsylvania.

I would ask everyone that when the people are testifying, if we show the testifiers a certain amount of respect when they are testifying. So I’m going to ask you to please not call out when the people are testifying. I think we have to show them that courtesy. And again, I realize this is really, really a passionate issue.

And from my perspective, I mean, I think it’s important that we hold this hearing. We have got a very fair and balanced hearing, and I want to thank the staff on both sides, Republican and Democratic staff, for all their hard work on putting this together.

And from my perspective, I have got a lot of serious concerns about doing this. I really do. And I go back to just recently this issue with the sheltered workshops that was implemented the 1st of July. I understand there is a lawsuit that has been filed by some of the providers and some of the other groups around the State.

And for me, I keep knocking up against that wall that the families, the families should be the main people who should be making decisions for their loved ones, and I just can’t get past that. Whether it’s a
sheltered-workshop issue or the closing of these two centers, I think the families should have the most say in what happens with their loved ones. And that’s what I just can’t get past, on why we are closing these two centers.

So with that, I’m going to ask my other Chairmen that are up here, Representative Zimmerman first, if you have a few comments.

MAJORITY HEALTH ACTING CHAIRMAN ZIMMERMAN: Sure.

Thank you, Chairman. I appreciate that.

Yeah; so I am sitting in, acting as Health Chairman here this morning in place of Representative Kathy Rapp, which would normally be here. So I’m just filling in for her. So I just want to make a couple of comments.

In my district in northeast Lancaster County, we have two facilities, one called The Lighthouse and another one is the Ephrata Area Rehabilitation Services, and both of them have 200, or in excess of 200 individuals and do an outstanding job working with these folks, generally, you know, very vulnerable to whatever is going on around them when there is intellectual disabilities involved.

But we met with staff many times in both of these facilities, and they are just phenomenal individuals that thoroughly, thoroughly care about these individuals and their well-being. And so without those facilities in my
district, I’m not sure what things would look like, so it gives me pause on the thought that we might close Polk and White Haven.

And really, at EARS, as we call it, the Ephrata Area facilities, we actually do case study work up there once a month where we spend a day, have one of our staff up at that facility so we can kind of interact with those folks and have families come in and so forth. And it has just been a great relationship, and I’m just impressed with the quality of work and the care for these individuals.

So again, I’m very interested in hearing the testimony on both sides today, but really, I think the important thing is that somehow we find a way that these people are dealt with in a good way going forward, whatever that is.

So thank you, Mr. Chairman.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: Okay. Representative Madden.

MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN: Thank you, Mr. Chairman.

I’m here filling in for Chairman Angel Cruz, who is unable to be here.

I echo the sentiments of my colleagues. I attended the White Haven public policy hearing and heard the really moving testimony from the families of residents
there, from the people whose job it is to take care of the people. And I understand that we have a waiting list of people that need to be served and we have these two wonderful facilities, and I’m still trying to wrap my brain around why we would close a facility when we have a need, and certainly it’s not a one-size-fits-all need. So I’m looking forward to the testimony and being able to make an informed decision.

Thank you.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Representative Frankel.

MINORITY HEALTH CHAIRMAN FRANKEL: Thank you, Chairman DiGirolamo, and thank you to everybody who will be testifying today.

You know, I’ve been here for now more than 20 years, so this is not the first time we have dealt with closing one of these centers. And I know how gut-wrenching it can be, and, you know, I understand that there are sometimes unintended consequences.

So I am looking forward to hearing from the parties today. I can’t stay beyond noon today because I have another commitment, but will follow this very closely, and I appreciate the opportunity to hear from all the parties who have an interest in this very serious and complicated issue.
Thank you.

PANEL NO. 1

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Okay. With that, I’m going to call our first testifier up, which is Kristin Ahrens, who is the Deputy Secretary for the Office of Developmental Programs in the Department of Human Services.

And I would also like to recognize the presence of Representative Boback, Representative Heffley, Representative Cox, and Representative Kinsey.

With that, Kristin, Dave has given me a box up here to keep time, so I’m going to try to figure out how to work it while you’re talking.

DEPUTY SECRETARY AHRENS: Well, I hope you give me 2 minutes to figure it out, because I think I have got a little more than 5 minutes here.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Okay. Well, you can begin whenever you wish.

DEPUTY SECRETARY AHRENS: Sure.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: And again, I would very respectfully ask you to try to stay within the time frame as much as possible.

Thank you.
DEPUTY SECRETARY AHRENS: Will do. All right.

Well, good morning, Chairman Zimmerman, Chairman DiGirolamo, Chairwoman Madden, Chairman Frankel, and Members of the House Health and Human Services Committees and other Senators that have joined us today.

I am Kristin Ahrens. I am the Deputy Secretary for the Office of Developmental Programs within the Department of Human Services, and I thank you for inviting me to testify today.

First, I would like to begin by affirming two things that we all agree on. First, we believe that people with intellectual disabilities should be treated with dignity and respect and deserve compassionate person-centered care that meets all of an individual’s needs. We also know that our State Centers deliver this care every day to their residents.

The Wolf Administration firmly believes that all people deserve the opportunity to live among their peers and their families in integrated, supportive homes. The Administration is leading with this philosophy through our work to increase opportunities for people with disabilities to live more freely in their community and still receive the much-needed supports.

We do not take the decision to close Polk and White Haven Centers lightly. All of us at DHS know that
there are very strong, often competing perspectives on how we care for people with intellectual disabilities. I think it’s imperative to think about this decision in the broader context of how this system has changed and stayed the same over the past century.

Pennsylvania’s State Center system was designed at the turn of the 20th century when institutionalization of individuals with intellectual disabilities was considered the standard of care. At the peak of institutionalization, we housed more than 13,000 people in our State Centers in what were called MR or ID units in Pennsylvania. The majority of both Polk and White Haven residents that are there today were admitted during that time period.

But the world has changed pretty dramatically since the 1960s. Back then, caring for a loved one with a significant disability for families who didn’t have means was often impossible. There wasn’t a community system or much of a community system to support people.

In 1981, Congress enacted the Medicaid Home and Community-Based Waiver. At this point, sustainable funding for community-based services allowed States to invest in establishing strong infrastructure for those community-based services for people with intellectual disabilities and autism.

The trend for deinstitutionalization accelerated
throughout the 1980s and 1990s. Today, Pennsylvania serves more than 40,000 people in community settings. More than a quarter of these people receive services, 24/7 residential services, very much akin to what is provided in our State Centers.

Backed by Federal and State law and policy, parents today expect inclusion as much as possible and individualized supports to allow for that. The millennial generation grew up sharing classrooms and extracurricular spaces with children with intellectual disabilities and autism. That’s the standard now and that’s what they are expecting for their own children.

Today, institutionalization is now a temporary or last-resort option for care. Pennsylvania does have a waiting list for services for people with intellectual disabilities and autism, but it is not a waiting list for State Centers. People are specifically waiting for home and community-based services.

When a person or their family member applies for services, they are provided a choice between an intermediate-care facility or community-based services. The 13,000 people that are on the waiting list today have selected to wait for community services instead of taking that option for an intermediate-care facility, in spite of the fact that there are about a hundred vacant beds today.
in our intermediate-care facilities.

Today, we operate just four State Centers with approximately 700 residents. Each year, this number continues to decline because we have aging residents who pass away and people do move to the community. Admissions happen infrequently, because alternative options are available in people’s homes or elsewhere in the community.

As the census declines, obviously the cost of the facilities grows. The cost now hovers at between $400,000 and $450,000 per year per person in our State Centers.

In May, the House Human Services Committee held a hearing on the State Center system and expanding admissions. DHS was not invited to testify at that hearing. I am aware that following the announcement to close Polk and White Haven Centers, the call to reopen the doors for the State Centers really began in earnest.

DHS does not control State Center admissions. State Center admission policy is governed by interrelated statute, regulation, and case law. Statutes include the Mental Health and Intellectual Disability Act of 1966; the guardianship statute, which does not allow a guardian to voluntarily admit a person to a State Center; and the Federal Americans with Disabilities Act.

So admissions are managed through a process that was established in regulations. The regulations are
55 Chapter 6250, which followed a 1976 court decision which requires that a court determination -- it requires a court determination for anyone to be admitted to a State Center, demonstrating that a person cannot be served in their home or community. This is also consistent with the United States Supreme Court’s decision, the 1999 Olmstead decision.

This decision to close Polk and White Haven Centers was not made to disrespect families’ wishes. The centers may be the only home that some of these individuals have known. Families chose the center because it was the best option available at the time. I need to acknowledge this, because myself and everyone at DHS understands the gravity of this decision.

At the same time, given advances in developing the community infrastructure that I have discussed and the wide array of options that are available in the community, we see very low admissions to the remaining State Centers, and four State Centers are no longer needed to serve this population’s needs. We are confident, based on our experience with the Hamburg closure, that the needs of the State Center residents will be served just as well, if not better, in the community.

It would be irresponsible to make these decisions based on emotion. We have a responsibility to our
families, the residents, the staff at each of these facilities, and also to all Pennsylvanians, and we need to consider the sustainability of the system as it stands. If we don’t make this decision now, then at what point, when there is 50 residents? 20 residents? 10 residents? 1 resident?

With each drop in the census, the cost does rise. That is more funding that cannot be redirected to help people seeking services in the community or people who are on ODP’s waiting list. The more money we spend on serving people in State Centers, a level of care that is available in privately run community facilities, the more people who have to wait for services.

I want to be clear, the decision is also not a slight on the quality of care in the centers. The 1,179 employees of our State Centers provide exceptional loving care to the residents of Polk and White Haven every day.

We are committed to working closely with these employees over the next 36 months to help counsel them towards employment opportunities with the Commonwealth or with the private providers that ultimately may serve many of these residents. All former Hamburg State Center employees who expressed an interest in continued State employment following the closure of Hamburg were offered
jobs with the State.

As we move forward with this process, I hope that all of us -- Members of the General Assembly, advocates, stakeholders, and families -- can work together as partners. Through our experience with the Hamburg closure, we know that is possible. Families who never imagined their loved one could live in the community found placements that exceeded their expectations, and for the first time in their lives, residents had homes that they truly understood to be their own.

These are not just my words; this is actual experience that we heard from individuals and families that were formerly residents of Hamburg. And as part of your packets, I believe you have letters from some of those same residents of Hamburg and their family members.

So I know this is a difficult decision for many people affected. It’s why we are committed to counseling residents, their families, and staff through every step of this process. We began meetings the day of the closure, and those continue regularly right now. DHS will not abandon anyone throughout this 36-month closure process.

I thank you for the opportunity to testify today. On behalf of all of us at DHS, I look forward to working with you on moving this forward.
MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. Kristin, thank you.

And if you would be able to stick around for a little bit, so if there are some questions at the end.

DEPUTY SECRETARY AHRENS: Will do.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: We would very much appreciate it.

DEPUTY SECRETARY AHRENS: All right.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay.

PANEL NO. 2

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: We have a panel next, and I would ask them to come up.

We have Sherri Landis, who is the Executive Director of The Arc; Jamie Ray-Leonetti, who is the Associate Director of Policy for Temple Institute on Disabilities; Jackie Beilharz from the Disability Rights Network; Marian Baldini, President and CEO of KenCrest; and Gary Blumenthal, who is the Vice President of Government Relations and Advocacy for InVision Human Services.

And I would like to welcome everybody. And again, I’m going to ask you to please try to keep your testimony within the 5-minute limit.
If you look on the table, on both corners there’s a green light, and then when you get close to the 5 minutes being up, you’ll see the red light go on, so that way you’ll know that your time is up.

And we’re going to start with Sherri Landis first from The Arc. Sherri, you can begin whenever you would like. Thank you.

MS. LANDIS: Thank you.

As you can see from my notes, I had to abbreviate once I got the 5-minute warning, so I will try to be brief.

I want to thank everyone, Chairman, for having us here today. As you know, my name is Sherri Landis. I’m the Executive Director of The Arc of Pennsylvania.

For the past 70 years, The Arc of Pennsylvania, its 33 local chapters, and 8,000-plus members have worked to ensure that children and adults with intellectual and developmental disabilities receive the support and services they need, are included in their community, and can have control over their own lives.

The Arc of Pennsylvania applauds Governor Wolf, Secretary Miller, and Deputy Secretary Ahrens on the decision to close the State Centers at Polk and White Haven and to transition all current residents to their local community over the next 3 years.
The Arc of Pennsylvania has stood with families who rejected the notion to institutionalize their child, families who created services where no other services existed, and families who decided to move their family member out of a State Center. The Arc of Pennsylvania stands with families.

We know that families are integral to a successful transition, and we are committed to supporting individuals and their families in whatever way we can to make this a successful move from an institution to their own home in a typical community.

Having attended the Polk and White Haven Act 3 hearings and subsequent hearings on this issue, it is evident that many of the people in strong opposition to the closing of Polk and White Haven Centers are the people who make their living there and people who have concerns about the community system. Let me address these issues in greater detail.

Issue 1: Why was the decision made to close two State Centers when there is a long waiting list that exists right now?

There is a misunderstanding about the waiting list. The current waiting list is a list of 13,000 people. It is a list of people waiting for community services, not State Center services. Just opening up the State Center
will not address this waiting list.

People already have an entitlement to State institutions, but people don’t want those services. That’s why they are on a waiting list for community services. And similar to the closing of Hamburg, no person from Polk or White Haven will be added to the waiting list.

Issue 2: Why move people to a community system that has a high turnover and low-paid staff?

The community system currently serves well over 55,000 people in a variety of locations with a variety of services. It is heavily regulated, and monitoring and oversight by various systems are utilized to assure safety.

We know that there is not a system that is perfect. We know health and safety incidents occur to people living at Polk and White Haven. When one looks just at the numbers of reported incidents, it appears the incidents are higher for people living in the community as compared to the number of incidents of people living in the State Centers, but it’s a false comparison. The Centers serve roughly 700 people, while the community serves over 55,000.

We also know that people with disabilities are safer when they live among their families, friends, and community members and others that care about their dignity and safety. Research shows that people are safer in the
community because there are more sets of eyes who see the person. When the community staff see you every day, abuse is more apt to be spotted and action taken. When you are in an institution, only the State Center staff will see an individual.

This is not a commentary of the very good people who work at the State Centers, but it is human nature. This is why the child welfare system no longer places children in orphanages. Despite the imperfections of foster care, this Committee would never argue an orphanage is a better place for a child.

Issue 3: The argued disparity between wages earned by State workers in the institutions versus DSPs working in the community are indeed documented.

But I would be remiss if I did not reiterate that the General Assembly has direct impact on the wages of DSPs. The Arc of Pennsylvania has and continues to ask the Legislature to address the direct support professional salary issue to promote quality. You have the ability to improve DSP compensation and not use it as an excuse to keep people with disabilities needlessly institutionalized.

Issue 4: The closing of Polk and White Haven will result in people living on the streets and in local prisons.
Unfortunately, politicians and those in the media often confuse State mental hospitals with State Centers for people with ID. They are very different systems. Some deinstitutionalization of people with mental illness may have occurred in the seventies without sufficient community-based capacity, but it has never been the case that State Centers for people with ID were closed without proper planning and community-service capacity being in place for people returning to their community. No one from Hamburg ended up in prison or living on the streets.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Sherri, I’m going to have to ask you to try to finish up here, if you can.

MS. LANDIS: Okay.

Once again, thank you for this opportunity to present the views of The Arc of Pennsylvania.

It is 2019. The debate about institutions and whether the community is better was over decades ago. It’s sad the debate is resurrected when one of the few remaining institutions is slated for closure.

Quite frankly, it’s embarrassing that Pennsylvania still operates State-run institutions for people with intellectual disabilities. We applaud Governor Wolf in his decision.
MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. Thank you.

Before our next testifier, I would like to recognize Senator Muth, who is here in attendance. And Representative Klunk is also here in attendance as well.

Up next, we’re going to have Jamie Ray-Leonetti, who is the Associate Director of Policy for Temple’s Institute on Disabilities.

Jamie, you can begin whenever you would like.

MS. RAY-LEONETTI: Thank you, Chairman DiGirolamo, and thank you to the Members of the Health and Human Services Committees for the opportunity to provide testimony here today.

My name is Jamie Ray-Leonetti, and I am the Associate Director of Policy at the Institute on Disabilities at Temple University.

The Institute is Pennsylvania’s University Center for Excellence in Developmental Disabilities, or what we call a UCEDD. We are a Center for Excellence in Developmental Disabilities Education, Research and Service, and we are a statewide program.

We are one of a network of 67 centers that are funded through the Administration on Intellectual and Developmental Disabilities within the United States Department of Health and Human Services to conduct
training, service, technical assistance, research, and
dissemination activities on behalf of people with
developmental disabilities in this Commonwealth. The
Institute has been Pennsylvania’s UCEDD since 1973.

Since 1999, the Institute on Disabilities has
collaborated with the Pennsylvania Office of Developmental
Programs, ODP, to conduct and analyze data from Independent
Monitoring for Quality, or what we call IM4Q, a statewide
initiative to assess the quality of life of people with
intellectual disabilities and autism in Pennsylvania.

This initiative is part of a national effort
called National Core Indicators, in which 46 States
participate. Through National Core Indicators, performance
data indicators have been developed, and States measure
their performance on these indicators.

In Pennsylvania, data are collected from a
representative sample of individuals living in a variety of
settings, including family homes; their own homes; group
homes consisting of one to four and sometimes five-plus
individuals; public intermediate-care facilities for people
with intellectual disabilities, ICF or IDD centers; private
ICF/IDD centers; and Lifesharing situations.

The data are collected through interviews with
individuals with intellectual disabilities and their
families. Trained teams of individuals conduct the
interviews, and each team includes at least one person with a disability or a family member.

The data are collected by nonprofit organizations who are free from conflicts of interest, meaning that they do not provide any waiver services. The Institute on Disabilities analyzes the data and reports are issued for the statewide sample and for each of the 48 intellectual disability programs across the State, as well as for the State Centers.

As of the most recent data, what it shows from 2017 to 2018 is that people living in public ICFs were slightly more satisfied than in other settings. However, with regard to dignity, respect, and rights, the people in the public ICFs experienced less dignity than any other group other than private ICFs. The data are even more troubling, though, with regard to choice and inclusion, where the State ICFs scored significantly lower than any other group.

In addition to the data mentioned, contrary to popular belief, it is not the people with mild disabilities that are most likely to succeed in the community but rather people with the most significant disabilities. As the Pennhurst study showed, there was no one for whom a community placement was not possible.

As a corollary to that, I was once told that for
every person living in an institution, there is a similarly
situated person living in a community program. And I would
like to add to that corollary by saying that for every
person living in an institution, there is a similarly
situated person successfully in the community and a
similarly situated person who is living at home with their
family.

With regard to data at the national level,
according to the State of the States in Intellectual and
Developmental Disabilities, the population of State
institutions has decreased by 12.7 percent nationally and
by 9.4 percent in Pennsylvania. With four institutions
open in Pennsylvania, it is in the top 50 percent of States
with institutions. The annual cost of supporting a person
in a State institution is $255,692 nationally and over
$300,000 in Pennsylvania.

It has been suggested that Polk and White Haven
could be downsized or used for things such as respite, and
to that end I say, ask the families. But not the families
of sons and daughters who live in institutions; ask the
families of sons and daughters who have kept their family
members at home for 20, 30, 40, and 50 years.

On the other hand---

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Jamie, excuse me. I’m going to have to ask you to wrap up,
please.

    MS. RAY-LEONETTI: I’m almost there, Representative. Thank you.

    I am sure that none of these families would find a State Center to be a suitable place for their relative, even for a short weekend.

    Thank you.

    MAJORITY HUMAN SERVICES CHAIRMAN DIGIROLAMO:

    Okay. Thank you.

    Next, we have Jackie Beilharz, who is from the Disability Rights Network.

    MS. BEILHARZ: Thank you very much.

    I am here reading the testimony of Ms. Judy Banks, our Deputy Director.

    Thank you for inviting the testimony from Disability Rights Pennsylvania on the closure of Polk and White Haven Centers.

    Disability Rights Pennsylvania is the designated Federal protection and advocacy system for Pennsylvania.

    We have been the federally mandated protection and advocacy system in our State for over 40 years.

    Our mission is to protect and advocate for the rights of persons with disabilities so they may live the lives they choose, free from abuse, neglect, discrimination, and segregation. Our vision is a
Commonwealth where people of all abilities are equal and free.

Disability Rights Pennsylvania supports the decision of the Pennsylvania Department of Human Services to close Polk and White Haven Centers. Pennsylvania has a long and successful history of closing State Centers and supporting community integration of people with intellectual disabilities.

Through several closures of State Centers, I have been directly involved in helping individuals and their families with their transition planning in preparation for individuals moving into the community. I witnessed firsthand the wonderful and positive transformation of lives and was encouraged by their resiliency and determination to enter a new phase of their lives.

With Hamburg Center, with Hamburg being the most recent State Center to close, that closure empowered 80 people with the choice to live in the community, a place where we all live.

During the Hamburg Center closure, individuals and families became better informed about the closure and transition process and their essential role in those processes. Family members and individuals were given extensive information about community services and supports and opportunities to explore community residential, day,
and employment options, meet provider staff, visit community programs, and to learn about health-care access and health-care providers. In the end, about 50 people and families chose community living. However, all voices were heard, honored, and respected throughout the closure and transition process.

Under the system set up by the Pennsylvania Department of Human Services, if after being engaged and informed about all of the options for community living the person decides they want institutional care, they can still make that choice. However, it is inaccurate to say that individuals with intellectual disabilities and other disabilities cannot live in the community.

For every person who resides in Polk and White Haven Centers, there is a peer in the community. With appropriate supports and services, all people with disabilities can live successfully in the community. Ninety-six percent of people with intellectual disabilities who need services receive those services in the community. These individuals have varying degrees of behavioral health, physical health, and communication needs.

One voice that I would like to include in my testimony at this time is the voice of a man that lived at Hamburg Center since he was a child and who chose to live in the community. This is Gordon Bensing’s statement:
“Thank you for inviting us here today. I have been involved in advocacy for many years and appreciate the opportunity to speak here on behalf of all individuals with special needs. Peter and I lived at Hamburg Center since we were children and I became involved early on in the plans to relocate its residence and close the center. We would like to thank the many people who cared for us at Hamburg Center over the years. They did a fantastic job and we will be forever grateful for that care. Through Excentia Human Services Peter and I moved into our new home in Lancaster County on June 27, 2018. We each received a key to our new home and quickly adapted to our new lives in the community. We each have our own rooms and got to choose the paint color. I chose blue and Peter chose pink. I have always wanted a pet and in December I purchased a Cockatiel which I named Frankie, after one of my good friends at Hamburg. She brightens my days with her endless whistling and talking and has even learned to say ‘Love You Gordy.’ Peter has a beautiful fish tank in his room which we have to turn off at night so he doesn’t stay up all night watching the fish. We are able to spend our days lounging in the sun on the back deck, working in our little vegetable patch, visiting with friends and neighbors, walking in the park, going to church or community events, bowling, fishing, watching football and sporting events in
our man cave, and shopping as we please. It is our choice what time we want to go to bed, what time we want to get up, what music or movies we want to play in our own rooms and even what flavor beer we want to drink while watching the game. Our favorite is Angry Orchard.

“I was asked to speak about how life has changed since moving to the community but I only have 5 minutes so I will highlight the most important. The biggest difference has been the change in Peter’s and my health. I was in and out of the hospital on almost a monthly basis but since moving in June 2018 I have only been admitted to the hospital once. The same goes for Peter. His health is much improved and in fact, after being unable to eat or drink anything by mouth for almost 20 years and receiving all sustenance and fluids with an enteral feeding tube, Peter is now eating and drinking, much to his enjoyment, and has had his feeding tube removed. I am still unable to eat anything by mouth but I do get to do tastings. I tried cotton candy for the first time in my life and MAN was it good. Angry Orchard doesn’t taste too...” good, but that’s okay.

“I want to advocate for other individuals still living in institutional care to have the chance to experience the richness of life that we have since moving to the community. To advocate for the same rights for all
people, no matter their special needs. In closing, let me say...how thankful we are to be here today and even more, how thankful we are for OUR home with Excentia Human Services and to be part of a community where we feel valued and included. Have a great day and don’t forget... GO EAGLES!!! (or GO STEELERS...)” That’s from Peter.

So that’s---

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. Thank you very much.

MS. BEILHARZ: I’m not -- oh, I’m sorry. Let me just, can I make---

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: I’m going to have to ask you, Jackie, please wrap up.

MS. BEILHARZ: I will.

Segregation of people with disabilities is contrary to actualizing the civil rights of people with disabilities. For the first time, many individuals living at Polk and White Haven Centers will be able to do what you and I take for granted -- live in a house that they can call their own; choose where they will live, nearby family and friends if they choose; have a say with whom they live; have wide-ranging options for social and recreational participation; go grocery shopping and choose what they will eat; where they will live; how they will spend their days, evenings, and weekends. The possibilities are
endless.

Thank you.

MAJORITY HUMAN SERVICES CHAIRMAN DIGIROLAMO:

Okay. Thank you.

And before we continue, I would like to recognize the presence of Representative Nelson, who has joined us; Representative Oberlander; Representative Mustello; and Representative Todd Polinchock has also joined us.

Okay. With that, Marian Baldini, who is the President and CEO of KenCrest. You can begin whenever you’d like.

MS. BALDINI: Good morning, and thank you for the opportunity to speak today. I’ll talk really fast and try not to go over the limit.

My name is Marian Baldini. I started working in the field with directions from my grandmother that all people with intellectual and developmental disabilities belonged in the community. I have over 45 years of leadership in this field and currently serve as the CEO of KenCrest.

For over 114 years, KenCrest has served the community. Most of those years were dedicated to supporting children who were not developing as expected and supporting adults with intellectual disabilities.

We serve over 12,500 people on an annual basis.
One hundred fifty community group homes are in our scope of business. Our mission is to help serve people to thrive as our neighbors with or near their families and receive support in their own homes through positive person-centered approaches.

Throughout my career, I have been responsible for transitions for multiple institutions, including Elwyn, Pennhurst, Embreeville, and the Hamburg Center. The teams I have led invested countless hours to ensure that these transitions have been impactful and effective.

It has been more than a few years since we started the work in support of the transition of the residents at the Hamburg Center. Of specific interest to the Department of Developmental Programs was our success in supporting individuals with significant health concerns. At that time, KenCrest operated four highly specialized homes for individuals with complex medical needs requiring 24/7 nursing care, and those were for children or adults.

The process that was rolled out by the Department engaged us right away in meeting and speaking with families. We were directed that proposals would be required which would show our interest and our capacity to serve the individual in their lives, and those families would need to approve those proposals to move forward.
We shared our capacity to serve, and we want you to know the specific responses of the families as we first started working with them. One family was immediately interested in the proposal. The balance of the families were not. Most were skeptical. A few were willing to see what we could offer directly for themselves. Others were interested in the opinion of the social worker with whom they had a trusted relationship at Hamburg. So either the family or the trusted social worker visited our homes.

All of the families who saw what we had to offer or consulted with the social worker agreed to review our proposals. Those proposals took many hours to develop as we got to know the individual’s needs, talk with the staff, review their records, and become truly confident that we could make a difference in those folks’ lives.

We drafted 10 proposals. Eight of those proposals were accepted by the families. After we reviewed those proposals and had them accepted, we deployed a staff of nurses and professionals to continue to visit these individuals and follow them, along with the Hamburg staff, to make sure that we could continue to meet those needs, and that assured both the KenCrest leadership and ODP that we would be current when those individuals were ready and their homes were prepared for them.

Since then, many of these individuals have
progressed in their health and social interactions, and
we’re discovering their interests every day. The community
has rallied around them. All of those residents have
strenthened their connections with their families.

We’re expecting trick-or-treaters again soon at
all of our homes, and we give out candy while encouraging
and educating our neighbors on the care that is being
provided for each of these individuals and to show the
value of the life of people who are different but important
to all of us.

We know how to staff these homes. We have nurses
24/7. We have a primary physician who got to know them
while they were at Hamburg and who continues to make the
old-fashioned house call as needed. We know how to adapt
environments to support complex needs and how to make a
welcoming home with a few things like a track system for
barrier-free support.

I understand that weighing the conflicting
interests is difficult, but I have to tell you that some of
the choices that we have today were not available when
these folks originally went to these institutions. I have
lost track of the number of parents who told me during my
career that they were advised that an institution was the
right choice or the only choice, and in fact in those days,
it was true. We have learned and developed since then, and
we know the real value of inclusion.

What matters most in transition planning now is learning, discovering what is possible, and mobilizing our resources to create something special. We accept that responsibility to ensure that everyone in our care has quality, no matter what their ability, and supporting people to live out their lives in the most meaningful and fulfilling way. And this is by pursuing a choice and knowing what those choices are, which means immersing people into the community and a place close enough for their family to spend time with them.

We were excited to hear that the staff who supported the Hamburg transition from ODP were going to continue to provide the same supports to the families of Polk and White Haven folks.

We invite the Members of the Committee to visit KenCrest’s community homes that specialize in people with medical needs. Over the past year, we have had multiple Legislators visit these homes, and each was extremely impressed with the high level of quality.

On behalf of KenCrest, thank you for listening and for allowing me time to lend a voice of success for those people who are now living as our neighbors.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay, Marian. Thank you.
And next, Gary Blumenthal, who is the Vice President of Government Relations and Advocacy for InVision Human Services. Gary.

MR. BLUMENTHAL: Thank you, Mr. Chair, Madam Chair, and other assorted Chairs and Members of the Committee.

I understand the perspective you all are coming from. I’m a former Legislator. I have participated in the closing of State institutions in other States, and I understand the challenge you have in front of you.

I also respect the feelings, the expertise of the Polk community and the White Haven community. I believe those people have provided excellent care for people under their charge. I also think that it is critically important that we look at the entire array of people in need of services in this State.

I’m not going to read my testimony to you. As a former Legislator, I know you can read, so I’m not going to read it to you. I am going to hope that you will look at the data that I have in my testimony and the data presented by my colleagues here that validate that quality care equal to or better is available in the community.

I want to address the biggest elephant in the room. The biggest elephant in the room here with respect to why this is happening, why the Department has made this
recommendation, why people are coming to you, is the fact
that you as a General Assembly, this Administration, prior
Administrations, have established a multilevel system in
this State. You have established State institutions, you
established community programs, and you have funded them at
significantly different levels. You have a State Center
system that costs 435,000 to 450,000 to support the people
at White Haven and Polk Centers, and you have 13,000 people
on a waiting list.

We would not be here were it not for the fact
that you as a Commonwealth do not and have not provided the
sufficient revenue to support the system that is in place.
As a result, when you make a decision to keep a two-track
or three-track or four-track system that has some people
who are more valued and they have a support system of
435,000, what are you saying to the families of 13,000
people, many with the same disability profile who are going
without services?

You may be receiving hundreds of calls from
people who are upset about Polk and White Haven closing.
There are 13,000 people who are struggling to get through
the day, supporting their loved ones, who cannot make the
calls to you. But when you make the decision of how you
are going to spend revenue, you do that each year.

You also direct ODP and DHS to live within its
budget. You tell them when they are putting together
budgets to live within that budget, come to us with cost
savings, and then when they come to you and say, we have a
difficult choice, that we are operating systems that have
identical people with identical needs with the same level 6
and level 7 disability profiles, but one we’re going to
give a significant amount of revenue to and the other we’re
going to keep a 13,000-person waiting list, I don’t know
how that can be justified.

If you decide to keep these centers open, you may
do so, but tell me what your response is going to be to the
13,000 people who are suffering at home, who also have
aging parents, who have siblings that will die as well who
aren’t receiving any services at all.

I did see that you have proposed a bill, that
apparently it’s going to be acted on today or tomorrow,
that essentially says until everyone receives HCBS services
who are on the waiting list, you won’t allow closure of the
ICFs that are proposed for closure. What is the price tag
of this?

If you have let 13,000 people, and that list of
13 was 14,000 2 years before, 15,000 prior to that, 20,000
prior to that. You’re going to fund everyone on the
waiting list? Are you going to do that? Because that
requires a significant use, effective use of dollars, and
it requires significant tax increases.

Well, I’m a Democrat from Kansas, and I voted for virtually every tax increase that came in front of me. I look forward to the day when this General Assembly does the same so you can support the people who are in need, support the families that are desperately crying out for supports and services.

I don’t diminish the concern, the love, the support that the people of Polk and White Haven feel for the people they support, but when you continue to operate these programs ad infinitum, you are setting up these people at Polk and White Haven to come back year after year, because successive Legislators will also look and say, successive Governors will look and say, what is the cost? Why do we have these two separate tracks that are operating? And they will say, we need to look at cost efficiencies.

So I don’t know that you’re helping families by continuing with a system that is so disproportionate in terms of the amount of dollars it supports. You are setting up these families to come back year after year, to continue to fight, to keep a system that is diminishing in people that want to---

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: Gary, I’m going to have to ask you to wrap it up, please.
MR. BLUMENTHAL: I will, sir.

I hope before you enact this legislation tomorrow you will understand the cost implications of it, and if you decide you want to fund the waiting list, fund direct support professionals who are living on poverty wages, and you want to operate these State Centers, put your votes behind the revenues that will be needed to do this.

Thank you.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. Thank you all to the testifiers.

PANEL NO. 3

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. I’m going to ask our next panel to come up, which is Susan Jennings, who is the mother and co-guardian of Joey from White Haven Center; and Irene McCabe, who is the President of the Polk Center Parents, Friends and Family. And I understand Tom is not going to testify -- is that correct? -- today.

MR. KASHATUS: What was that, Representative?

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Were you not going to testify today?

MR. KASHATUS: If I can; if I can.
MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Well, why don’t you come up. We’ll give you a couple of minutes, if that would be okay. We would love to have you.

MR. KASHATUS: I got one page here.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. Come on up.

And I’m going to ask, Tom, if you would go first, and again ask the panel to please stay within the time frames. And if you look on the corner there, you’ll see a green light, and when it gets close, the yellow light will come on.

Tom, when you’re ready.

MR. KASHATUS: Hello. I’m Tom Kashatus, President of the White Haven Center Relatives & Friends, the family organization of White Haven Center.

More importantly, I’m the son of a bartender, a man who quit school at the age of 12, worked as a breaker, worked at the mines, lost his leg at the age of 22, then he became a bartender, and he educated three kids.

Thank you for the opportunity to come before you to express my opinion on the closure of the State Centers. Over the past 40 years that our daughter has been a resident of White Haven Center, some advocates -- I’ll call them the “Coalition” -- have waged an effort to remove our residents from their home, which is White Haven Center, a
number of times, some by choice and some by a forced
decision. They have almost achieved their goals except
one, and that is to close all State Centers as a matter of
a philosophy that was born out of the loins of the liberal
leadership of the Temple University Institute on
Disabilities.

Over the years, our State Center facilities have
come a long way to excel in professionalism, care, and
services to those who suffer from intellectual and
developmental disabilities and autism. Today, the
residents who are there, they and their guardians and
substitute decisionmakers choose to live on a campus-like
community with a lifestyle where all their required
services are met for a quality of life that they choose and
deserve.

The Olmstead decision actually gave
self-advocates a choice as to where they wanted to live.
Sadly, Olmstead also gave States some latitude here when
making policy. The policy established in Pennsylvania is
to push all those seeking residential services into the
community or private facilities.

Families are not given the opportunity to even
tour a State Center today. In the meantime, the waiting
list for residential emergency services that are offered at
our State Centers continues to grow for the citizens of
Pennsylvania seeking those services, while empty certified beds at State Centers total over 940.

Today, we come to do battle for the lives of our loved ones and those on the waiting list.

First, know your foe, the “Coalition”: Temple University Institute on Disabilities, The Arc of Pennsylvania, ACHIEVA, Disability Rights Pennsylvania, the Waiting List Campaign, Speaking for Ourselves, Self Advocates United as 1, Vision for Equality, and Northeast Pennsylvania Inclusive, just to name a few.

Secondly, the “closed-door” policy initiated by ODP is not working. The waiting list for residential services keeps on growing and growing. As we leave here today, the answer is simple: Just open the doors to our treasured State Centers and let people make their own informed choices for services that they need. And open the doors! Open the doors! Open the damn doors, and eliminate the waiting list.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: Okay. Thank you.

MR. KASHATUS: That’s all I got, sir. Thank you for giving me the opportunity.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: Thank you, Tom.

Next, we’re going to have Sue Jennings.
MS. JENNINGS: My name is Susan Jennings. I’m the mother of a severely autistic young man with intellectual disabilities and comorbid psychiatric disorders named Joey.

Unfortunately, he is not an anomaly. He is not a one-off. When deinstitutionalization started in the 1960s, only 1 in 10,000 births were autism. Today, it’s 1 in 59, and they are coming of age. Forty percent of the DHS caseload is autism, 80 percent of them are children under the age of 18, and they will be coming of age in the next 10 years and they will need intensive services. Between 10 and 50 percent will be just like my son.

Anyway, he began by living in the community, freely in the community, in the group homes, and in the short space of 4 years’ time, he was discharged from six different group homes who could not manage him. They Section 302’d him into psychiatric wards. One of his stays was for 6 months because he had nowhere to go.

It is particularly ironic for me to hear from KenCrest and InVision. KenCrest refused him admittance, and InVision told me they couldn’t manage him.

While he was in the community group homes living freely, he was toxically overmedicated, which left him with Parkinsonian tremors, Serotonin syndrome, and disfiguring female breasts. He was never more isolated and never more
segregated than in the community. They put him in one-person group homes. He was so lonely, he would call us up to 18 times a day.

He was finally rescued by the professional and therapeutic environment of White Haven Center with its skilled, caring staff and its multidisciplinary teams of nurses, doctors, behaviorists, psychologists, therapists, dietitians, and supervisors. White Haven gave him opportunities to socialize at dances, barbecues, trips to restaurants, movies, and amusement parks. There exist no equivalent services in the community. It just isn’t there.

Now, he is one side; he’s the autism side. The other side are the elderly, medically fragile people who have lived at Polk and White Haven for 30, 40, 50 years. They are subject to dying of transfer trauma if they are moved out. Fifteen out of 80 of the Hamburg residents died. That’s close to one in five people died when they were moved away from Hamburg. ODP considers that a great success. Everyone else is appalled by that. That is simply not acceptable.

Now, the Department will tell you that none of the 13,000 people on the waiting list want services in the intermediate-care facilities and the State Centers. I know and my husband knows that as a family, we were kept in the dark as to what ICF care meant, that the State Centers even
existed. We simply had a paper pushed in front of us and said, check off the waiver box. And when I said, what are these three little letters “ICF”? She said, that doesn’t apply to you.

So I unwittingly, unknowingly, signed away my son’s legal rights to ICF care. When I later found out accidentally from my own research about the State Centers, the social workers told me in no uncertain terms, those are closed to admissions and you can’t get in.

Now, I am calling upon our Legislators to please investigate the waiting list of 13,000 people and find out how many of those families were never told what an ICF was, were never told about the existence of State Centers, and were never given any real choice. This needs to be exposed.

Secondly, the assertion that the money taken from the State Centers can be used to substantially reduce or eliminate the waiting list is demonstrably untrue. In 2016 when Governor Wolf poured an extra 196 million into community services -- and that’s 58 million more than the State Centers altogether spent -- they only removed 39 people from the waiting list. I don’t know where the money went.

You were told by the Department that the State Centers are not sustainable, but what do they mean by
“sustainable”? Polk Center has sustained itself for 120 years, and White Haven has sustained itself for more than half a century. All four State Centers account for less than 7 percent of the Office of ODP budget, and they are more efficient, provide superior comprehensive services, and they can pay higher wages and benefits to their stable, professional staff than the community. All of this fiscal efficiency is achieved by the State Centers in spite of the policy of closed admissions.

It is the community system which is unsustainable. They eat up over 93 percent of the ODP budget, and yet, they cannot staff their waiver homes. They lack 11,000 direct support personnel for each shift. They go in and out of business. They neglect to report critical incidents to State authorities, resulting in multimillion-dollar lawsuits against the State, such as the $4.5 million lawsuit being battled in Oregon, where DHS Teresa Miller presided over ICF closures 10 years ago.

The Department and the advocacy groups will tell you that shutting down good institutions like ICFs is the historical trend. They exaggerate. Thirty-nine States have wisely retained their ICFs and are in compliance with Olmstead. With over 900 certified empty beds at the State Centers, why close them when they have the experience and skill to provide needed services for the 13,000 on the
waiting list and for the coming tsunami of young autistic adults coming of age. Why evict the 300 residents who love and appreciate the State Centers? Open the centers to voluntary admissions.

It is decline by design. The census numbers have been declined by design, not by choice. I implore you to sponsor and support House Bill 1918, the moratorium on the closure of White Haven and Polk Centers, until a thorough study and investigation of all the grave consequences of this decision is taken.

Thank you.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. Sue, thank you.

Next, Irene McCabe, who is the President of the Polk Center Parents, Family and Friends.

MS. McCABE: Thank you so much.

I really don’t know how we came to that. Thank you so much. It’s so divided. I feel this division, and I want to apologize. I mean, I want to apologize, because I don’t know how we got to be so divided over something like caring for the most vulnerable people. I don’t know how that happened.

I do think that this is structural disconnect.

Polk is a health facility. It’s licensed by the Department, by the United States Department of Health, and
its head here is Rachel Levine.

Let me go back to my notes. I’m just upset, because I’m so appreciative you are listening and I’m just so kind of done away by this panel that is so not understanding who I am or what I want or how we can achieve it. Let me go back to the notes. I apologize.

Polk is a health-care facility licensed by the United States Department of Health, inspected by the Pennsylvania Department of Health, but the Secretary of Health is not here today to praise Polk, but instead we have people ready here to bury Polk, and that’s a disconnect. It seems harsh, but I am really reacting to their insistence that we all must be compliant with their wishes; otherwise, we have no value. It seems like looking for gold in a silver mine.

I know the value that we have at Polk, and I know the value that we add to the system of care. Polk and White Haven are first and foremost health-care facilities. They are publicly run health-care facilities, run by the Commonwealth for its most vulnerable population as part of the State’s original promise to take care of the most vulnerable population.

And ODP, on the other side, they set group home reimbursement rates for private-pay providers, and they manage policy around that activity, and that’s appropriate,
but that is not health care. It’s a service. It’s a human service. And so there’s disconnect between what is health care and what is a service.

I’m sorry that the doctor is not here to talk about how valuable Polk is, what extraordinary care is given there. As Sue said, we’ve been there for 100 years. We’re the fifth generation of caregivers, and the community supports that effort.

I think that the problem maybe is between authority and power. Health has, the Department of Health has the authority to run the State Centers. They are investigated by the Health Department. But the Human Services has the power to close down, and the difference between the authority to run the facility and the power to close it down creates a vacuum, and into that vacuum indeed has come the University of Temple Institute on Disabilities, who in the vacuum has become like a sole arbitrator of what is good policy and what is good form.

Good ID policy is policy that they say is good policy. It was never -- we were never thought to be a part of that. We were never asked to be a part of that. We never -- we were never considered to be a part of that, and that, I think, is really the problem.

Temple, in my estimation, has taken in more than $30 million over the last 30 years. They get hundreds and
hundreds of thousands of dollars every year because they are an Institute of, the only thing in Pennsylvania, the Institute of Excellence. I think knowing that you get $30 million, you would have thought good form would have indicated to them to share some of that with us, but instead, they rail against our existence.

They put so many more lobbyists on the payroll. It’s me and Joe and Sue. You see us? You see us? This is what -- that’s who you got. I don’t have stationery. I don’t have a lobbyist. I can’t invite you to dinner and get you a plaque. I can barely get the words out, for God’s sake, you know what I’m saying? It’s just us. That’s all they are. Well, and the workers and the people here. I’m just saying, 24 lobbyists is a lot of lobbyists, even in a town that has got a lot of lobbyists.

But what I want you to understand is that intellectual disabilities is a $3 billion business in Pennsylvania, and investing in lobbyists is a business strategy. Sherri was a lobbyist before she took over at Arc and is valued as a lobbyist because that’s -- you need to be a lobbyist to get things prepared and get them going. Or I don’t know; we don’t have lobbyists.

I wanted to ask you---

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Irene, can I ask you to please wrap up?
MS. McCABE: Yeah.

I want to just say that there is big money, and I want you, because I think you maybe forgot to attend to all the money that there is in ODP, there’s currently a $12 million contract that was in Commonwealth Court for a year, and it’s a contract called SIS, and it says that we can move, we can move people from one category to another category. But it’s not a service contract, and it’s not even money to go to the waiting list. I’m just saying, in a business environment, there’s a lot of money and there’s a lot of lobbyists and a lot of slick talk, but we really are here to plead for recognition, and we thank you. Thank you very, very much for your ability to try to solve this problem for us.

Thank you.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: Okay. Thank you, the three of you, for your testimony.

PANEL NO. 4

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: I call our next panel up. That is Panel No. 4 and the last panel. It’s Darrin Spann from AFSCME; Bill Hill, who is the maintenance at White Haven Center and from AFSCME; Tammy Luce, who is the Residential Services Aide at Polk
Center and also in AFSCME. If the three of them would come up, please.

And I would also like to recognize -- I think I have got everybody -- Representative Keefer is in attendance. Representative Schlossberg, Representative Struzzi, Representative Murt, and Representative Innamorato have joined us as well.

Okay. We have only two testifiers? Okay. You can begin whenever you’re ready.

MR. HILL: Okay. Thank you, everybody, for having us. I appreciate it. I appreciate your time and looking into this situation.

Members of the Committee, my name is Bill Hill. I’m a maintenance repairman. I’m also the White Haven Center President of AFSCME Local 2334.

I just want to say that this is a matter of right and wrong, life and death. There is, as we heard before, the transfer trauma and things of that sort.

We, every day, take care of the individuals at White Haven and Polk Centers. We have the training that our aides go through, a 6-week training before they’re even in their homes, a 6-month probation. We have full-time LPNs and physicians and maintenance and everything of that sort. Our drivers are CDL trained. I mean, the care that we give.
And I know we talk about price, but the more people that we put into the facilities to be taken care of, that number comes down, and we all know that. That’s just common economics.

And this needs to be made right. We need to open up the centers. We need to take our most vulnerable citizens and help them.

And I am not disagreeing, there is people that are in the community and they are thriving and they can do very well, but there is some people that need our type of 24-hour, very, very excellent care, very hands on.

Also, when you have your staff that’s familiar. I mean, we have individuals that live at our facility that just the grimace on their face, our aides know what’s wrong. Even though they can’t speak, there’s that care. There’s that everyday care. The individuals see the same people every day, and that care can’t happen anywhere else. It really can’t.

And I urge you to look into this further and investigate everywhere you can. This has to be done.

I thank you for your time.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Okay. Bill, thank you very much.

And next, we have Tammy Luce, who is a Residential Services Aide at Polk Center and also an
AFSCME worker.

MS. LUCE: Thank you.

Members of the Committee, my name is Tammy Luce. I am a Residential Services Aide at Polk Center, and I am also the President of AFSCME Local 1050. Thank you for the opportunity to hear our testimonies.

I know Bill touched on it, but it can never be overstated: We are here for the individuals who we care for at Polk and White Haven. They get taken care of at our centers. They get everything they need. I can’t imagine them out in a group home and not having what they have at our centers.

I hear a lot of talk from DHS about “community-based” settings and “empowering individuals” to make their own decisions. Both of these points are disingenuous. What they need to remember is these State Centers are communities within themselves, and they are crucial parts of the surrounding communities that they are a part of. This is home for these individuals. They have friends and family there. They have activities that they take part in. They have their own store at Polk Center. This is a community.

I don’t know what’s so empowering about forcing them out of their home. This doesn’t seem to be the residents making their own decision. The decision was made
for them and for us as employees, and none of us were consulted, nor were the families of these residents.

The way this was handled was a total disgrace and a slap in the face for everyone who lives and works at Polk and White Haven. If DHS wanted to go through with this, there was a much better way to handle this than the way they did. They need to reverse this decision and go back to the drawing board. There are more humane ways to balance the budget than killing our jobs and ripping vulnerable people out of the place that they call home.

We are here as the voice of the individuals we care for. We are their voice, and they are our hearts. Members of the Committee, please stand with us. Stand against this ill-advised decision to close these centers. Stand up for those who are unable to stand up for themselves. Do the right thing, please.

Thank you.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: Okay. Tammy, thank you.

PANEL NO. 5

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: And we have our last panel: Maria Gunta Ferrey, who is a Residential Services Supervisor/Qualified ID Professional
at White Haven Center and a member of SEIU; and also
Bill Bailey, who is a Psychological Support Specialist at
Polk Center and also a member of SEIU.

   Maria, if you would like to go first.

   MS. FERREY: Thank you, everyone.

   My name is Maria Ferrey. I am a Residential
Services Supervisor/Qualified Intellectual Disabilities
Professional at White Haven Center. I have worked there
for 15 years. I am also the SEIU Local 668 Chief F5
Steward.

   Thank you to those of you who sponsored
House Bill 1918 and those of you who have signed on to it.

   Again, I’m going to begin, as I have said over
and over, we are not an institution. We are the home of
305 people. The residents of State Centers are fully
integrated into their respective surrounding communities,
have participation in community service organizations.

   Everything that has been cited by the previous
panel is offered at White Haven Center -- all of it. We
are members of the Lions Club, Chamber of Commerce,
Knights of Columbus. We do roadside cleanup. Local
businesses ask about our residents. We have forged the
bonds in the community.

   Our residents’ self-esteem is enhanced by our
presence in the community. Those who cannot leave Center
grounds due to the extreme fragility of their medical status enjoy the many activities we bring to them -- therapy animals, family visits, volunteer events, and religious services.

As disturbing as it is, I need to remind you of DHS Secretary Teresa Miller’s words on August 14th when she referred to the closure announcement of White Haven and Polk centers as, quote, “an incredible moment in our history in Pennsylvania.”

Please remember that White Haven Center is situated on 192 acres of what is considered prime real estate. Mr. Kevin Dressler has already admitted that there are interested parties in regards to our site.

Again, Secretary Miller and Deputy Secretary Ahrens, please remember their inability to provide any coherent responses to questions other than their usual evasive and canned rhetoric, manipulation of data, skewed statistics, and outright lies.

Many employees of White Haven Center have been there for decades, upwards of 20 and 30 years, some even 40-plus years. The average age of our residents at White Haven Center is 62. The average length of stay at all State Centers is 47 years. What do these numbers say about the quality of care that we provide?

There is a place for everyone to call home.
Whether it be a group home, Lifesharing, or a State Center, each person needs that individualized care tailored to their specific needs. For many members of the intellectually and developmentally disabled community, the most appropriate and least restrictive placement is one of our four State Centers.

I’m not going to rehash the waiting list. We have heard over and over about it. As was stated previously by our wonderful family members, people on the waiting list are not offered the option of a State Center. So all 13,000 of them were refused services? Even the 5,000-plus who are in crisis? I think that is ludicrous, that if anyone actually believes that. I can guarantee you that some of them would choose State Centers if they knew they were available.

Please know, since the closure announcement, White Haven Center receives two to three calls per week from families who are desperate for services and begging us to admit their loved ones. What does that tell you? That they don’t even know that State Centers exist.

Another question for Ms. Landis: Why has The Arc of Luzerne County publicly stated that there are no current placement options and that they are very concerned about the welfare of our residents if White Haven Center would close one of their own organizations?
In conclusion, please keep White Haven Center and Polk Center open. Open the doors of our State Centers to help these people on the waiting list who don’t even know we exist, that the services are out there for them, especially 5,000 of them who are in crisis.

As Ms. McCabe said, how did we get to this point?

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Thank you, Maria.

Next, Bill Bailey. You can begin.

MR. BAILEY: Representatives and Senators, my name is William Bailey. I work as a Psychological Services Specialist at the Polk Center. I’m also one of the Chief Shop Stewards for the Service Employees International Union there, and I would like to address some of the points that have recently come up.

I did submit written testimony. I’m not going to bother rehashing it, because as someone earlier said, we all know you can read.

My concern right now is how difficult this process is going to be for you. The State Centers were created by acts of legislation, and in testimony you have heard comparing analysis. So people have talked about how studies done after Pennhurst closed 40 years ago showed that everything was so much better.
In my Senate testimony, I actually cited the World Health Organization report from 2000, which showed people forced out of intermediate-care facilities had an 83-percent higher mortality rate.

So there was testimony given today that transfer trauma may not be a real thing. In the report that’s being issued to the families, and this is actually part of the packet, I would like to point out that they indicated of the 74 people who transferred from Hamburg, 13 have died in 32 months. So it’s a percentage. If you do the same percentage with the 300 people between White Haven and Polk, you’re looking at 48 people dying in the first 32 months after these facilities close. That’s a pretty high rate, and it supports that 83-percent higher mortality rate.

As a Chief Steward, one of my biggest concerns has been the absolute lack of transparency from the Departments of Health and Human Services. I brought up during multiple labor-management meetings that we are not being told what’s going on. Everybody seems to believe that this was a sudden decision that was made in August.

In June of 2019, or in July of 2019, the Service Employees International Union was told that two individuals would be role released from their positions to cover what we were told were special State projects. We weren’t told
what those special State projects were. A month later, the
closure announcements were made, and that’s where we were
informed that those two people had been role released to
oversee the SIS assessments and the ALP process. The
processes are being used to expedite people moving out of
the State Centers and into the community.

We also were just told that we have until
December 31st to get those processes done. So the closure
announcements were in August, and despite the fact that the
Departments of Health and Human Services are saying that
this is not going to be done rapidly, that it will be done
with compassion and according to policy, they seem to be
expediting the process as quickly as possible, and no one
is willing to sit down and explain why those numbers are
happening.

Every individual at the State Center has an
individualized service plan review once a year. I asked
the question why we couldn’t just do the SIS assessments
and the ALP assessments during their ISP. I was told the
decision came from Harrisburg that they need to be done by
December 31st. This is 300 people.

There is a lot of disparity around costs
associated. It has already been discussed that we have
open beds at the centers. I work in a building that has
68 people currently in it. We have 150 certified beds just
in that building alone. So we could double the population just in one building at the Polk Center. There are five buildings at the Polk Center that currently have certified beds. If you add more people to the Centers, the cost goes down. The per diem annually goes down.

No one wants to address the fact that despite the proposals to support people in the community, no one has actually addressed how they plan on addressing the current 4,905 individuals who are on the emergency-needs waiting list. That number went up by 200 over the last 18 months. That’s available as public knowledge.

I’m concerned, because since August -- the announcement in August took everybody by shock, but since that time, no one seems to be giving any information on what is going on. The House Bill 1918 really is looking at a moratorium to slow things down so that you as the Legislature can make a more informed decision. And I really truly hope that that bill passes, because things are happening very quickly.

Once December 31st rolls around, in theory, every single individual at the White Haven and Polk Center will have all the paperwork necessary to move into the community. I don’t understand why this is happening with such quickness. To me, it doesn’t seem like it addresses the needs of care. It seems to be more like something akin
to human trafficking.

That’s all I have to say.

MAJORITY HUMAN SERVICES CHAIRMAN DIGIROLAMO:
Okay. Thank you all for testifying.

I’m going to open it up now for questions, or if there is not questions, for comments. And we have about a half hour left, so what I’m going to do is ask the Committee Chairmen, the four Chairmen, if they have any questions first, and I would ask them to try to leave it to one question and keep it under 5 minutes.

I’m not going to ask any questions, although I have quite a few, and I’m going to ask Representative Zimmerman from the Health Committee first for questions and answers.

MAJORITY HEALTH ACTING CHAIRMAN ZIMMERMAN: Thank you, Mr. Chairman.

So I guess my question kind of revolves around the wrap-up here. So do I understand closure, that that information, you were given that information in August and you’re to be closed by December? No?

MR. HILL: No.

MR. BAILEY: A 3-year plan.

MAJORITY HEALTH ACTING CHAIRMAN ZIMMERMAN: A 3-year plan.

MR. BAILEY: But all of this paperwork---
MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Please talk into the mic when you’re answering questions.

MR. BAILEY: In August, it was announced that there was a 3-year plan to close the White Haven and the Polk Centers.

MAJORITY HEALTH ACTING CHAIRMAN ZIMMERMAN: Okay.

MR. BAILEY: We had testimony before the Senate, and after that we found out that the SIS assessments and ALP assessments were expected to be completed for all residents of the two centers no later than December 31st.

MAJORITY HEALTH ACTING CHAIRMAN ZIMMERMAN: Oh, okay. Okay. Because it would clearly take time to get those residents taken care of in another way.

MR. BAILEY: Yes.

MAJORITY HEALTH ACTING CHAIRMAN ZIMMERMAN: Yeah. Okay. Thank you.

MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN: Thank you, Mr. Chair.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: Representative Madden.

MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN: Thank you, Mr. Chairman.

I have a comment, and then I have a question for Sherri Landis.

So I spent a number of years teaching children with intellectual disabilities, anywhere from a mild
disability to a severe disability, and so I know that when we were working with a 20-year-old grown man who had cerebral palsy, who was blind, who was nonverbal, and it was time to change his undergarments, I was kicked in the jaw. It would take everybody in that classroom, and there were three of us, just to take care of that gentleman until it was, you know, we were done. And we had a number of children like that.

So I guess my question is, how many people are you anticipating to each group home, and how many people do you anticipate will be taking care of those people?

Just let me add one more thing, because I have been getting phone calls from my constituents who say, my son, one in particular who came to see me -- it brought tears to my eyes -- said, my son requires so much attention that maybe after 3, 4 hours at the most, he has to be passed off to someone else because he just exhausts people.

And I'm just trying, in my head trying to figure out how that works in a group home setting. If you have maybe four to six people in a group home setting, you know, what is the ratio? Is one person taking care of one person? Are there extra people for those people who require that extra level of care?

MS. LANDIS: So let me first clarify something.
So The Arc of Pennsylvania, even though we have some chapters that are providers, that’s not the majority of our chapters, do not provide DSP. We do not -- some have group homes. Some have community programs. But we are not a provider organization, so I am not able to ask you what the ratio is.

What I can tell you is that the group homes operate very much probably like Polk. There is probably -- and White Haven. There is probably a shift change, you know. I can’t give you the ratio.

And I think people with significant, you know, challenges in the community, I think that Sue Jennings’ point is well taken. But let me tell you that there are, for every person that is in the State Center, there is a replicate in the community right now. I mean, we are providing the majority of care for the majority of people out there.

And I guess the question, because I keep hearing about this waiting list, the waiting list. The waiting list, if you’re going to fund it, the bill says about putting a moratorium until everyone is off the waiting list. Do you know the Fiscal Code to that? It’s billions of dollars.

So if you are going to address the 700 people in White Haven and Polk, what are you going to say to people
who are waiting for care, because you can’t do both. We’re
not -- the waiting list is not being helped at all.

MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN:
And one quick question.

The 13,000 people who are on the waiting list,
every one of their families have been contacted and every
single one of them said, no, we don’t want to go into an
institution; we want to be in a group home -- every single
one of them, including the ones in crisis.

MS. LANDIS: So---

MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN:
Because you did allude to the fact that they wanted to be
in group home settings.

MS. LANDIS: So once again, I can’t speak for
13,000 people. I mean, there are, there’s a person---

(Audience talking.)

MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN:
Be respectful, please.

MS. LANDIS: Well, that doesn’t happen either.

So I can’t speak for the waiting list, because
Ned Whitehead is not here. But I can’t imagine, and I
think Kristin Ahrens said that in today’s society, they are
demanding more inclusion, and I cannot imagine that they
are demanding getting in to a State Center.

    I have employees that work for us with children
with significant medical and complex needs, and they are
choosing. Her biggest fear is that she will end, that her
daughter will end up in an institution once she passes.

        MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Okay.

        MINORITY HUMAN SERVICES ACTING CHAIRMAN MADDEN:
Thank you.

Thank you, Mr. Chairman.

        MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Representative DeLissio.

        And please, I might ask to be---

        REPRESENTATIVE DeLISSIO: Very short,
Mr. Chairman.

    Two things.

    In terms of a comment, Mr. Chairman, I am hoping
that we can sincerely develop a format here where a lot of
good questions that I’m sure we have will be able to be
funneled to somebody or some group and then get good
answers that we can disseminate, and particularly where
there is conflicting information. Or maybe the
information, these are accurate by omission or commission?

        I have extensive notes from this testimony, and,
for instance, I heard very clearly, perhaps I heard wrong,
that only a court can admit somebody to an institution. So
opening up the waiting list is not a court. Court is
court. So lots of clarification is needed.

The one thing I will comment on the legislation
since it is now running tomorrow, and I do sit in the
Health Committee, if we equate, and I have only spoken to
one of the prime sponsors, not all three yet, but if the
Medicaid Waiver-eligible individuals have received
authorization and it only happens when funding is
available, then this is not a moratorium, as I understand
moratorium. Because by my calculations, that task force
would convene somewhere around the 12th of never.

Now, I have been in this Legislature 9 years, so
I have sat through nine budgets, and I am very familiar
with the allocations that have been and the fact that the
waiting list also grows as well.

So this, to me, is not a moratorium, and I am
hoping that this task force will convene concurrently with
this discussion and almost immediately, which will serve a
lot of the needs that I have heard today: one,
transparency; the other, the ability for significant input
by all parties.

As the Chairman said, I appreciate this is not an
easy discussion, at all.

Thank you, Mr. Chair.
MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Representative Toohil.

REPRESENTATIVE TOOHIL: Thank you, Mr. Chairman.

My questions are to be directed to Deputy Secretary Ahrens, if possible. And I would just like to thank all of you for availing yourselves of this very difficult hearing.

I have just a number of short questions.

DEPUTY SECRETARY AHRENS: Sure.

REPRESENTATIVE TOOHIL: Thank you.

What is the estimated cost of the closure of Polk?

DEPUTY SECRETARY AHRENS: The long term, we will have savings from the closing of Polk.

REPRESENTATIVE TOOHIL: But---

DEPUTY SECRETARY AHRENS: During the transition period, we are not anticipating savings. We are currently working with the Appropriations staff right now, so we will have the full analysis to the Appropriations staff.

REPRESENTATIVE TOOHIL: So there is an estimated cost to closure?

DEPUTY SECRETARY AHRENS: During the---

REPRESENTATIVE TOOHIL: Do you have some of the number of that?

DEPUTY SECRETARY AHRENS: During the transition
period, there will not be savings.

        REPRESENTATIVE TOOHIL: Okay. But there’s---

        DEPUTY SECRETARY AHRENS: Savings will occur
post-closure.

        REPRESENTATIVE TOOHIL: So there has been no
estimation of what the closure for the Polk facility would
cost?

        DEPUTY SECRETARY AHRENS: The savings from it?

        REPRESENTATIVE TOOHIL: No, the cost of closure,
for implementing closure.

        DEPUTY SECRETARY AHRENS: Correct. We are
currently---

        REPRESENTATIVE TOOHIL: Is there a ballpark or an
estimation?

        DEPUTY SECRETARY AHRENS: We are currently
working with the Appropriations staff, so we’ll have that
full analysis shortly.

        REPRESENTATIVE TOOHIL: Would that be in the
Senate or the House?

        DEPUTY SECRETARY AHRENS: We are working with all
of the Appropriations staff.

        REPRESENTATIVE TOOHIL: So then it would be the
same answer for White Haven---

        DEPUTY SECRETARY AHRENS: Correct.

        REPRESENTATIVE TOOHIL: ---it’s just undetermined
the cost of closure.

And what is the cost for services of the 13,000 waiting? What’s the estimated cost? Maybe you in the spring testified what that would be, the cost for us as the State to provide for the entire 13,000 on the waiting list.

DEPUTY SECRETARY AHRENS: So the thing to understand about the waiting -- there’s a few things to understand about the waiting list.

First of all, the waiting list is 13,000 people. About 5,200 of those individuals are in what we consider the emergency category, needing services now or within the next 6 months. The types of services those individuals need vary. Some of those individuals are looking for a 24/7 residential-type program. Some of those individuals are looking for supports with employment, respite care for their family members, so that varies.

The remainder of the people of that 13,000 fall into two categories. One is critical, which means people need services within the next 2 years, and then we also have what is called the planning category, so people know they will need services within the next 5 years. So to do that analysis, you really have to take all of that into account.

The other thing that we need to understand about the waiting list is only about 20 percent of people who
have intellectual or developmental disability are even known to our system currently. So we currently have about 57,000 people that are enrolled for services, but there are many more people out there in Pennsylvania that have a diagnosis, if we just look at census data and prevalence, that are unknown to us.

So what we see with the waiting list is, as people approach graduation from high school, we see -- that's when people come to us. So definitely the waiting list contains a spike around age 17, 18 when individuals and families are starting to prepare for that transition.

So it is definitely a very dynamic waiting list, and what people are looking for varies tremendously.

REPRESENTATIVE TOOHL: That's very helpful.

And is there, of the 5,200 emergency individuals, is there a ballpark number for the State looking at funding that if the Legislature -- I mean, many of us are here today.

DEPUTY SECRETARY AHRENS: We can provide that for you.

REPRESENTATIVE TOOHL: Oh, that would be excellent.

And you had mentioned in your testimony that there was a percentage of Hamburg employees who were, this is just on the staffing side, that during the Hamburg
closure, that there was a percentage that were offered
employment, or they were specifically offered State
employment. Can you---

DEPUTY SECRETARY AHRENS: By the time -- by
June of this year, every Hamburg employee that wanted
State employment was offered State employment.

REPRESENTATIVE TOOHIL: So would that be
considered a cost shift and not a savings?

DEPUTY SECRETARY AHRENS: Well, I can only tell
you about the impact on our system. So we did have, some
of those individuals did move to one of our other State
Centers. They moved to employment in one of our other
State Centers. Others moved on to Corrections or the
county assistance offices. So in terms of, I can only give
you the budget for ODP.

REPRESENTATIVE TOOHIL: And just two more really
quick ones.

DEPUTY SECRETARY AHRENS: Okay.

REPRESENTATIVE TOOHIL: So we had had the hearing
in May with the Human Services Committee where Tom Kashatus
from White Haven and Sharon McCabe from Polk and
Susan Jennings, White Haven, had testified. Do you feel
that that testimony had a negative impact or that
White Haven and Polk could be somehow considered to be more
vocal advocates and that that then somehow translated into
what is occurring today with closure?

DEPUTY SECRETARY AHRENS: No.

The State, the decision to close State Centers takes into account a lot of factors. So as someone who administers programs for ODP, you know, we are constantly looking at all of our programs, and some of the things to take into account when you are looking at the four State Centers are the age of infrastructure, the condition of infrastructure, the census, where admissions are coming from, any kind of hiring issues, the number of residents, cost per resident. So all of those things are taken into account -- the needs of the individuals being served in each of those centers.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Kristin---

DEPUTY SECRETARY AHRENS: So decisions about center, which center, is really based on that combination of factors.

And to give you an example of age and condition, in terms of Polk Center, I think, you know, some of the information that has hit the news is about the water treatment plant and how we are proceeding with this big capital project around the water treatment plant. But that’s not actually even the end of the water problems that we have at Polk. We have had Legionella at Polk since
December of 2018 and have been working to eradicate it.

Our last series of tests, we still have Legionella at Polk---

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Secretary, thank you. I have other people that want to ask questions, so thank you.

DEPUTY SECRETARY AHRENS: Sure.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Representative Toohil, thank you.

Representative Mullery.

REPRESENTATIVE MULLERY: Thank you, Mr. Chairman.

I had a whole line of questions, but given the time, I’m going to limit it just to two that caused some headshaking by people who testified when Ms. Jennings testified.

The first is for you, Ms. Landis.

You testified pretty adamantly that nobody from Hamburg Center ended up in prison or in the streets. I don’t think it can be denied that some ended up in the morgue.

When Ms. Jennings testified and said that there was 15 of 80, you pretty vehemently shook your head no. So I’m going to give you the opportunity now to tell us why you were shaking your head no, and if you have a different number than that, please share it with us.
MS. LANDIS: It’s not about different numbers, Representative; it’s about the average of fatality with the people who live in State Centers is approximately five a year. So when you take 36 months, it’s, you know, 3 years times five is 15.

REPRESENTATIVE MULLERY: You are not in any way insinuating that transfer trauma is not real and will not have an effect on the people at White Haven Center or Polk Center, are you?

MS. LANDIS: I am not saying that transfer trauma is not real. I am not a physician and I can’t, I can’t say that it would. It’s a possibility; yes.

REPRESENTATIVE MULLERY: You were present at the Senate hearing. We did have a physician there, and he talked about how real it was and he estimated the number of deaths that would be expedited by the move, correct?

MS. LANDIS: I was, correct, because we were the only two -- I was one of two advocacy organizations that was allowed to testify at the Senate hearing.

REPRESENTATIVE MULLERY: Given your extensive history in this field, what has been your experience in the rate of transfer trauma with closures of this type?

MS. LANDIS: I don’t have an extensive experience in this field.

REPRESENTATIVE MULLERY: Does The Arc have an
acceptable number or an acceptable percentage of transfer trauma deaths in the name of full community inclusion that is acceptable to The Arc?

MS. LANDIS: Representative, I mean, no. There is no acceptable number of deaths. But look at the average age of people who live at the State Centers, and some of these people are going to pass away. It’s part of life.

To directly point the finger at transfer trauma I think is -- we’re all taking a stab in the dark. We’re all looking at the numbers the way that we want to look at them. It’s---

REPRESENTATIVE MULLERY: Thank you.

DEPUTY SECRETARY AHRENS: I would be happy to---

REPRESENTATIVE MULLERY: I’m getting you next.

DEPUTY SECRETARY AHRENS: Okay.

REPRESENTATIVE MULLERY: Because the second headshaking I saw occurred when Ms. Jennings referenced Secretary Miller’s work in Oregon. A quick LinkedIn check will confirm that both you and Secretary Miller had extensive work history in Oregon. So why on her testimony to that was your head shaking so much?

DEPUTY SECRETARY AHRENS: To my knowledge, Secretary Miller didn’t work on ICF issues in Oregon. I did work on ICF issues in Oregon in the late eighties, early nineties.
REPRESENTATIVE MULLERY: Okay.

And the SIS assessments that are being performed right now in the Commonwealth are being performed by KEPRO, correct?

DEPUTY SECRETARY AHRENS: That’s correct.

REPRESENTATIVE MULLERY: Are you aware that KEPRO was the agency hired to perform the SIS assessments in Oregon?

DEPUTY SECRETARY AHRENS: I was not.

REPRESENTATIVE MULLERY: Okay. Are you aware that in Oregon right now, there are multiple lawsuits against the State of Oregon and KEPRO for the way they are handling the SIS assessments?

DEPUTY SECRETARY AHRENS: I am not, and I would like to know what that has to do with what is happening here with SIS assessments.

REPRESENTATIVE MULLERY: Well, I mean, are you aware that every SIS assessment that was completed by KEPRO in Oregon that has been challenged has been overturned?

In short what I’m saying is that every assessment done by KEPRO in Oregon that said a patient’s service could be provided in the community upon more closer inspection was deemed that it could not. Are you aware of that?

DEPUTY SECRETARY AHRENS: So KEPRO does not make recommendations for the State of Pennsylvania. Our
contract with KEPRO is for them to administer a
standardized normed instrument called the Supports
Intensity Scale. We do this to the tune of about a
thousand people in our community settings each month. We
have been applying this across our service system,
including State Centers.

It is an assessment used in 20 States,
internationally, that gives us a standardized way of
looking at an individual’s needs. It does not tell us how
to meet those needs or where to meet those needs.

REPRESENTATIVE MULLERY: My last thing isn’t a
question, it’s more of a comment.

To hear you, Ms. Ahrens, talk about the factors
that went into the consideration for these closures is
extremely disingenuous. I mean, it is crystal clear, and I
believe it was stated at a meeting in White Haven, that the
reason for these closures has nothing to do with budget.
So to hide behind budgetary numbers is, again, the only
word I can come up with here in a polite manner is
disingenuous.

This is a philosophical decision. I mean, is
that something that you’re willing to stand by today, that
it is the philosophy of this Administration that people
should not be treated in institutional care, that they
should be treated in the community, and this has nothing to
do with budget?

DEPUTY SECRETARY AHRENS: Ultimately, the
Wolf Administration has been very clear that
philosophically, yes, people should be served in their
communities close to their families. That was the driving
force behind the decision here, the driving force behind
the decision to close Hamburg as well, the driving force
behind the incredible waiting list initiatives that this
Administration has put forth. But also, budgetarily, it is
unsustainable to continue to manage four State Centers.

REPRESENTATIVE MULLERY: And that’s where you
went too far, and I would urge my colleagues on the
Health Committee, the Human Services Committee, do not fall
into the budget trap. This has nothing to do with budget.
So don’t buy into it. If you have any questions, don’t ask
them. This has nothing to do with budget.

Thank you, Mr. Chairman.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:
Okay.

(Audience applause.)

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: I
have three Members that have asked. It’s Representative
James, Representative Murt, and Representative Heffley. If
I could ask them to maybe just limit their time to 2 minutes, maybe make a statement, if that’s possible.

REPRESENTATIVE JAMES: Sure. No trouble.

MAJORITY HUMAN SERVICES CHAIRMAN DIGIROLAMO: Representative James.

REPRESENTATIVE JAMES: Thank you, Mr. Chairman.

I believe if there is a response to my comment/question, it will probably come from members of Panel No. 2, which just to remind us includes The Arc, Temple, the Disability Rights Network, KenCrest, and InVision.

First of all, thank you very much for your advice on how we can take our $33 billion annual budget and appropriate it according to your wishes. We’ll be sure and let the taxpayers know how you feel about voting for a tax increase.

One of the first things we learn here when we come to the House is not to call into question the motives of any other Member when he or she is talking on the floor. I detect a tone of negativity from Panel No. 2, which is usually the haven of people who are losing the argument. To besmirch the workers, the 1,100 workers of these two institutions by saying their only reason that they are interested in keeping them open is to save their jobs is just, that’s the wrong thing to say.
I have talked with members out there frequently. I have never had a question about save my job. All the questions come, what’s going to happen to Mr. X, Miss Y? So that part is wrong.

You folks will go to the mats, literally, to defend the preferences of academics, nonprofits, and the Department of Human Services people, but you won’t even talk to the guardians of the people who live and thrive in these institutions.

(Audience applause.)

REPRESENTATIVE JAMES: I don’t know how you can justify that. You’re welcome to try if you want to.

The other thing I want to point out is, a comment was made to me this morning by another Member -- I won’t identify that person -- that they actually talked to one of your folks from Arc who said, are you serious about you want to keep that center open just to save the job of a gas station attendant? I can’t believe that was said either. Bad deal.

At Polk Center, it’s $134 million a year, $134 million a year that goes into our economy. Seven hundred forty people are going to have one dickens of a time trying to find employment. I don’t really think
you're going to be able to fill those bills.

So you're welcome to---

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: No,
we're not going to allow you to answer the question. It's
against time, and I can't allow you to answer the question.

REPRESENTATIVE JAMES: Okay. So I guess I'm
done. I -- thank you.

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Thank you.

Representative Murt for just a brief comment.

REPRESENTATIVE MURT: Thank you, Mr. Chairman.

This will be a statement.

Mr. Chairman and Members of the Committee, I
concur with the speakers that talk about the quality of
life in the State Centers. I visited every State Center,
some two or three times. I was at White Haven not too long
ago. I went with Mrs. Jennings and Mr. Kashatus and so
forth. And I would certainly encourage the Members of this
Committee to visit these centers as well so you know what
we're talking about here and you know what the dynamics
are.

You know, when we were listening to all the
testifiers and so forth, you know, sometimes I ask
rhetorically out loud in my mind, what problem are we
trying to address here? This is a system that works. This
is a system that delivers care with compassion.

And, you know, the one thing I didn’t hear today, because I came in late, but I’m sure it was said, you know, for many of the residents at the State Centers, our staff that care for them are family, because some of them don’t have family to visit them. White Haven is a long way from Philadelphia, especially on public transportation, and many of the families just cannot come and visit their loved ones at White Haven, or at Polk, for that matter.

And this is the last thing I will say. If we really want to address this in a meaningful way, we have to fund the waiver program and we have to fund programs and services for adults with special needs. Every year during the budget cycle, we grovel, some of us grovel, some of us beg, some of us plead for more money to take care of adults with special needs.

The one population we didn’t talk too much about today are the Pennsylvanians who have intellectual disabilities or developmental disabilities who are adults, some 60 and 65 years old, who live home and are cared for by their parents who are 90 years old. I kid you not. This is in every legislative district. And what are they waiting for to get a placement into a group home? They’re waiting for one of their parents to die. And this is a very, very sad reality, a painful reality, but this is
something that we have to address.

And I hope all the elected officials in this room, my colleagues, I hope we remember this conversation during the budget hearings for the next 6 or 7 months when we’re asking, begging for more money to address this crisis.

The last thing I’ll say for any family members like Mrs. Jennings or Tom Kashatus or anybody who has a loved one in the system, if this is where you want your son or daughter, this is where they belong, and we should be making that a reality.

Thank you.

(Audience applause.)

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Representative Heffley for a brief comment.

REPRESENTATIVE HEFFLEY: Thank you, Mr. Chairman.

And this is one of numerous hearings we have held on this issue, so I want to thank you for your leadership on here.

And just to follow up with the philosophical question earlier or the statement that it is a philosophical difference, I would just say, as Representative Murt had suggested, these folks have chosen
to be in these facilities. They don’t have to be there, right? There are some options in the community. But just to say that now we’re going to force them, we’re going to take that option away, so we are taking options away from them and their families. Because this is a level of care, and a lot of these folks have been through the system already and this is where they settled; this is where they’re going to get the best care.

My other concern is with the mental health. Some of these individuals need this type of care and they need to be in this type of facility, and when you put them in another setting, it could lead to issues with the criminal justice system, or, you know, some of these folks just need that type of care, and I’m very concerned about it.

I was actually contacted by a woman in my district, an elderly woman, who her son was in one of the State facilities, and she was deathly afraid of him getting, you know, released into another setting because of threats that he had made. And she had done everything for her son and found that this was the best for her and also for the safety of her family because of the conditions that he had.

So I think that those need to be taken into consideration, and I would hope that it’s not just about a philosophical difference. This is about individuals and
the level of care that they need. So I think that they should be put first. It’s not about, you know, the economic impact that these facilities have on the community is very important, but at the end of the day, my concern is for those individuals receiving the care that they need.

So thank you, and I hope that will be the number-one consideration as we move forward.

(Audience applause.)

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO:

Thank you.

I’m sorry, we have to -- I want to just make a quick comment, because we have to be up on the floor at 1 o’clock, and it is just 1 o’clock now.

I want to thank everybody for their testimony today, from both sides. And my comment is that there’s a bill; it’s a moratorium bill. It’s House Bill 1918. I know the Senate has a similar bill over in the Senate. The bill in the House was sent to the Health Committee, and from my perspective, if the bill comes out of the Health Committee and comes up for a vote on the floor, after what I’ve heard today, I am a “yes” vote on that bill.
(Audience applause.)

MAJORITY HUMAN SERVICES CHAIRMAN DiGIROLAMO: So with that, I would like to call this hearing of the Human Services and Health Committees, ask that it be adjourned.

Thank you.

(At 1 p.m., the joint public hearing adjourned.)
I hereby certify that the foregoing proceedings are a true and accurate transcription produced from audio on the said proceedings and that this is a correct transcript of the same.

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