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MONDAY, MARCH 21, 2016
10:00 A.M.

PRESENTATION ON INTELLECTUAL DISABILITIES ACROSS THE LIFESPAN

BEFORE:
HONORABLE THOMAS MURT, ACTING MAJORITY CHAIRMAN
HONORABLE JOE EMRICK
HONORABLE TEDD NESBIT
HONORABLE JACK RADER
HONORABLE BRAD ROAE
HONORABLE CRAIG STAATS
HONORABLE JUDITH WARD
HONORABLE DAVID ZIMMERMAN
HONORABLE STEPHEN KINSEY
HONORABLE DANIEL MILLER
HONORABLE EDDIE DAY PASHINSKI
HONORABLE MIKE SCHLOSSBERG

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COMMITTEE STAFF PRESENT:
VALERIE BAROWSKI
MAJORITY RESEARCH ANALYST
PAMELA HUSS
MAJORITY LEGISLATIVE ADMINISTRATIVE ASSISTANT

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DEMOCRATIC EXECUTIVE DIRECTOR
RACHEL ROMANOFSKY
DEMOCRATIC RESEARCH ANALYST

INDEX

TESTIFIERS

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TESTIFIERS (continued):

SUBMITTED WRITTEN TESTIMONY

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(See submitted written testimony and handouts online.)

P R O C E E D I N G S

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ACTING MAJORITY CHAIRMAN MURT: Let’s begin with the Pledge of Allegiance. Could everyone please rise.

(The Pledge of Allegiance was recited.)

ACTING MAJORITY CHAIRMAN MURT: Good morning, everyone. Welcome to our hearing.

We’ll be discussing intellectual disabilities across the lifespan.

Before we call forward our first panel, I’m going to ask everyone, all of our staff members and the Representatives that are here, to please introduce themselves.

My name is Representative Tom Murt. I represent part of Philadelphia and part of Montgomery County, and I’ll just be chairing until Representative DiGirolamo gets here.

MS. BAROWSKI: Valerie Barowski, Research Analyst, House Human Services Committee.

REPRESENTATIVE MILLER: Dan Miller, 42nd District.

REPRESENTATIVE NESBIT: Tedd Nesbit, 8th District, Mercer and Butler Counties.

REPRESENTATIVE ROAE: Brad Roae, 6th District, Crawford and Erie Counties.

REPRESENTATIVE RADER: Jack Rader, 176th District, Monroe County.

REPRESENTATIVE ZIMMERMAN: Dave Zimmerman, northeast Lancaster County.

REPRESENTATIVE SCHLOSSBERG: Good morning.

Mike Schlossberg, 132nd District, Lehigh County.

MS. ROMANOFSKY: Rachel Romanofsky, Research Analyst for the Democrats.

MS. McCAHAN: Ashley McCahan, Executive Director for the Democratic Chairman.

REPRESENTATIVE KINSEY: Representative Stephen Kinsey, Philadelphia County.

ACTING MAJORITY CHAIRMAN MURT: Also, I just want to recognize Pam Huss, who is here from the Human Services.

And I also recognize one of my interns that is here today, Danielle Moore from Lafayette University, a graduate of Hatboro-Horsham High School from my district.

Just a reminder that today's hearing is being recorded.

PANEL ONE

ACTING MAJORITY CHAIRMAN MURT: I would ask our first panel to please come forward: Secretary Thaler; Celia Feinstein from Temple University; and Sheila Stasko from the Waiting List Campaign.

Good morning.

MS. THALER: Good morning.

MS. FEINSTEIN: Good morning.

MS. STASKO: Good morning.

ACTING MAJORITY CHAIRMAN MURT: Thank you for being here today.

Before you testify, I just wanted to mention briefly, in my opinion, what we're doing here today is the highest moral ground there is in politics. This isn't even politics; this is public service what we're doing here.

This is the most important issue for me personally, and for many of my colleagues as well. Caring for adults with intellectual disabilities and autism and caring for our brothers and sisters who have challenges with mental health is really a very, very important issue, and we are very grateful for all the testifiers who have taken the time out of their busy schedule to be here today.

DEPUTY SECRETARY THALER: Good morning to the Members of the House Human Services Committee and the staff.

My name is Nancy Thaler, and I am the Deputy Secretary of the Office of Developmental Programs within the Department of Human Services. And on behalf of Secretary Dallas, I would like to thank you for the opportunity to present testimony regarding DHS's efforts to support citizens of the Commonwealth with intellectual disabilities and with autism and their families to achieve greater independence, choice, and opportunity in their lives.

DHS provides services for over 53,000 people with ID and/or autism. The vast majority of the people DHS serves -- that is 70 percent or over 36,000 -- are living at home with their families. Services are funded predominantly through Medicaid and with State and local funds through county government.

Specifically, there are three Medicaid home and community-based waivers which fund services in the community. The three programs serve approximately 31,060 people, and the three of them are the Person/Family Directed Supports Waiver, which serves over 13,000 people and is itself capped at a $30,000 limit per person; the Consolidated Waiver, which serves 17,500 people and has no cap; and the Adult Autism Waiver, which serves about 560 people and has no cap.

In addition, the Department of Human Services operates an Adult Community Autism Program known as ACAP, which is a managed-care program for individuals with autism, and it serves about 152 people.

Finally, DHS funds institutional services in private intermediate-care facilities for people with intellectual disabilities -- there are about 2,200 people in that program -- and our State-operated facilities, which have today approximately 950. In addition to all of those Medicaid-funded programs, our county programs serve approximately 20,000 people with a combination of State and local funds, and that together makes up the 53,000.

Services have been evolving over the years, and we have made tremendous progress from the 1970s when almost everyone was receiving services in an institution away from their families and community. In today's reality, almost everyone is living with their family or in supported homes in the community.

But our progress has been more than changing the location of services. Providing services to people in the community has changed the program's focus and goals. Our goal is not simply to provide care but to create opportunities for growth and learning, to help people get a job, practice their faith, join a health club, make friends and "hang out" with them, become civically engaged; in other words, to fully participate in their community and live a typical life like yours and mine.

While we serve over 53,000 people in our service system, there still is a significant number of people and families who need but do not receive services. I will provide you with waiting list figures and explain what the Department's plans are to remove people from the waiting list at a reasonable pace.

First, the number of individuals waiting:

There are two lists. One list for individuals with intellectual disabilities has about 13,900 or close to 14,000 people on the waiting list. The other list, which was created later, is maintained as an interest list for autism services, and it has approximately 2,000 people. Many of the individuals on the autism list may also be on the waiting list for ID services. In other words, there is some duplication.

The waiting list categories:

The waiting list categories apply to the ID waiting list. We have 4,863 people listed as "emergency," which is defined as needing services within the next 6 months; 5,521 are listed in "critical" need, which is defined as needing services sometime within the next 2 years; and the remaining 3,500 are listed as "planning," which is defined as needing services more than 2 years but less than 5 years away.

Waiting and receiving services:

Of the approximate 10,000 people who have been reported as needing services within the next 2 years -- that is the “emergency” and “critical” categories -- 7300 of them, or 7,300 of them, are getting some level of service while the remainder are not receiving services at all.

Of the 4,800 in the “emergency” group, 3,500 are receiving some level of services. Of that 3,500, 1,500 are enrolled in one of our waivers and have expressed a need for additional services, and 2,000 are receiving some limited services from our county programs.

While a large percentage of people in the “emergency” category are receiving some services, the services people are receiving are typically either for the P/FDS Waiver, which is capped at $30,000, or they’re getting services through our county program, which provides an even lower amount.

The same pattern holds true for the “critical” list. Of the 5,000 individuals, 3,800 are receiving some type of services, again through the P/FDS Waiver, but mostly through our county funds.

And in the “planning” group, the same is true. Of the 3,500 listed as needing services in 2 to 5 years, 2,500 are getting some level of service.

And I would say that -- it’s not in my written testimony but to sort of wrap that up -- the vast majority of people who are waiting in any of those categories are getting some level of service that does not detract from the part of “emergency” and “critical.” So the good news is they’re getting some services to hold on to, but that doesn’t mean that their needs are met.

The ages of individuals waiting:

Individuals on the waiting list are typically between 3 and 88. However, almost 50 percent of them in that “critical” and “emergency” category on the waiting list are between the ages of 15 and 27. A large number of these individuals are young adults who are beginning to transition from school to adulthood or who have graduated from school and are home with a working-age parent or parents. Without services, these folks cannot navigate the community or get a job, and the concern is that over time, they begin to lose the skills they have acquired in the school system.

The age of families of people on the waiting list:

Of all the 13,900 individuals on the waiting list, 2,000 are living with a caregiver over the age of 60. Caregivers under the age of 60 tend to be working, working-age adults. Therefore, this number suggests that most of the individuals on the waiting list are living with families who are working.

What we do not know about people on the waiting list:

The instrument used to collect information for people on the waiting list provides basic demographic information about each person, but it does not provide a standardized assessment of each person’s clinical and support needs, nor does it provide information on each family’s situation, which would help us shape our program design and budget more accurately.

So to summarize:

There are over 10,000 people who have reported that they will need services within the next 2 years. Seventy-three hundred of them were getting some level of service and the remainder are not receiving any services. The vast majority are individuals in their late teens to mid-20s whose parents are working age. These are the families often referred to as the “sandwich generation,” because they are typically caring for children and their own parents as well.

The data suggests that our service expansion should focus on young adults who are transitioning or who have transitioned from school as well as their families. The provision of adequate supports for these individuals would allow them to live at home and their families to work more easily. The additional support would allow parents to maintain family members at home rather than seek more costly out-of-home services.

Why don’t the waiting list numbers fall more quickly:

The total number of people on the waiting list has decreased overall in the past 6 years from about 16,400 to 13,900 today. This reduction has been made possible through two strategies. The first is expansion in the number of people served over the 3 years from 27,300 to about 30,000 today in the waivers, and the second is through turnover in the existing system. Each year, about 800 to 1,000 individuals are enrolled to fill vacancies made available by people who leave the system. Each month there are changes as people leave the program and others enroll.

The waiting list does not decrease as rapidly as enrollment increases, predominantly because of the impact of the baby boom demographic. The US Census Bureau reports that when persons born between 1946 and ’64, commonly known as the baby boom generation, began turning age 65 in 2011, we started to witness a rapid growth of the wait of persons 65 and over. The country and our State are aging.

As the population over 65 grows, then demand for long-term-care services increases in the general population over 65. The people with ID and autism are 1.55 percent of that baby boom generation. So as the Baby Boomers age, the percentage of them that have ID is also aging, and so their need for services is coming on us, as it is with the typical population.

In addition, though, there are Baby Boomers who are 65 and older who are not disabled and who don’t need long-term care but who have children with ID and autism. These aging families are losing their capacity to care for their adult children and are now seeking services. Had there been no waiting list before the Baby Boomers began to age, the increased demand due to the aging population would have resulted in a waiting list.

DHS’s actions to address the waiting list and the interest list:

First, the service expansion:

- The Department is currently implementing the fiscal year ’15-16 budget initiatives, which will reach about 1,050 people with intellectual disabilities and autism. So that expansion is beginning now.
- The Governor’s Executive Budget for ’16-17 includes $12.3 million in State funding, to reach an additional 850 individuals with intellectual disability and autism over the next year. So that, again, is program expansion.

- Through turnover, the Department will be able to accommodate approximately 800 to 1,000 individuals from the waiting list each year.
- And there's an additional $41 million in the budget to accommodate the increased needs of the people coming from the waiting list.
- And lastly, the Department is funding $500,000 in the budget to leverage an additional $1.8 million in Federal vocational rehabilitation funds to expand employment services for individuals with intellectual disability and autism.

Second, improving supports to families:

Recognizing that a majority of people receiving services are living with their families -- approximately 70 percent -- and that many families are looking for in-home supports, the Department of Human Services is implementing program initiatives to improve supports to families.

Pennsylvania is joining the National Supporting Families Collaborative with 15 other States to explore together ways that State policies and programs could be transformed to better support individuals and their families throughout their lifespan.

DHS will invite six counties in Pennsylvania to participate in a statewide collaborative to redesign local programs and practice. Local collaboratives will include individuals and families, local community organizations, and relevant public entities to develop community solutions. Most important, Supporting Families Collaborative will focus on methods of supporting families of individuals on the waiting list and interest list.

As we prepare to launch this initiative, DHS has sponsored the Pennsylvania Family Network, a family-operated program that will provide information and training to families across the Commonwealth. The network's efforts will build the capacity of families to plan for the future and access resources throughout their community.

Managing resources:

DHS is launching an effort to establish a new fee schedule for residential programs. Currently, over a billion of our $3 billion supports people living in group homes.

The move in fiscal year '11-12 from county-negotiated contracts to cost-based rates established by the Commonwealth was a good step toward standardizing rates and strengthening accountability. But after 4 years of implementation, the methodology of cost settling every residential location has become burdensome for both providers and the Commonwealth, and more importantly, has resulted in a disconnect between the reimbursement and the degree of service each person needs. A reimbursement fee schedule that more adequately matches their individual need will improve the management of our resources.

Lastly, planning for the future:

DHS plans to improve the instruments and methodology used to identify and plan for people on the waiting list and interest list. The Department intends to maintain one list for people with ID and autism, while assuredly maintaining an indicator for each unique diagnosis, and to design a single assessment that will provide adequate information about each person's disability, the type and degree of support the individual needs, and his or her living situation, including the needs of the family, in order to improve our planning and our budgeting. In addition, the Department is looking to standardize the criteria used to prioritize individuals on the waiting list for services.

Program expansion in the future should focus on supporting families with services, information, and training. We must reach families early in life so that they can prepare and plan for the future, discover resources in the community, and also create a positive vision for their family member. We must support families to connect with other families from whom they can learn and enjoy the benefits of peer support.

Our services to people living with their families should focus on employment, because a good job enables more independence and having a valued role in the family and community. Ideally, we should connect with individuals before they complete their education so that the skills they develop in school are not lost but instead are used to get a job.

The renewal of the two Medicaid home and community-based waivers beginning in July of 2017 provides an opportunity for us to strengthen our ability to support families and individuals with disabilities.

Thank you for the opportunity to provide this information today, and I will be happy to answer any questions that you have.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Secretary.

Just a point of clarification. We’re going to wait until the very end to do the questions and answers, if that’s okay.

But I also wanted to recognize some of my colleagues that have joined us: Representative Craig Staats, Representative Eddie Pashinski, and Representative Judy Ward.

Good morning, Celia.

MS. FEINSTEIN: Good morning.

Good morning, Representative Murt and Committee Members and staff. I thank you for the opportunity to testify before you today.

My name is Celia Feinstein, and I am the Co-Executive Director of the Institute on Disabilities at Temple University.

The Institute is one of 67 centers throughout the country funded by the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000. We are Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research, and Service, UCEDD, and although our primary location is on Temple University's main campus in Philadelphia, we are a statewide program with a satellite office in Wexford, PA.

Our charge through the Developmental Disabilities Act is to provide interdisciplinary pre-service training in order to prepare the next generation of professionals, to do community training, technical assistance and service, and research and dissemination, all on behalf of people with intellectual and developmental disabilities and their families. We have been Pennsylvania's UCEDD since 1973, celebrating our 43rd anniversary this year.

One of the core responsibilities of the UCEDD is to be a resource to the disability community, both in developing information and then in interpreting information that exists. It is in this capacity I stand before you today.

I have been asked to present data on the issues facing people with disabilities and their families, particularly those individuals graduating from high school and those individuals with aging caregivers.

For purposes of this testimony, I will be referring both to national data sources, primarily from the National Association of Directors of Developmental Disabilities Services and from the University of Minnesota, and to the waiting list information provided through the Pennsylvania waiting list instrument referred to as the "Prioritization of Urgency of Need for Services," or PUNS.

From a national perspective, there are several assumptions that we must consider. This is hard for you to see. I apologize, members of the audience, but I thought having a visual might be helpful.

Ah, there's a big screen in the back. Oh. So okay; okay. Awesome.

Okay. So just some basic assumptions:

One is that growth in public funding is slowing down, and we know this.

The second, which is the bottom chart, shows that the workforce will not keep pace with the demand.

Typically, those who provide supports to people with intellectual disabilities are women between the ages of 25 and 44 providing supports, and in many cases to those 65 and older, to those with lifelong disabilities.

As the chart shows, while the population of individuals age 65 is on a steady increase, the population of women between the ages of 25 and 44 has flattened.

Additionally, the population of individuals with intellectual and developmental disabilities is competing with the aging community and other communities who utilize the very same population of middle-aged women for support.

The next assumption:

Families with whom 87 percent of individuals with intellectual and developmental disabilities live nationally are also continuing to age. Of the 4.7 million people with I/DD nationally, 13 percent are receiving services outside the home, 12 percent are receiving services at home, and 75 percent are not receiving services.

In addition to these national data, we also have data about individuals with I/DD who are waiting for services in Pennsylvania. As Nancy said, currently the waiting list includes currently 13,933 people, of whom 35 percent are in “emergency” need, defined as needing services within the next 6 months.

As the PUNS data from January of 2016 shows, of the 13,933 people waiting, 2,516, or 18 percent, of the caregivers are over age 60. Of these individuals, 744 were in the “emergency” category and 1,742 in the “critical” category, needing services within 2 years.

When you look at whether these individuals are receiving any services, the following slide elucidates the situation:

Of those waiting for services, approximately 53 percent are unserved, 47 percent underserved. If we add to the mix those individuals who have been authorized or enrolled in the waiver but are not yet receiving services, there are still 5,658 individuals who are unserved.

The national data from the University of Minnesota finds similar demands for services.

I think -- go forward one. There you go.

So this difficult-to-see slide just shows you the demand for services since 1999, and you can see how that pattern has formulated.

Okay. The National Core Indicators is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services, NASDDDS, and the Human Services Research Institute. The purpose of the program, which began in 1997, is to support State developmental disabilities’ agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time to compare results across States and to establish national benchmarks.

Pennsylvania has participated in NCI since its inception. Currently, 46 States and the District of Columbia participate in NCI efforts.

As the NCI data shows, 64 percent of caregivers are over 55 years of age. This is inclusive of the 11 percent who are 75 years or older.

Next.

In Pennsylvania, as the next chart shows, of the individuals with I/DD receiving services, 57 percent of them are living with family members. The Pennsylvania percentage is similar to the national average of 56.5.

Another issue that must be considered in making decisions about how to support people with intellectual and developmental disabilities and their families is to look at the situation that finds so many families in poverty.

From the 2011 NCI data, as the next slide shows, 46 percent of the people interviewed in the adult family survey are living in poverty, defined as below $25,000. The HHS poverty guidelines for a family of four in 2011 was $22,350.

Another area of need identified in Pennsylvania is the need for supports for those transitioning from high school to adult life.

ODP, the Bureau of Special Education in the Pennsylvania Department of Education, and the Office of Vocational Rehabilitation in the Department of Labor and Industry have made tremendous strides in supports to students with I/DD, so that when students reach the age of 21, that feeling of falling off a cliff into an abyss has lessened for many.

However, despite the strides made, more needs to be done on behalf of students, both while they are still in school to prepare them for life after high school and once they graduate from high school. Whether a student chooses to continue their education through a postsecondary option of some kind or begin life in the world of work, supports should be available as needed.

The PUNS data reflects the following:

As the data shows, there were 739 individuals who are 21 and leaving the education system, according to the January 2016 PUNS report. Of those individuals, 518 were in the “emergency” category, and 176 were in the “critical” category. These individuals are primarily waiting for employment and other pre-vocational supports. And as Nancy stated, this does not include people with autism who are not receiving supports, who are not captured through the ID waiting list.

The two groups of people I have spoken about today represent among the most critically needy individuals on the waiting list. However, others wait as well.

I have not talked about the families who struggle to make it every day yet still need support. They may only be in their 40s or 50s, but if one of the two parents becomes ill, if the parents divorce, or if like so many of us they are sandwiched by taking care of children and parents at the same time, they are minutes from disaster on a daily basis.

It is our greatest hope that families will be kept together with just a little support from the system when they need it. It is our sincere hope that resources will be made available to support everyone on the waiting list who needs support.

Thank you for your time.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Celia.

Good morning, Sheila.

MS. STASKO: Good morning.

I am pleased to be here. I thank you, Representative Murt, as well as Members of the Human Services Committee.

I am pleased to have this opportunity to share information with you. I am the mother of a man who is nearly 40 years old. He has an intellectual disability, a hearing impairment, limited and difficult speech. John is one of 6 children, 13 grandchildren, and 2 great-grandchildren.

I am part of that sandwich generation. My mother is soon to be 90, is in a memory-care facility with severe Alzheimer's. John and I visit my mother nearly every day to make sure she is protected and taken care of.

It's a different kind of life, certainly not one that we would have chosen. But we love our family and we love our 40-year-old man, and our lives would crumble without any kind of support.

I am here today because I am passionate about the 14,000 people who are on waiting lists across Pennsylvania, whose lives will be torn apart because of unrelenting caregiving. Forty-five hundred people are in "emergency" need, according to the county system.

I attended the Human Services Committee meetings in both the House and the Senate, and I was really taken aback by how strongly you advocated for the things that touched your heart and you are interested in, those who have family members or people in your districts who were concerned with drug and alcohol, or early childhood, or mental health, long-term care.

And Legislators felt very strongly that no one should ever wait, that you needed funding now, and yet I don’t understand why it’s okay for this population of people to wait. Why is it okay to take this segment and say, it’s all right; you can wait because you have families who are going to take care of you.

The thing is that we are taking care of our children until we can no longer take care of them. Our concern is, what’s going to happen to them when we die? Who is going to be there for our children?

From the moment of birth, we are dealing with a system that really doesn’t fill our needs. Any parent will tell you it’s about filling out the paperwork and personal plans. We run to doctors and hospitals more. We cry a little bit more. We do battles with schools and the administration. We’re constantly explaining and fixing things. As everyday life brings on challenges and the support to help ease through transitions to a regular life, that’s exactly what we’re looking for in everyday life.

I can honestly state that changes are finally being made. Deputy Secretary Thaler has stood up and recognized the role and importance of families in the system. She’s working on and implementing change with the involvement of families, to which I say, finally! Up until this point, we were rarely afforded a seat at the table.

There are policy and regulatory changes that need to happen to make our system flow for families, and it’s important that they are stated and recognized.

First of all, that waiting list does need to be recognized. Families across the Commonwealth, and you’ll meet them here today, they’re from all areas of the Commonwealth, especially those who are on the “emergency” waiting list. The Governor’s budget will only help 250 people on that “emergency” list, leaving nearly 4,500 without hope.

We need to address more than 1,200 people on that Priority 1 list for autism services. We need a more aggressive approach or we’re going to be in big trouble. We have 20, 30, 70K, the unknown number out there, of people with autism. The Bureau of Autism is not ready to support the tens of thousands of people in Pennsylvania who have loved ones with autism. The adult system only serves a very small number of those who will need help.

There shouldn’t really be a separation between ID and autism. The ID and autism systems operate very differently, and many families struggle to understand the system that can best meet their needs. When a child reaches 21, we get the calls. They don’t know who they’re supposed to be going to, or what they’re supposed to be asking for, or which is the best waiver, or how are they going to have their needs met.

The Office of Developmental Programs should change the process so they understand who qualifies for both systems and make both processes for waiting lists fair enrollment, transparent, and based on need and easy to navigate.

Please restore county-based funding. It’s a lifeline for many people. County-based funding was cut dramatically in the Corbett Administration and it needs to be restored. Families on the waiting list often relied on those limited resources to help them get through these emergency and rough patches until a home and community-based waiver funding was available.

Restore family support funding at the county level. In the past, counties would have limited amounts of funding to offer family support. That funding has essentially dried up. What it did was give families a limited amount of funding that they could use on things that they really wanted and needed, whether it was respite, the ability to just have someone watch their child for a couple of hours, day camp. And for a family to be able to choose exactly what they needed and to have that flexible amount, little amount of money, it was a godsend, and I remember using that years ago for my son.

We need to provide relief for the older caregivers in “emergency” status. There are 2,516 family caregivers over the age of 60 who need support. Nearly 800 are in emergency situations, which means their loved one’s health and welfare is at risk and they need help immediately.

The next one, No. 7, “Succession of care,” ties into that. When we talk to a family about what it is they need, we’re not talking about wills, trusts, and estate planning. We’re talking about, what’s going to happen? Who’s going to take care of my kid when I’m not here to take care of them any longer? That planning isn’t strong enough. It really isn’t done in a measured way.

So all the planning we do, all the fighting, the struggling, it’s for nothing, because when we’re gone, the people who take over aren’t going to be fighting and carrying the torch forward. So we can build a wonderful life for ourselves, but if there isn’t someone who cares as deeply about our individual as we do, it’s just simply not going to happen.

We need to eliminate high school grads on a yearly basis. Essentially, the waiting list for adult services begins when a person leaves high school, and if the State plans for each and every graduate from school to enroll into services, that’s where we can stop that waiting list. We’re cutting it off right at the neck.

If we could provide a half million dollars in

State funding for the 2017 high school graduates -- the budget year 2016-17 includes the high school graduates for June ’16 and June ’17 -- that half million dollars will support the June 2017 graduates. They would only need 1 month of support next fiscal year, and that would provide them and their families the support they need so they could just continue on with life.

The last one is a very big one, and we said, why is it that we struggle so from year to year, and it’s because the Department needs to be stabilized. We see great changes happening. Every time a new Administration comes in, we have new issues, new problems, and new changes, and we have had some very drastic changes in the last Administration, which really hurt a lot of people.

So I don’t know how you can do it, but there really needs to be something that allows a smooth transition from one Administration to the next, and that would be a godsend for individuals and families.

So you have always been responsive to our needs, and we know this because we come to your offices and we talk to you. And we have witnessed, truly witnessed, a greater understanding and a willingness to support our families and those most vulnerable in the system, and we thank you for your support.

Thank you very much.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Sheila.

MS. STASKO: You're welcome.

ACTING MAJORITY CHAIRMAN MURT: Just this panel, we're going to ask you to take a few questions now, because we know Secretary Thaler cannot stay with us until the end. And if I could just begin, Secretary, and I think this is an easy one.

In your testimony on page 5, you mention that there are some people that leave the system, and my question is, why would an individual with an intellectual disability or their family decide to leave the system?

DEPUTY SECRETARY THALER: I don't have the exact numbers, but people surely pass away. The good news is that people live a long life, but they do pass away. And sometimes people just simply leave the State. There is rarely a withdrawal from service because they don't need service anymore; it's usually leaving the State or passing away.

ACTING MAJORITY CHAIRMAN MURT: All right. Dan. Representative Miller; I'm sorry.

REPRESENTATIVE MILLER: Thank you, Tom. I know we're short on time.

There was a lot there, and I just want to bottle it here. And I appreciate the work that you and the

Administration are doing on this and the comments brought together by all the panelists. But one of the quotes that came up was “the waiting list needs to be recognized.” Just more of a comment, and my hope is to hear more on this later.

To be honest, I don’t want it recognized; I want it eliminated, all right?

DEPUTY SECRETARY THALER: Right.

REPRESENTATIVE MILLER: So I don’t see -- and I know that there are numbers being kicked around and so forth, but every day that is ticking by, I mean, we’re talking, one of the speakers referenced how, well, it’s not about trusts and estates. The majority of people who are dealing with a loved one, caring for a loved one with a disability, they’re not going to be really leaving much in a trust and estate. So that is almost an irrelevant part of the conversation. I’m glad to work on it, but not really where the meat of it is.

DEPUTY SECRETARY THALER: Right.

REPRESENTATIVE MILLER: The reality of it is that these families are hanging on by the thinnest thread, and a simple breeze one way on the wrong day and the whole thing is off.

So I would ask you, Madam Secretary, as you go back, and hopefully as we continue the conversation with it, what I'm looking for from the office -- and I appreciate the summary data for it -- I want a plan with real numbers. And I know there's going to be a lot of it there, but I want a plan with real numbers that doesn't recognize it, that eliminates it.

So thank you very much for your time. I appreciate it.

ACTING MAJORITY CHAIRMAN MURT: Representative Pashinski.

REPRESENTATIVE PASHINSKI: Thank you very much.

And thank you all for your testimony.

Could you please go back to the last Administration, because we had an $84 million cut, right? Okay. So now, how did you deal with that $84 million cut?

And initially Governor Wolf had indicated he wanted to restore that over 3 years, $28 million each year. Could you lay out how that would work? What happened with the 84 -- what happened to all these folks, and now, if the $28 million came back per year, how that would restore whatever your needs are.

DEPUTY SECRETARY THALER: Sure.

I think the amount you're talking about is the human services from the money that goes to counties, and this Governor proposed restoring it every 3 years. That's probably the most responsive and flexible money we have in this system, because it goes to county government, and county administrators are free to resolve problems as they occur on the spot.

And quite frankly, with less funds, they first took money away from structures, like we have monitoring teams and health-care quality units. So first they cut them, because it wasn't service, and so they undermined the ability of those two entities to do their jobs. And then they simply authorized less service. There were people who didn't get services for that amount because the money simply wasn't there.

REPRESENTATIVE PASHINSKI: So therefore, that increased the number of people on the waiting list.

DEPUTY SECRETARY THALER: Yes.

MS. FEINSTEIN: Yes.

REPRESENTATIVE PASHINSKI: Okay.

DEPUTY SECRETARY THALER: Or it made -- people may have gotten less. You know, I talk about this sort of lifeline. A lot of people on the waiting list are getting something. That doesn't change the fact that it's critical or an emergency or they're not stressed out; it just simply means we're keeping it together day by day so it doesn't fall apart. And I think that's what that local money does for people, and not having it undermines their ability to do that.

REPRESENTATIVE PASHINSKI: And what other cost drivers do you have that would increase the need for dollars?

DEPUTY SECRETARY THALER: I think there are probably two: the demand for service, the need for services; and the other is just simply the cost for service. So providers having to, for instance, absorb the cost of the Affordable Care Act, which gives more people health insurance. Or the recent Federal Department of Labor rules on both overtime and payment to supervisors, staff, or the right -- raising the threshold at which you can exempt people from overtime.

So providers have those increased -- plus, these days, the cost of living doesn't go up astronomically but it does go up some, and providers want to be able to compete for the workforce.

So it's both increased costs and the need for services are the two big drivers.

REPRESENTATIVE PASHINSKI: Thank you very much.

Thank you.

ACTING MAJORITY CHAIRMAN MURT: Representative Kinsey.

REPRESENTATIVE KINSEY: Thank you, Mr. Chairman.

Also, I want to thank the three of you for being here this morning. I think I have had opportunities in the past to talk with each of you. I actually had the opportunity to work with you, Ms. Thaler, years ago.

DEPUTY SECRETARY THALER: Right.

REPRESENTATIVE KINSEY: A couple weeks ago when the Appropriations Committee met, we met with the Secretary, Secretary Dallas, and I think for the second year in a row I have asked a similar question, and you sort of touched on it a few minutes ago, Secretary Thaler.

You know, I shared how I was once a provider, still am a provider, actually, but not a direct-care service provider. And the question that I asked, and I think, again, you just touched on it, but I have asked the question in regards to the folks that are providing services. And, Ms. Feinstein, in your report you mention that the workforce will not keep pace with the demand.

Going back to the workforce in and of itself, I had asked the question of Secretary Dallas about an increase for those individuals that are providing services to individuals. And unfortunately, I don't believe -- and Secretary Thaler, you can correct me -- but I don't believe that there were dollars allocated to provide an increase for those individuals providing services.

DEPUTY SECRETARY THALER: Right.

REPRESENTATIVE KINSEY: So, Ms. Feinstein, then back to your report, I mean, so if there are no dollars to provide additional moneys to those individuals who work in that profession, I mean, you provide training. I mean, is that one of the keys that we're finding out in regards to the workforce, you know, not meeting the demand?

MS. FEINSTEIN: Absolutely. I think the wage issue is huge. The availability of bodies is another issue. So what are we doing, and I can speak for my own university.

The College of Education at Temple University has made a decision that teaching teachers is not all we should be doing in the College of Ed. We should be preparing people who might come through a college of education to learn to work in human services in another capacity.

So I think universities are aware of the population trends. We're deeply aware, because it is affected by our enrollments every day, although now that we have a good football team, that's not so much of an issue for Temple.

REPRESENTATIVE KINSEY: And basketball.

MS. FEINSTEIN: And basketball. They had lost last week.

But truly, we're all reinventing ourselves, recognizing the population trend needs.

REPRESENTATIVE KINSEY: Thank you.

Thank you, Mr. Chairman.

ACTING MAJORITY CHAIRMAN MURT: Any other questions for our panel?

Thank you very much for testifying today.

PANEL TWO:

SCHOOL/TRANSITION

ACTING MAJORITY CHAIRMAN MURT: Can we ask our next panel to please come forward?

Good morning, everyone. Thank you for being with us today.

Tom, do you want to go first?

MR. TOM CARASITI: I'm going to let Marisol speak first.

ACTING MAJORITY CHAIRMAN MURT: Sure.

MS. RAMOS: I'm sorry; I was supposed to go second.

ACTING MAJORITY CHAIRMAN MURT: That's okay. Take your time.

MS. RAMOS: So I will start to thank you, all of you, for this support that you have given to me and my family over these years.

My name is Marisol Ramos, and 22 years ago I came from Puerto Rico with my husband, Jose. I had my daughter, Naomi, and my son, Justin.

I work for a company called Vision For Equality, and this company helps educate families with people with disabilities. And I work there because I became to advocate for my children and for other people, and this is a pleasure for me. My husband works at the city of Philadelphia in the Health Department.

And I want to tell a little briefly about Naomi. She was premature. Now she -- I'm sorry. She had a lot of medical and physical disabilities, impairment. She requires a lot of care and around-the-clock supervision.

After she was born, the doctor tell me, like, it's really a good idea to put her ahead in an institution, but my husband and I feel like that's not a place for my daughter. Also, I want my daughter to be with us at home with all the love. The only I ask for my kids is to have the same opportunities like other people have.

After I had my daughter, 6 years later Justin came. Justin had autism. For us, it's really sad, but at the same time, already they start working with him for he gets the therapies they need.

Now we have nursing services like every week, like 50 hours a week. And she had a nurse for 10 hours. And in this moment I'm really upset, because a couple months ago they tell me they want to cut the nurse for Naomi, and that is really bad for us, because without support -- I also had a mental health support hearing. It’s only me and my husband. So I’m in the second appeal for trying to get this service back for her, because really she requires, because she had all that stuff, she really needs the services.

Plus now, to continue without services, my husband or I have to quit our jobs. And it got to be really bad, because us really want to provide for our children. Us want to give them all the stuff they need, but without a job, that got to be impossible.

So the thing I can ask to do is try. I’m sorry I’m not reading the thing I’m coming with.

Like, thinking of all the families like our family who is in the waiting list, some of the people are really, like, only they need a little support to continue helping the kids, because they deserve, like, the same thing everybody has.

So thank you so much for listening to us. I have to leave, but thank you. Thank you very much.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Marisol.

MR. TOM CARASITI: Representatives, the testimony that was submitted earlier for mine, it was a little long. So in the interests of time, I kind of -- the same content, but I brought it down some. And I will give that to Pam later so that she can put this testimony on record.

Good morning, Representatives. My name is Tom Carasiti. I'm from Pike County. I'm here with my wife, Teri, and my 24-year-old son, Glenn.

Thank you for this time to make our appeal for your support; specifically, to fund high school ID and ASD graduates.

Our son has an intellectual disability, an IQ of 54, and the many, many challenges that accompany severe autism. He was not fortunate to have the skills you and I have for life's journey, but in collaboration with advocates, Legislators wrote and passed laws so that Glenn received an exclusive special education. So instead of being institutionalized, left rocking and self-stimming, Glenn was educated and learned many basic skills and is able to participate in family activities.

Despite his challenges, you enabled him to exercise his right to the pursuit of happiness, but only through school age. At graduation, our ID and ASD adults then have the right to be institutionalized at tremendous costs, but we waived that right for a chance, the waiting list, at a much less costly but much improved life at home and in the community.

Fortunately for Glenn and our family, thanks to most of you who were here during the 2012-2013 budget process, Glenn received the graduate initiative and came off the waiver waiting list, so thank you very much.

(A slide-show presentation was played.)

MR. TOM CARASITI: What has Glenn been doing with the taxpayers' dollars on the waiver program? Back up. Back up two. Thank you.

Glenn goes off to work 5 days a week. Two days he volunteers, and 3 days he's actually in competitive employment in a restaurant.

So Glenn, what are you doing in this picture? Do you see the picture, and what are you doing in this picture?

MR. GLENN CARASITI: He's cleaning the -- he's cleaning the thing up on the tank truck.

MR. TOM CARASITI: Okay. You're cleaning the water tank truck.

Okay. What are you doing in this picture?

MR. GLENN CARASITI: He's cleaning the fire truck panels for the fire truck supplies.

MR. TOM CARASITI: Yes. One day a week, we volunteer at the firehouse.

This day he's volunteering at a fitness center. What are you cleaning at the fitness center?

MR. GLENN CARASITI: The handles.

MR. TOM CARASITI: Okay. We hope eventually this can lead to competitive employment.

Now, this is competitive employment. He gets minimum wage.

MR. GLENN CARASITI: I take out the pizza boxes, and it’s unflattable.

MR. TOM CARASITI: Yes. You take them from being “unflattable.”

What are you doing in this picture?

MR. GLENN CARASITI: I take the raw chicken legs. It’s not crispy. (Blah.) And put it on the oven tray.

MR. TOM CARASITI: He puts the raw chicken on the oven tray.

MR. GLENN CARASITI: But I like the buffalo boneless chicken wings crispy. I take the barbecued chicken wings.

MR. TOM CARASITI: Okay. He’s elaborating now.

MR. GLENN CARASITI: It’s good. I put bacon on the tray.

MR. TOM CARASITI: There he’s putting bacon on the tray.

MR. GLENN CARASITI: On the middle of the tray. It’s on the middle of the tin oven tray.

MR. TOM CARASITI: Now, Glenn has a -- last, what’s this activity, Glenn? Glenn, what are you doing here?

MR. GLENN CARASITI: Onion rings.

MR. TOM CARASITI: Talk into the microphone.

MR. GLENN CARASITI: Onion rings. I put them on the scale.

MR. TOM CARASITI: How many ounces?

MR. GLENN CARASITI: Seven.

MR. TOM CARASITI: Okay. He makes sure the portions are only 7 ounces. Okay.

Now, and this is the coworkers, Glenn’s coworkers at the restaurant. And he does -- probably there are at least about 20 different tasks he does for the restaurant, similar to what you just saw.

So like us, even with an IQ of 54, he gets the connection of work and the quality of life it brings.

MR. GLENN CARASITI: Lisa.

MR. TOM CARASITI: Oh; he’s naming his coworkers. Okay.

He enjoys the self-worth of being productive, earning a wage, and choosing his spending. He likes earning his “bucks,” as he calls it, and the ability to purchase “stuff” and planning his vacation time. And that’s something now that has been of the last couple of years. He likes planning his vacation time.

Glenn, what do you plan -- what’s your vacation you’re planning for this year?

MR. GLENN CARASITI: They're juicy.

MR. TOM CARASITI: No, no; we're going to do better than that.

MRS. CARASITI: Where are we going for summer vacation?

MR. GLENN CARASITI: New England.

MRS. CARASITI: New England.

MR. TOM CARASITI: He wants to go to New England. Why to New England? What do you want to see?

MRS. CARASITI: What buildings?

MR. GLENN CARASITI: The Capitol Buildings.

MRS. CARASITI: The State Capitol Buildings.

MR. TOM CARASITI: From coming here to Harrisburg to advocate, he now likes Capitol Buildings. We have made quite a few Capitol Building stops across the United States.

MRS. CARASITI: Seven under our belt so far.

MR. CARASITI: Yes.

And Glenn, where did we go last year? Where was your vacation that you picked last year?

MR. GLENN CARASITI: Canada.

MR. TOM CARASITI: Why Canada?

MR. GLENN CARASITI: Ottawa.

MRS. CARASITI: Ottawa. We went to Ottawa.

MR. TOM CARASITI: Ottawa, because of their

Capitol. It’s a double Capitol, as he calls it, because it---

MR. GLENN CARASITI: And Paris.

MRS. CARASITI: And Paris -- Ontario.

MR. TOM CARASITI: Yes. Yes; we did not travel---

MRS. CARASITI: Paris, Ontario, not Paris, Europe.

MR. TOM CARASITI: Okay.

MR. GLENN CARASITI: Ottawa. Like a Parkway City Hotel?

MRS. CARASITI: Yes, it was like a Parkway City Hotel.

MR. TOM CARASITI: Okay.

Your voting for graduate funding in 2012, that was the enabler here. We raised the expectations, you provided the funding and the job coach, and he grew with the challenge.

Without the funding, he would be idle at home, his skills and behaviors eroding. Without it, he would regress, possibly becoming too difficult to handle in our advanced years, and therefore, institutionalized at a higher cost with an outcome unlike the results we have now.

So we have a new class of graduates that need your support, and only you have the power to enable them the same support that you afforded Glenn, the same opportunity most Pennsylvanians, like us in this room, enjoy just by virtue of birth.

And here are some reasons why I think you should fund -- whoops; how did that happen? Let's see if you can rotate that. There you go.

First of all, there's the highest standard, that Representative Murt even mentioned at the beginning, set forth by Thomas Jefferson in the Declaration of Independence: All citizens have an inalienable right to pursue happiness. They can't pursue happiness idle at home or in institutions. Without a waiver initiative, we deny them the natural right that you and I enjoy, a right we give them for education but not for adulthood.

On average, special education students cost $17,000 annually. The more severe, like Glenn, the costs are higher. For Glenn's job coach, for the outcome you just saw, that cost is only about 9,000 per year in State dollars.

That cost, that doesn't waste the education investment already paid for by taxpayers. It helps support up to three jobs: Glenn's job, his job coach, and in some cases, a parent won't have to quit work to stay home with their son or daughter.

The third bullet: It's a smart investment, because it immediately leverages a 52 percent Federal match. It's a 100 percent return directly back into the Pennsylvania economy, not to the individual, but to jobs.

There's also a new emphasis in legislation for schools and OVR to place individuals in jobs before they graduate high school, but the school supports for those jobs, transportation for one, end at graduation. If you do not pass the graduate initiatives, those students will lose their jobs and we have wasted education and OVR dollars. We need to be consistent with our other legislation.

Funding here provides the positive benefits just noted and avoids other government costs for results such as welfare or increased medical mental health costs. Without a graduate initiative, a parent may have to quit their job to remain home with their son or daughter. What does a single parent do? This could tip the family income balance to require other government assistance programs.

We should take the proactive approach and transition our graduates to productive outcomes with Medicaid dollars and avoid using government assistance reactively for unintentional costs. Instead of paying for the safety net, let's pay so the individuals and families don't fall to begin with.

And lastly, relative to the whole, what I have just described is rather inexpensive. The proposed budget calls for an overall 7.1 percent increase. The proposed initiative only impacts the budget by 0.05 percent, or 5/100^{ths} of a cent.

I have one additional request that Sheila spoke about. And you can go to the next.

We would like another line item to fund 1 month of the 2017 graduates, because even on an on-time budget initiative, there's a large gap before services can begin, 4 to 6 months at best, sometimes longer. This gap causes hardships on the family wage earners and can cause skill regression and loss of jobs created by the schools and OVR.

If we had a second initiative for 2017 graduates for 1 month at a cost of only $500,000, then services can begin immediately when they graduate. Graduates and caregivers can then plan their future in advance, similar to what typical high school graduates enjoy.

Typical grads are not in limbo on a waiting list subject to budget debates. If you add $500,000 this year for the 2017 graduates, they can be the first class to begin adult services immediately when school supports end, and then next year we won't be back here asking for $5 million more for graduates, only $500,000, to start the next class and so on.

You have the power to solve this problem and have an impact on large numbers of families' lives. That one $500,000 change to the budget, or 0.0015 percent, would make a major difference on how Pennsylvania solves the special needs transition from school to adults.

Thank you.

ACTING MAJORITY CHAIRMAN MURT: Thanks, Tom.

Maureen, good morning.

MS. CRONIN: Good morning.

Thank you so much for the opportunity to talk to you today about the waiting list for persons with intellectual and developmental disabilities. I am extremely honored to speak before you with all the best advocates across Pennsylvania today.

I'm the Executive Director of The Arc of Pennsylvania, and as such, many of you know about The Arc. The Arc is a member of the national The Arc US, and in Pennsylvania, we have 34 chapters and 8,000 members.

And you have my written testimony, and I won't go through that. Instead, I'm going to keep this pretty short.

Quite frankly, I feel like I'm speaking, certainly singing to the choir. Many of you I have worked with personally. If I haven't, the chapters of The Arc have worked and sung your praises to me, so I appreciate all the work that you are doing.

I'm really here to give you some ammunition, some more information as you make decisions in your caucuses, because this is a tough time, and I think everyone comes with very, very compelling reasons of how tax funds should be spent. And I want to tell you a little bit more about people who are students who are transitioning from school. They have been in special education for 12, 18 years, and then they are transitioning to adult life.

And, you know, when I think about my own son, typically developing son when he was transitioning and we went to high school, it was a pretty simple process. Many of you will remember, you know, you start freshman year. God willing, chances are in 4 years he'll graduate, you know. We had pretty much a plan.

You know, the school was very good, helped him get applications and do his SATs. And, I mean, it was a couple months worrying about what college he was going to go to, but it was a pretty smooth process between high school and college.

And sure enough, he got into Temple, and we heard a lot about Temple earlier. And, you know, it was very predictable. We even knew what dorm he was going to live in. We knew what branch campuses or what bank branches were on campus. So we were a little bit nervous, but it was a very predictable process, and we knew we were joining the ranks of a whole lot of other people who smoothly transitioned high school kids to college.

That’s not how it is with people with intellectual disabilities and autism. And I think even looking around the room, most of us know what we’re going to be doing in a year. Even if we’re changing jobs, we work through a plan B. So it’s a pretty predictable life of how it’s going to be.

For people who have sons and daughters graduating from school, if you go up to them now and you say, “So·what’s your son or daughter going to do when he graduates from school?” Every single one of them will say, “I don’t know. I’m waiting. I’m waiting to hear from the county. I am very nervous. I’m waiting to hear if he’s going to get waiver services. I don’t know if he’s going to be prioritized. You know there are other families that are waiting for services, too, in my county, and I just don’t know if he’s going to be at the top of that list.” It causes extraordinary stress.

And I want to tell you a little bit about one of my board directors. So this is -- you know, you picture one of my board directors on the Board of Directors of The Arc of Pennsylvania -- a pretty connected person. She has been a lifelong advocate since her son was born. The time that he was 20 -- he was going to be turning 21 -- she did not know what was going to happen when he turned 21. So this is a person who has, you know, worked tirelessly as an advocate, connected to the county, knew who to call, knew what to do.

It was pretty clear what her son was going to need. He was in, you know, this system for 21 years. He had been tested, evaluated. Everybody knew what he would need. He can't be home alone. He would need services and supports. Everybody knew it for 21 years. So it's really kind of hard to understand how, in this case, it still broke down.

I would call her periodically, "How's it going? Surely by now you would have heard how he is doing, whether he's going to have waiver services." He's going to be 21. He's now receiving EPSDT services, which would include nursing services.

The nursing agency got a little nervous. They knew he was going to turn 21, and they knew the funding that paid for the nursing would stop the day he turns 21. The EPSDT funds would not continue. What's going to be the plan for transition?

If you ask the county, the county said, well, you know, we have other families that are waiting that are in, believe it or not, even more dire circumstances than this situation. A little tough to picture, you know, as an outsider, what were those other situations that were worse than this 21-year-old, medically fragile, couldn’t be home alone, needed a lot of supports, two parents working. So I can imagine, those kinds of emergencies for the other families must have been pretty impressive if this really stressed the county in trying to figure out who they were going to support.

You know, people say, well, the parents, you know, they were both working: “One could stay at home, couldn’t they?” Well, quite frankly, one would have stayed at home the first time he got sick, you know, and almost died when he was 3. It was tough to continue to keep working when he had such medical needs. It would have been so much easier when he was younger to have one person working, but that wasn’t possible. They would not have had a home if they lived off of one income, and it’s just as simple as that. They would not have had a home over their heads.

So both of them worked. They have been doing the best they could, loving their child, but now this loomed over them. I would call the board director and say, “How’s it going?” She would be crying. This is one of the strongest women I know. She has done monumental things caring for her son, and she doesn’t know what’s going to happen. This is now the beginning of January, and she still doesn’t know what’s going to happen.

So not only are they looking at who’s going to quit their job, but also their retirements. You know, half of their retirement is affected, so the safety net for their future is now something that they’re concerned about.

Sure enough, many calls to the Department of Human Services’ Office of Developmental Services -- Programs; sorry -- and multiple calls, and finally a week before he turns 21, he is now going to be in a waiver. All is well.

I mean, a huge relief for the family, but can you imagine that stress for those few months. I mean, it’s just a horrible situation that didn’t have to happen. He was going to be 21 for 21 years, you know? I mean, and we knew what he was going to need.

So, you know, putting families through that kind of stress, just, it’s not fair. None of us go through it. We don’t live like that. And I can tell you many, many stories, and I know time is tight. Just know that I’m happy to meet with the individual and tell you more.

But, I mean, I have people that work with me. They waited months between high school graduation and when their son received services. And another family used their retirement to hold over. They paid for day supports until their daughter was finally in a waiver.

And the people I hang out with are good friends. They are connected to The Arc. And if they are going through this, I can only imagine what it's like for people who don't know who to call and who are really waiting for services and are in dire straits.

And we know that if you let things really implode in a family, the types of supports they are going to need are going to be so much greater. It's going to be so much more costly. You know, if we can do some of the things that you heard earlier, is put supports in right when the student is graduating, you don't wait for the whole family to implode.

You know, if you wait long enough, the family implodes, and then they need an intermediate-care facility, and we know that that's really expensive, and that's what happens if we don't provide supports early on.

So in conclusion, I just want you to know that you appropriate funds each year for graduates, and that's an amazing thing. But what has happened, because of the shortage in funding, the funding wasn't released until 9 months into the year. So you thought you did the best you could, but a family actually is waiting in between when their son or daughter graduates. They don't know what it's going to look like.

The counties, counties with resources kind of string together things and keep families going. Counties without resources, the family is just hung out to dry.

There are a whole lot of families who, when they go to their counties, the county goes, we don’t have any money, so they’re not even put on a waiting list. They’re not even counted in terms of what their circumstances were, because the counties are so tired. They know they don’t have money, and they just say, there isn’t any money, and so the families don’t even try. So we don’t even know how bad it is. But we figure if the people that come to us who are connected with The Arc go through all of this, that people who are not connected must really, really have it bad.

So I want to thank you very much for the time that you have spent listening to me today, and I want you to know that at The Arc, we’re going to do our best. We are going to really, really in the next few months try to get every Legislator to understand how much this funding is needed.

We’re going to help with, you know, fighting for revenue. I mean, we think that’s a critical piece to this. And we know that you are here, too, and we know that you are doing your best and you know how important this work is.

And I don't want you to get discouraged. I really do think it's doable. I think it is -- it can be a small amount of money. I don't think you have to be overwhelmed by it. But just know we'll work together, and thank you so much.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Maureen.

Good morning, Sharon.

MS. DUCKETT: Hi.

Hello. My name is Sharon Duckett, and I am the disabled mother of special needs twins, Christian and Christina, who both have intellectual disabilities and autism. They will be graduating June of 2016. I am here today to share what I and thousands of other parents are faced with with young adults trying to transition out of high school to adult life.

Graduation is usually a time of great joy and promise. The future is awaiting, and now you can pursue all your dreams. But for the special needs young adult, it is a life on hold, a waiting game, and many are still waiting. It is a tragedy that does not have to happen.

I received a letter stating both of my twins were eligible for waiver services, but at this time, there is no funding. My heart felt like it was going to stop, and tears began to flow. I could not breathe now.

No funding? How can my twins put their daily lives on hold? They will surely lose all their skills they worked so hard to achieve. Waiver services provide supports to help them live in the community and stay at home, the only life that they know.

No funding? They will lose both internships. One works at Marshalls and the other at the library. They cannot continue without supports. Their lives will be interrupted. Waiting will destroy them. They will lose hope and their dreams to live an everyday life in their community, like you and I.

How many years will they wait? They will wait like thousands of others who are still waiting, waiting and will lose their skills and supports they need daily to take walks, to go to work, to go to the library, to get out of bed. And just like you, we have lives. We need services and supports to live.

Why must we wait to live our lives as productive human beings on this earth? Why? Why must children also wait, and for how long will they be waiting to exhale?

I ask today that you find more funding for the Waiting List Campaign so that our young adults can breathe and live their dreams, reach for the stars like we have promised them their entire lives. Why must they live a dream deferred -- a dream deferred?

What happens to a dream deferred? Does it dry up like a raisin in the sun or fester like a sore and then run? Does it stink like rotten meat or crust and sugar over like a syrupy sweet? Maybe it just sags like a heavy load, or does it explode? You have the power to stop this explosion. Please find more funding for the waiting list so that our children can live their dreams.

Thank you.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Sharon.

REPRESENTATIVE MILLER: Tom?

ACTING MAJORITY CHAIRMAN MURT: Representative Miller.

REPRESENTATIVE MILLER: Are we still doing any questions?

ACTING MAJORITY CHAIRMAN MURT: Well, we were going to ask our testifiers to wait until the end, and we're going to hold the questions until the end.

REPRESENTATIVE MILLER: Thanks. No problem.

PANEL THREE:

OLDER CAREGIVERS

ACTING MAJORITY CHAIRMAN MURT: Could we ask our next panel to please come forward?

Just a reminder to the testifiers as well as the Representatives, we're due on the Floor at 1 o'clock, so we have to conclude by 1300 hours.

Good morning, Nancy.

MS. MURRAY: Hi.

Good morning. My name is Nancy Murray. I'm the President of The Arc of Greater Pittsburgh at ACHIEVA, and my husband and I have two adult children with intellectual disabilities.

ACHIEVA supports more than 12,800 children and adults with disabilities and their families throughout western Pennsylvania. We provide early intervention, advocacy, family support, inclusive community activities, employment, residential supports, in-home care, special needs trusts, and long-term planning services.

Waiting for supports and services has an impact, as you've heard this morning, not only on the person who is waiting but also on their family. While waiting, individuals lose educational and employment skills, and families have to ensure that a caregiver is always available.

So in two-wage-earner families, one person often has to give up a job to stay at home to provide care and supervision. In a family in which there is a single caregiver, that person will desperately have to juggle caregiving demands while trying to also work. Many families are forced into near poverty, relying on SNAP and other government benefits. They lose their health-care coverage, and they lose their retirement benefits.

And then there are the families in which there is an elderly caregiver in their 60s, 70s, or 80s who is still caring for an adult child who is now 40, 50, or 60. These mothers and fathers are just not caring day in and day out for their adult child with a disability; they may be doing this alone, as their spouse may have died or is not physically able to help any longer.

These mothers and fathers are also living with the issues that accompany aging that all of us face, including serious or chronic health issues, loss of stamina and energy, and the daily worry and fear of who will care for their adult child when they are no longer able to do so.

Today, I wanted to bring three families that I have known with me, but unfortunately, due to their caregiving responsibilities, they could not come, so I will tell you their stories.

First there's Cathy, a mother I met almost 40 years ago, who is now in her late 70s and who is a cancer survivor. Cathy had six children when her husband was sent to prison. When he was released years later, he moved to Florida. He never really supported his family, yet he came home at the end of his life when he was dying and needed someone to care for him.

Cathy worked and supported her family. One of Cathy's six children is now in her 50s. Amy has Down syndrome, and when she was younger, Amy attended high school alongside children who did not have disabilities, and she was extremely social. Amy had a promising future and was looking forward to having a job and maybe even living independently.

Gradually, that dream evaporated. Amy has since experienced a multitude of physical and emotional issues. She has lost her ability to speak, eat, and walk. She has endured countless surgeries and medication regimens. She now requires somebody to be with her 24/7. She still lives with her mother and, thank goodness, has some siblings who are willing to help her mother and able to help her mother care for Amy.

- Amy's mother just prays that she will now outlive Amy by 1 day.

Then there's Daniel, who is in his 50s and whose mother recently died, leaving Daniel alone in the family home. Daniel has some family members, but none of them are stepping up to assist.

In fact, I got the call about Daniel from a friend and her husband who had agreed to be his power of attorney when his mother was dying. When his mother died, Daniel was unknown to the system.

Since then, this couple has completed eligibility paperwork for government benefits and a special needs trust, has gotten him much needed medical attention, and has organized a group of people to check in on him multiple times each day. However, at some point, Daniel will be moved into a group home with people he does not know, and he is still wondering what happened to his mother.

- Daniel's mother did not outlive him by 1 day.

Then there is Nan, who is in her 70s, and her son, Drayton, who is in his 50s. Nan's husband died a few years ago.

Drayton was a successful businessman until one day, 7 years ago, while on a fishing trip, he had a heart arrhythmia, lost consciousness, thus cutting off his air supply. When he awoke from a coma 5 days later, he had no memory of the event. Today, he is unable to work and cannot retain his short-term memory. He has now moved back home with his mother, as he needs daily supervision.

He is not waiting for services through the ID system; he is waiting for services through the Office of Long-Term Living, but Nan found me through our parent network.

- Nan also hopes and prays that she will outlive Drayton by 1 day.

As you have heard this morning, there are thousands of elderly caregivers across Pennsylvania who are facing the need to be a caregiver while at the same time they are dealing with the death of a spouse, their own failing health, and the end of their own lives.

Maybe you know one of these families. If not, just for one minute try to imagine what it must be like to be in your 70s, to be someone's sole caregiver, to be exhausted at the end of every day, to be dealing with your own medical issues, and to wake up every day worrying about who is going to take care of your adult child when you become too sick or die.

So on behalf of these three families, all the families you've heard about this morning, and families who are not with us this morning, I hope that when you are voting for the Governor's budget that you will remember all of these families who are, without a doubt, some of the most vulnerable of Pennsylvania's families.

Thank you very much.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Nancy.

Mary? Good morning.

MS. OHL: Hi. Good morning, Representative Murt and Members of the Committee.

My name is Mary Ohl. Can you hear me? Good morning.

And I’m here to give testimony from the perspective of an aging older parent and caregiver. We live in northeastern Pennsylvania in a town called Milford, which is in Pike County.

I would like to insert a little humor, so bear with me; give a little levity here. I heard a wonderful joke, and it will only take 2 minutes.

This wonderful woman, she’s about 85 years old, she goes to the pearly gates of Heaven, and who’s there but the archangel Michael. And she’s all set to go in because she knows she has lived a beautiful, wonderful, moral life.

And he says, “Just one question, Mabel. You just got to do one thing.” She said, “What’s that?” He says, “You got to spell one word that I give you.” So she said, “Well, what’s the word?” and he says “Charity.” So Mabel goes, “C-H-A-R-I-T-Y.” “Fantastic; you’re in. Just do me a favor. Watch the gate for about 5 minutes. I got to take a break.”

With that, her ex-husband shows up at the pearly gate. Mabel’s not too happy to see him; he’s not happy to see her either. So he goes walking in. He says, “You know, I’ve been good. You know, I know you don’t think so, but I’ve been good, and here I am.” She says, “One thing. One thing. You have to spell a word that I give you.” He says, “Oh, okay. What’s the word?” She says, “Czechoslovakia.”

Anyway. Anyway, it helps my nerves when people laugh.

So Dennis was born 47 years ago and was diagnosed with intellectual disability, autism, multiple congenital cardiac defects. He’s also legally blind, about 60 percent deaf in both ears, and has a speech impediment. The doctors tell me that his hearing and vision will deteriorate yearly.

My testimony has been submitted to you all, but also in the interests of time, I would invite you to view a short video, a documentary done a couple years back depicting his journey in trying to obtain an everyday life in his community. The website is odpconsulting.net and it’s under “Featured Stories.” I really think you would enjoy it. It’s not long. It’s not boring. It’s pretty good.

So to briefly begin, I must tell you about the impact of Geraldo Rivera’s especially poignant documentary called “The Last Great Disgrace.” It exposed the atrocities in what was the largest institution in the

United States that has about 6,000 developmentally disabled people during the fifties, sixties, and seventies.

In this testimony, I'll only use the "R" word in its historical perspective. Remember that.

In 1972, he took his camera into the Willowbrook State School for the Mentally Retarded in Staten Island, New York, and exposed the unbelievable atrocities that thousands of residents lived in and graphically displayed the filth, the odors, the overcrowding, the inadequate and abusive care of these residents. This exposure prompted enormous public outrage, and subsequently, new laws and regulations were passed to protect people who lived in institutions. A long time coming, but Willowbrook closed in 1987.

A little fact there was that I lived in Manhattan at the time, so I was about 15 minutes away from this place, and I just couldn't get over the fact that it was going on 15 minutes away from me, and I couldn't get over the fact that this was happening in the United States of America.

This affected me so much that I knew one thing for sure about my son, Dennis. I didn't know a lot about Dennis. In fact, I really wasn't concerned about his intellectual disability. I just wanted the kid to live. I mean, he was sick in hospitals for 5 years. I said, God, do what you want with the MR, MS, whatever you want to call it, but let him live. So it affected me so much that I knew for sure that he would never, ever go into an institution.

Dennis was 18 years old when he moved to Pennsylvania and he enrolled in high school, the local high school. This was very exciting for him, because it was the first time he was with children his own age and in an intermediate unit. I dreaded the day he was going to graduate in 1989, because in those days, there was nothing for him after graduation, especially in a rural community. There was no supported employment, there was no integrated or competitive employment, even secondary education.

We were advised by people that were professionals and people that thought they were doing the right thing that sheltered workshop is the answer. “He won’t be sitting in front of the boob tube. You guys have to work, so it’s the next best thing.” We didn’t know much about sheltered workshops, to tell you the truth. But I’ll tell you, after a few weeks, my husband and I knew this was not for our son, a son who we loved and cherished.

There had to be something else, but what? Along this time, we registered with our county’s MH/MR, it used to be called. Now it’s the MHDS agency. I can’t keep up with all the changes, but I certainly am going to try.

Along this time, we registered and was assigned a supports coordinator. Soon, we enrolled Dennis into an adult day program. This certainly beat the sheltered workshop that looked like a big airplane hangar with hundreds of people sitting at tables doing different tasks. The level of noise itself was deafening as time went by. I'm sorry: As time went by, I began to search for answers to questions about Dennis's life, his future, and how I could make it better and fulfilling.

Unlike the stories you have heard here today, and they were very powerful, and the thousands that you haven't heard, Dennis was enrolled in the home and community-based service waiver. He was not -- I repeat -- he was not on the waiting list. Heretofore, I would like to show you how a young man's life was changed because he was not on the waiting list.

(A slide-show presentation was played.)

MS. OHL: One thing for sure was that this mom had to get educated in a very serious way. You see, when Dennis was born, I did not get the manual that teaches a new parent how to raise a child to adulthood with significant intellectual as well as physical disabilities.

So, off to Harrisburg I went. Why? Because everyone I spoke to said Harrisburg is where they all have the answers, know how to support your child and have a good quality of life. Everything is going to be great. Oh, wait till you see when you go to Harrisburg. It’s wonderful.

Sitting before you in the room giving testimony today are most of the people, heroes, mentors I call them, the people that are sitting back here and the people that are sitting up there, as well as fearless advocates that I met so many years ago. We won’t go into how many years ago, but we met them a long time ago. I met them a long time ago.

They mentored to me. They encouraged me. They cried with me. They struggled with me and forged an unbreakable bond that created a second family for our family. The bond was this: how to make sure our children’s future was safe, healthy, fulfilling, and to be assured of the same opportunities as everyone else’s sons and daughters by birthright had.

They were talking about people living in their own communities, not institutions. Even maybe living in their own apartments or homes; working at real jobs in their very own communities. Paying taxes. By the way, my son votes in every single election. Volunteering and being respected and valued members of their communities. Having goals and dreams and never, ever, ever forget about their dreams.

Now Dennis is living in his own home that he rents, has caring staff that support him, and is leading a self-determined life. I implore you to see how outcomes, lives, and futures are in the balance. Almost five decades, that’s almost 50 years ago, a young mother faced tremendous odds. The people sitting here changed the complete trajectory of how my family’s life would be.

They also enabled Dennis to meet the many challenges he has had to encounter throughout his whole entire life. Please take a look at that picture and how one person in his life was totally changed because of important decisions being made by this body that you represent. Your mission is for all people with disabilities to enjoy their lives with greater dignity, opportunity, and self-determination.

A few months ago, my elderly husband was diagnosed with Alzheimer’s disease, and even though this has been hard to ingest, I know the Lord is going to save us, and we believe in Him and He has always been with us.

The aging caregiver is going to continue to believe that these extraordinary individuals, families, and this committee, this wonderful committee that you are sitting on, will always believe and advocate for the right that all people have opportunities and choices and be valued members of society, living in their own communities free from abuse, neglect, and discrimination.

With your indulgence, I would like to take a moment to mention some of the true pioneers that are sitting before you in this room today.

Of course, this distinguished body, I thank you.

Our leaders and mentors for many years:

Nancy Thaler, she’s impossible to understand. She’s from Mars, I think, because she just doesn’t belong on this earth. She’s just solar somewhere.

Celia Feinstein, my God. Talking to her, she never changes her sense of humor. She’s wonderful.

Sheila Stasko has been doing this waiting list I think for 5,000 years.

MS. STASKO: It feels like it.

MS. OHL: It feels like it is right.

Maureen Cronin, come on. With a name like that, you know I love her. Look at all the work she has done.

Graynle Edwards over there. Look at him. He has been on boards. He has worked hard advocating.

Dee Cocchia, need I say more? You all know her. She’s a firecracker. She’s not going to take any bull, and she’s going to fight until the day she dies.

Maureen Devaney. She has a sweeter way of talking, but she’s going to get you. She’s going to get you.

Lisa Tesler. By the way, she's going to be the coordinator of a wonderful happening thing. It's the Family Parent -- I think it's the Parent Family Network. Was I supposed to say that?

MS. TESLER: That's fine. The Pennsylvania Family Network.

MS. OHL: I don't think it's a secret anymore.

But a long time ago, we had partnerships, and what this partnership did was teach families, how to teach families, and self-advocates, how to teach self-advocates. If there's one thing I can stress, teach the families. Remember, when I had Dennis, I knew nothing. You have to teach the families, and understand, families will teach other families.

Um, who else? Nancy Murray. I'm not going to say anything about her because I'm mad at her today. But anyway. Anyway, Nancy Thaler and me have been going back for years and years and years -- I mean, excuse me; Nancy Murray, back years and years and years. I love her. She loves me, I think.

And Shirley Walker, come on. What's she, 30 years with this business? Thirty-five? Is she here? Back there. But she's unending; I see her all the time.

And so many more that are not here today. Dennis and I and my husband are blessed; we're grateful to have you all in our lives. I wish you nothing but the best. God bless you all. You are on a good mission. Don't ever doubt it. Don't get bored of it. Don't keep saying, you know, oh, we heard it a thousand times. You are doing wonderful work.

I thank you, and any questions I'd be happy to answer.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Mary.

Good morning, Dr. Edwards.

DR. EDWARDS: Good morning, Representative Murt.

I want to thank yourselves as well as your panel for allowing me to come before you to share with you my experience as a parent of an intellectually challenged son.

Before I begin, I want Mary to be my campaign manager when I run for office.

I am here for the purpose of securing adequate financial support for dependent, intellectually challenged citizens of seriously ill and deceased parents.

I am a 79-year-old parent of a 50-year-old son who suffered brain damage shortly after birth and have acquired considerable knowledge of the struggle related to a special needs advocacy for the past 60 years.

His mother and I have a history of advocacy to ensure a meaningful life in this community since 1975, where we challenged the school system to provide a free and adequate education for our 8-year-old son. During the ensuing years, our advocacy manifested itself in a variety of ventures.

Beginning with myself:

I was a lifeguard. That's where I provided swimming lessons for cerebral palsy individuals.

I have had an opportunity to be a part of demonstrations, both in Philadelphia as well as Harrisburg, again on behalf of intellectually challenged citizens for adequate support services.

As an administrator, I was recognized for providing an atmosphere where all of our special needs secondary students were treated with respect and integrated into all of the school activities without prejudice.

As a building principal, incidentally, I oftentimes had to advocate for the parents who might have been bringing charges against our building, because oftentimes these parents were not represented adequately by an advocate, which meant that I saw the inadequacies of what was happening with the child, so I thought it was important to help that parent because the child needed that kind of support.

I have served on several local and statewide boards for the advocacy for a meaningful experience for the disabled, covering a period, again, of almost 20 years.

I have had a chance to speak before committees here in Harrisburg in the past as well.

The above activities are demonstrations of our commitment to enable all citizens to live a full and enjoyable life within the community of relatives and friends.

We have tried to afford our son with the same opportunities as evidenced by his extensive traveling in many cities, including Toronto, Canada; east of the Mississippi. He has participated in Special Olympics and an assortment of local social, sporting, and entertainment events throughout his life.

In recent years, there has been a reduction in some of these activities due to our aging, and we are having to come to grips with the prospect as to what will happen when we are gone. While some dependent adults have relatives who are willing to take on the enormous task of caring, there is a much larger group who have no such safety net.

Many of us are approaching our senior years, and more parents are approaching 75 and 80 years and even older. One needs to just view the trepidations that so many elderly parents, including ourselves, are experiencing because of the limitation of such safety nets that are committed to providing a full and meaningful life for their adult children.

Going on the website and downloading, quote, “Autistic Daddy,” end quote, you will be able to review the many testimonies of parents who are traumatized over the prospect of their child’s care when they no longer can.

We are hopeful that our children continue a meaningful life in the community, and we are deeply concerned, again, what will happen when we are gone. We have no desire to have our children warehoused in institutions. We have been collaborating with social welfare professionals and agencies for long periods of time to make sure that those kinds of places do no longer exist.

Who within the State legislative bodies and the Administration can parents rely on to address this present and real concern? The anticipated need for resources to address the needs of consumers who have lost parents and no relatives to care for them is extremely urgent.

There are local and statewide agencies that can provide critical data to substantiate the urgency of this matter, as you have witnessed here this morning.

We need a legislative declaration that these needs will be addressed with all deliberate speed and with resources. A lot of anguish and despair can be avoided with an expeditious response to this critical matter.

And I want to end with one note, and that is, under normal circumstances, parents expect certain things to happen in their child's life at critical stages. At the end of early childhood, they expect them to be able to go into elementary school. That did not happen for my son. It took us 3, 4, 5 years before an elementary school would accept him, and that was because of legislation that initiated in the Federal Government.

When it came time for him to -- when he graduated, there was no place for him to go other than at home because the services were not available. And what's so interesting is how he got a waiver. It was very fortuitous, but this is the story:

I happened to be running a high school at that time. I was on my way to work, and I stopped at a McDonald's to get a little sandwich before I got to work. And incidentally at this time, I was working in New Brunswick. This McDonald's was in Philadelphia.

A lady walked up to me and said, "Sir, are you going into New Jersey?" She didn't know me from a can of paint. I said yes. And she said, "Are you going to New Brunswick?" Well, now this was really eerie, because that's where my school was, was in New Brunswick. I said yes. She said, "My child goes to Rutgers University. I need a lift."

Now, this just blew my mind. So I said, "Okay; I will take you to New Brunswick." And as we drove and we began to converse, she let me know that she worked at Devereux. And we talked and talked, and I took her right to the university and dropped her off, and I let her know that my son had been sitting at home for 5 years. And she never promised me anything, but in a month's time, my son was placed on the waiver. I don't know what she did, but she did the right thing, that's for sure.

So our children should not -- or our adult children should not have to experience positive things in their life in that fashion. There needs to be something that is much more organized that we can anticipate certain kinds of supports are going to be in place when they reach certain stages of their lives.

So I want to thank you again for allowing us to come together and share with you our concerns. Thank you.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Dr. Edwards.

We were just saying that woman you met, that you gave a ride to New Brunswick, sounds like an angel, we believe.

DR. EDWARDS: Yeah.

ACTING MAJORITY CHAIRMAN MURT: Good morning, Joyce. Thank you for being with us.

MS. SNYDER: I think several of us parents have met some of those angels.

This is Tucker’s story:

Hello. My name is Joyce Satteson Snyder, and with me is Bill Satteson -- he’s a retired American veteran -- and my son, Tucker. We are not only Tucker’s grandparents, we are Tucker’s adoptive parents.

Tucker came to live with us after directly being released from the hospital after his birth. We started early intervention, and he was diagnosed with petite mal seizures, ADHD, intellectual disability, and autism.

Unfortunately, before we had full custody, Tucker suffered abuse at 12 months of age. The abuse occurred during a visitation with his biological mother. As much as we want to protect our children, he suffered another abuse early in life.

Our knowledge of this didn’t come about until Tucker was 17 and in therapy at KidsPeace, a residential treatment facility. Tucker is very trusting, and when placed in learning support in the local school, he was shown by older boys how to use the Internet to view pornography. He started to develop unhealthy obsessions that he could not understand.

We enrolled him in a county mental health program after finding out about Tucker’s history of abuse and obsessions. We worked with Tucker's mental health case manager to have him start to receive therapy.

Without even meeting Tucker, every agency that was called or referred to us refused to provide therapy services for Tucker. The reason that he was refused was because of his intellectual disabilities, autism, sexual abuse, and the sexual obsessions he had developed. None of them felt qualified to be able to provide appropriate therapeutic services for Tucker.

When we were not able to get appropriate services in Pennsylvania, we moved Tucker to Canton, Ohio, to live with his biological father. The Canton, Ohio, district had an academy for the autistic with full supervision. There, again, he became a victim.

Tucker called us if he could come home, asking us to please find him help. He returned home, where he fell into a depression. We were told that he was not allowed to attend his high school, so he lost the rest of that school year. His depression had worsened. From all the rejections from the school, the therapists, and the Lycoming County Mental Health, Tucker started to believe that there was no hope for him.

With little help coming from the mental health team, I turned back to my primary insurance case manager. By summer, his illness had become worse. The rages were happening more often, voicing self-harm. He had no hope of help. At one point, he tried to tear out his vocal cords with his fingernails.

His thoughts of suicide and thoughts of harming us escalated. He felt like he had a demon following him. He said he could no longer control his rages. His mind had taken away his will to stop. In one of his rages, he almost killed our cats. I drove him to the ER, terrified he might harm me.

November of 2014: He was hospitalized. Again I reached out to my primary case manager who was helping me to get Tucker into an RTC, where the only placement they provided was at KidsPeace. Lycoming County Mental Health fought this placement, telling me that they would not support that facility. I needed immediate surgery they had to postpone so I could focus on Tucker’s needs.

The first attempt to get approval was denied, but our case manager went to the medical director and got it overturned. Tucker was only granted 150 days, and then he would have to get his care in the community.

After his 150 days were done, he was scheduled to be released, but no Community Care had been found, let alone set up. I refused to have Tucker return home because I knew that he needed more therapy and care than what I would be able to give to him.

It was at this time that I had to undergo surgery due to the cancer that was found at my doctor’s visit. A high-risk assessment was done on Tucker, and it was found that Tucker was too high a risk to be released.

Lycoming County Mental Health was asked to find another placement in RTC or RTF or Community Care. It was at this time that I was told by a targeted case manager that if I would have or would let Tucker be arrested, Tucker would get all the mental health paid for under the criminal justice system. I was completely shaken by this statement.

Tucker was transferred to the Harborcreek Center in May 2015. KidsPeace had included in Tucker’s goals for repetitive training to retain the therapy. The therapist at Harborcreek confirmed the goal. Again, Lycoming Mental Health and Community Care were determined to remove Tucker from the RTF service, again saying services could be met outside of an RTF without having any idea where to find services.

Their plan was to put Tucker in an adult mental health group home with no supervision. Without supervision, I knew that Tucker would either be taken advantage of or would end up being arrested and put in jail.

So again, I started researching and calling everyone who would listen until I found the right people to help me. The Education Law Office listened to my story and coached me through the hearing process. Community Care has started their denial process, and I was coached on how to do the hearings.

After being denied over and over for services, Janice Meinert of the Education Law Office started attending Harborcreek monthly meetings. Out of continued desperation, I found Ned Whitehead, a disability rights advocate and member of the Pennsylvania Waiting List Campaign. Ned started to attend the meetings as well.

During this time of the hearings at Community Care and Harborcreek, Bill had a heart attack. In October 2015, he went under surgery. He lost his job as a truck driver. Just a month later, I was diagnosed with my second type of cancer for the year. Right now, I'm going through chemo.

None of this mattered to Community Care, Lycoming Mental Health, or the Harborcreek business manager. While both Janice Meinert and Ned Whitehead attended this particular meeting, the business manager of Harborcreek said in the meeting that if the money stopped, he would drop Tucker off at a homeless shelter in Lycoming County since his parents would not allow him to return home, never stating we were unable to because of our major health concerns. I was told I should choose my son over my health, meaning my chemo treatments.

By this time, I was in tears, and Tucker was listening to all of this. Janice Meinert and Ned Whitehead brought the meeting under control and refocused the meeting on Tucker's needs. Janice Meinert went to the Community Care medical director, who spoke to the Community Care administration, who made an executive decision to continue services for Tucker's care at Harborcreek until proper placement was found.

Ned asked why Tucker had not been signed up for the ID services. He stated that Tucker could be eligible for placement in an ID group home where his health and safety could be met. The meeting became productive again. Ned Whitehead and the PA Waiting List Campaign were able to go to the right person who could help Tucker receive services through the ID system.

My story doesn't end here. We're still very involved in getting Tucker's placement in a supervised ID group home in Luzerne County. We are looking for a therapist who can work with Tucker. There seems to be more opportunity in Luzerne County for Tucker and his ongoing needs.

We were fortunate to find the right people at the right time. How many other people are out there that are facing some of the same health issues we are? They may not be able to get the support services for their family members, and what is happening with these individuals?

During the whole ordeal, Bill and I were awarded guardianship over Tucker. Even if he's not in our home, we will always watch over Tucker's well-being.

I thank you for listening to Tucker's story.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Joyce.

And thank you to our testifiers. Thank you.

PANEL FOUR:

AUTISM

ACTING MAJORITY CHAIRMAN MURT: Our next panel -- if you could please come forward -- will discuss autism.

Thank you for being with us today.

Good morning, Lisa.

MS. TESLER: Good morning.

Good morning, Representative Murt and other Members of the Human Services Committee. Thank you for providing us with the opportunity to speak with you today.

My name is Lisa Tesler, and I'm the Policy Coordinator for the Pennsylvania Waiting List Campaign, and I'm also the parent of a 20-year-old with a diagnosis of autism.

You have heard a great deal of information about the waiting list for intellectual disability services, but we're going to talk about the autism service system.

The Bureau of Autism Services, BAS, has a completely separate and different application and enrollment process. They maintain an "interest list," not a waiting list.

The current autism system provides help for about 720 people. It has approximately 2,000 people on the interest list. So while we often talk about the waiting list and the PUNS numbers, we need to remember that there is this other population of people who may not be counted or reflected in that data.

The "Pennsylvania Autism Census Project: Final Report" was issued in October 2009 and then updated again in 2014. That report identified more than 17,000 adults with autism in Pennsylvania now, and the projections indicate that there will be more than 73,000 adults with autism by the year 2030. And I included the chart for your reference from that report.

While these numbers do appear overwhelming, we believe it is possible to address the need. Some of those individuals may not need waiver services. Some may access supports through other programs like the Office of Vocational Rehabilitation. Many are served through the intellectual disability system, and others may be supported by their families and other natural supports.

According to the Office of Developmental Programs, only 28 percent of the people who have intellectual and developmental disabilities actually access services. So if that percentage holds true for the autism population, the numbers do become a little bit less insurmountable. However, even that 28 percent is more than we have the capacity to serve now, and so the system will need sustained growth and expansion to meet those needs.

There is a great deal of time and attention paid to educating and supporting children with autism, which is important and essential. The education system and the behavioral health system have made significant strides in increasing their capacity and to provide services for their growing number of students with autism. However, it is time to recognize that those children grow up and become adults. The State, policymakers, families, and providers must prepare for and invest in a lifetime of supports for those who will need them.

So what changes are needed to support families caring for loved ones with autism?

First, reform the interest-list policies to assure that families actually know whether they are eligible for the Adult Autism Waiver, that they understand their entitlement to an intermediate-care facility or an ICF, and that they have the right to choose between the home and community-based waiver services or the ICF setting.

The Office of Developmental Programs should provide an initial evaluation for all people currently on the interest list and to those who request funding in the future.

Federal regulations outline assurances that States must make to the Centers for Medicare and Medicaid Services, CMS, for home and community-based waiver programs. The States must assure an initial evaluation "of the need for the level of care provided in a hospital, a nursing home, or an ICF/IID when there is a reasonable indication that a beneficiary might need the services in the near future (that is, a month or less) unless he or she receives home or community-based services." This does not happen now.

Once evaluated, if the person is likely to meet the ICF level of care, the Bureau of Autism Services should be providing information to those families regarding their entitlement to an ICF and offer them the choice -- ICF setting or home and community-based services.

Again, the regulations require "...when a beneficiary is determined to be likely to require the level of care provided in a hospital, nursing facility, or ICF/IID, the beneficiary or his or her legal representative will be---

"• Informed of any feasible alternatives available under the waiver; and

"• Given the choice of either institutional or home and community-based" waiver "services."

That does not happen now.

The current process of allowing individuals to languish on the interest list, without any evaluation of need or providing any information regarding the right to choose their service delivery preference, from our perspective, does not meet these assurances. Additionally, it seems cruel to allow a person and their family to continue to wait for service that ultimately they may not qualify for.

We also recommend that you provide additional capacity -- that is, serve more people -- in the home and community-based waiver programs to avoid institutional placements in either public or private intermediate-care facilities, nursing homes, or hospitals.

Pennsylvania includes ICF services in the Medicaid State Plan. Therefore, all individuals who have Medical Assistance and meet the level of care are entitled to that service -- no waiting.

People on the intellectual disability waiting list and those on the autism interest list who qualify could choose the ICF, and the Department of Human Services would be required to place them. The families don't want that, which is why they wait. They don't want isolation and segregation; they want community. However, the people on the interest list are entitled to be informed about their rights and to make that choice.

If the individuals currently on the waiting list or interest list exercise their entitlement, the cost to the system would be tremendous. Our public ICFs, or State centers, cost more than $390,000 per person per year; the Consolidated Waiver, serving individuals with intellectual disabilities, costs $123,000 per person per year; and the Adult Autism Waiver averages $51,000 per person per year. So it makes sense, both fiscally and morally, to expand the home and community-based waiver capacity to serve more people and avoid these unnecessary institutionalizations.

Prioritize people waiting to ensure that those who are most at risk are offered their services first. We need to make the process transparent and align with the ODP practices in place for the intellectual disability program.

So the Office of Developmental Programs utilizes the Prioritization of Urgency of Need for Services for the waiting list for the intellectual disability system. The Bureau of Autism Services maintains the separate interest list. ODP does not know how many or if there are overlaps between the lists, nor do they know or understand the risks or needs of the people who are on the interest list.

We recommend one standard process for determination of waiting list status and waiting list enrollment across all ODP programs to avoid confusion and duplication of effort.

At this point right now, families who may qualify for both systems must engage in application or a request for services through those two different doors. We also ask that the autism waiting list numbers be published monthly, just like the PUNS numbers are published for ID, to add transparency and accountability to the process.

We would like ODP to provide some basic level of support and information to families currently waiting for services through the autism program.

People with intellectual disabilities who are on the waiting list have access to Supports Coordination and sometimes to the base or county funding to provide some very limited services. Adults with autism do not access and cannot access those supports.

There was once a mini-grant program in the Bureau of Autism Services, but that was discontinued. So we recommend providing some very basic services along with Supports Coordination for adults with autism who need help now but are waiting to access waiver services.

Finally, we need to scale up the program to prepare for the tremendous needs as reflected in the Autism Census.

Pennsylvania emerged as a national leader in the development and design of the home and community-based service system for adults with autism with the creation of the Adult Autism Waiver and the Adult Community Autism Program. Our community is grateful for the groundbreaking efforts underway here. But as you can see, there is much more that will need to be done to fully meet the needs of the huge number of individuals who need support now and into the future.

So to that end, we recommend:

- A commitment from our Governor and our Legislators to provide adequate and necessary funding to support sustained growth in the autism services system for adults.
- We ask that the Office of Developmental Programs address the structural changes that will be necessary in order to expand their capacity to administer the Adult Autism Waiver program.
- We encourage the expansion of the qualified

provider network to serve all the adults with autism in need.

- And we also ask that the adult autism system include participant-directed services within the autism programs to allow individuals and their families maximum flexibility and control over how their home and community-based services are implemented for them.

In preparation for today's hearing, I reviewed many of the written comments to the Office of Developmental Programs that I had made in the past and dusted off my testimonies from previous hearings on the waiting list.

Since 2008, when my son was 12 years old, I and the Waiting List Campaign have been making recommendations regarding improvements to the autism system. Many of the concerns I shared in 2008 are still relevant now. I am hopeful, however, that as we move forward, the recommendations we offer today will lead to real systems change.

We all play an important role in increasing access to services and improving the quality of support across Pennsylvania and throughout the lifespan for individuals with autism and their families so that they can lead an everyday life like everyone else in their community.

Thank you for your time today, and I’m happy to answer questions at the end.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Lisa.

Good morning, Tom.

MR. FLYNN: Good morning, Representative Murt. Thank you. Thank you for this opportunity to speak to you today.

My name is Tom Flynn. I live in Etters, York County, and I am the proud father of a young man with autism. His future and the future of many other young people like him across the State brings me here today.

Brendan is 24 and considered higher functioning on the scale of autism spectrum disorders. He lives at home with my wife and me, and we are blessed that he has a job. We are able to meet his needs and plan to do so for the foreseeable future.

When he was diagnosed with autism at age 5, our son’s doctor informed us that the prevalence of that diagnosis was 1 in 10,000. Today, according to the Centers for Disease Control and Prevention, the prevalence is now 1 in 68, so our son and many more of his peers are at “the tip of the spear.”

Pennsylvania’s Bureau of Autism Services is aware of the overwhelming need but lacks the resources to handle it. According to figures available on the PA Waiting List

Campaign website, a total of 1,989 people were on the interest list for the Autism Waivers available through the Bureau.

In the 2016-17 budget proposal, the Department of Human Services has planned to fund 100 new spots in the Adult Autism Waiver, and as we heard earlier from Secretary Thaler, there are only 712 people currently being served with the Adult Autism Waivers.

And according to the Bureau's 2014 Autism Census update, 55,000 people with autism in Pennsylvania are receiving some sort of services, but as many as 130,000 more, using the State Census figures and the 1 in 68 CDC prevalence rate, are not receiving services.

Further, the 2014 Census update projects a doubling of adults with autism, from 17,075 in 2015 to 36,261 by 2020 who will receive some sort of State services.

So what are we to do? Our State is a national leader with its commitment to autism services. We know we are at the edge of a storm of adults who have already transitioned out or will transition out of school-based services. We have an interest list that will grow exponentially.

Fortunately, the Commonwealth does have a way to address these critical needs. The Autism Insurance Act, commonly referred to as "Act 62," was passed in 2008. Act 62 requires many private insurers to cover many of the costs of treating children under 21 with autism spectrum disorder.

Unfortunately, Act 62 enforcement has been exceedingly rare. The real-life result is that services that should be covered under private insurance instead are paid by Medical Assistance at a practical loss of millions of dollars to the State.

David Gates, a senior attorney with the Pennsylvania Health Law Project, estimated that in 2012, the Department of Human Services could save $25 million annually if Act 62 was fully implemented as intended. By comparison, the budget request for fiscal year 2016-17 for the Bureau of Autism Services is $24 million.

By directing the savings of Medical Assistance funds from Act 62 implementation to the Bureau of Autism Services, the Commonwealth can help those in need of adult autism services at a time when the demand will be intense, and that demand can be answered with a funding stream already in place.

As a member of the autism community, I ask for your support. Department of Human Services Secretary Ted Dallas has said members of his department will be meeting with counterparts from the Insurance Department and representatives of private insurers. We ask for your support for Secretary Dallas's initiative to secure Act 62 implementation, that a law already on the books is enforced, and that the resulting savings in Medical Assistance funds are directed to autism services.

That commitment will help my son and so many like him who have autism but will need the assistance and promise offered by the Commonwealth through the Bureau of Autism Services to lead a productive life.

Thank you very much.

ACTING MAJORITY CHAIRMAN MURT: Thanks, Tom.

Good morning, David.

MR. JASKOWIAK: Good morning, Representative Murt and other Members of the panel.

Thank you for your attention. I know it has been a long morning, but I'm here to share a personal story with you.

This is the first time for me. I'm not one of the people that Mary Ohl recited who have been here many, many, many times before, but this has become very personal for my wife and I.

We are the proud parents of a 23-year-old, but unfortunately for us, we're not receiving any waiver services whatsoever. And our son is not able to work, at least not at this time. He relies on us for all of his needs, and we are there 24/7 for him, and mostly my wife who is with him.

I wish he could be with you here today, but frankly, this setting is more than he could handle or absorb or comprehend. It’s a little tough for some of us to comprehend, too, what’s going on, so I certainly can understand.

I wanted to share with you a couple of snippets about our experiences in dealing with this system, though.

When he graduated from high school, we didn’t get any help from the high school in terms of what to prepare for. We really didn’t. Transition services were really nonexistent. Although they called them that, no one talked about the waiver programs whatsoever. So thankfully, soon when he reached 21 -- and by the way, he left high school a little bit early because they had run out of things for him to do.

So we started looking into it, and with the help of somebody, they said, look into the ID system. The problem is, our son is a little bit above that arbitrary threshold of 70 IQ and lower. And it’s frustrating, because our son will never be able to live out on his own, we suspect. He can’t right now work. He needs supports and services.

And we checked with OVR, and they were unfortunately a little bit pessimistic about it, because they made it very clear, well, we only take people who can work for competitive employment. Well, our son right now needs those supports and services. He can't just take a week or two of instruction and then go out and get a job and stick with it. He needs that guidance and assistance. And we trust that he could be one of your success stories if given that opportunity, but unfortunately, there is nothing out there that we have been able to get.

Our first attempt to get onto the Autism Waiver was never actually completed. We called into that number; we never got a call back. I continued to look at all the different options and then tried again, and finally in September of 2014 we did get some kind of an acknowledgment back.

But to this day, we still don't know what we're waiting for. We're kind of like that airplane that is circling the airport. We don't know when or whether we're ever going to get a chance to land.

We asked the Bureau, where do we stand on the list? The answer we got was, the Bureau doesn't give that information out. And I share Ms. Tesler's concern; we need transparency, because, you know, right now, I'm almost 61 years old. My wife is a little bit younger than me, but not much. We’re scared about what’s going to happen to our son going forward. Who is going to take care of him? Who is going to provide for him? Who is going to make sure that he’s safe going forward?

He doesn’t have the social skills. Although he is verbal, he doesn’t have the social skills to know when people are trying to manipulate him, when people are trying to take advantage of him. He needs that kind of a setting where he can at least get some friends that he can trust, the things that you and I take for granted every single day. But right now, he doesn’t have that. He has our small family.

You can’t always count on friends and family outside of the immediate family. They have their lives, and frankly, they don’t always understand what you’re going through.

The one thing about autism is that there are sometimes quirky behaviors that people who don’t know what you’re dealing with get a little bit alarmed about. And it’s not like you can just call somebody and say, can we have a babysitter for 5 hours so we can go out to dinner? People don’t want to do it. They’re a little bit concerned about doing that.

So one of the things that we found, though, it has been actually -- it will actually be 4 years now, I think, he’s out of high school. He had to get out a little bit earlier. We’ve seen regression, and that’s the thing that scares us the most. The last year has been extraordinarily difficult for us. We’re back into a little bit better of a place after just about a year ago now it all started, and we had some very grave medical concerns.

We saw a lot of doctors, and at the root of it all, they finally said, a lot of the things that we’re seeing physically with your son, we’re seeing because he’s not dealing very well with the lack of activity, although we try to do everything we can with him and we spend all the time that we can and get him out as much.

He knows that there is more to life. He’s smart enough to know that there’s more to life than the life that he has got right now. He was promised that in school. At various points of time, they put into his mind, you’re going to go live out on your own; you’re going to go live with friends; you’re going to have a job, and then he gets out and finds out the world is not as hospitable as he thinks it should have been, and frankly, he has had a tough time dealing with that.

So thankfully, with the help of some very, very good doctors, we are able to get back to a better place right now, but we’re scared. It’s a slippery, you know, situation we’re in. He could backslide at any point in time. And try as we might, we just hope that we don't go down the same roads that we went down before.

We're asking, we're pleading with you to please do all that you can to make sure that this waiting list for autistic individuals who may not qualify for the ID system can still get the supports that they need. It's a good economic investment for us, because otherwise, we'll all be spending a lot more money going forward. But more than that, it's not a budgetary thing; it's a human problem.

We need to take care of these people. We need to do the right thing. And I thank you for your time.

ACTING MAJORITY CHAIRMAN MURT: Thank you, David.

Good morning, Mary.

MS. HARTLEY: Hi.

My name is Mary Anderson Hartley. I'm here today as a parent to advocate for the future needs of my almost 16-year-old son, Jack, and young adults like him.

I begged, even bribed him with the promise of a movie, hotel, and pizza to make the trip from Pittsburgh and speak, but he would not miss his work at school. That is the kind of young man he is -- and worth fighting for.

I want to first thank you. Because of the work of the Pennsylvania Legislature, my son will need less support than adults like him in other States, because kids with autism in Pennsylvania get wraparound services, and in

Jack’s case, that has been invaluable. He also receives significant special education resources, enabling him ultimately to be fully included in both middle and high school.

Autistic adults, too, might get services in Pennsylvania, but very few. It took a lot of tremendous advocacy to get to this point, and our family is grateful for the service of those who laid the groundwork. But we need to do a whole lot more to ensure that all autistic adults have the opportunities for the future and that more people can get access to services, even while they wait.

For me, for many of us, it’s the uncertainty of not knowing. My husband and I work very hard to plan for Jack’s future. We affectionately say that we can live anywhere and eat bread and peanut butter, but our son will get what he needs. I hope and pray we have enough at the end, even with the help of our family, to support him.

So I’m grateful there is a hope of the Autism Waiver. It relieves some of the stress, but at the current rate of delivery, the last person on it today will wait 20 more years or so to see services.

The Bureau of Autism survey estimates that in the next 4 years, 36,000 adults with autism will live in Pennsylvania. We have so far funded, of the typical Autism Waiver, 576 slots. Jack will be one of those 36,000. He deserves a chance to use what skills he is developing now with a little more support to achieve independence in adulthood.

I know Pennsylvania does not have the resources now for every person who will need services when my son graduates at 21. He is doing everything he can to be a success in life -- to live, to work independently -- and we are certainly doing our part to make sure of it.

So today I'm asking you to do more and better with the resources we have -- yes, to increase the numbers for autistic adults -- but also to build a system for those individuals who will never get access or will wait decades for a waiver to keep them out of institutional settings, hospitals, group homes, homeless shelters, and prisons, far too costly options in terms of human potential and our financial resources. But they are in those places now at too high a price.

I'm proposing that there be more help in place for everyone who is waiting. You sign up at 18 for the Adult Autism Waiver, but nothing happens until 21. You don't even know if you qualify. You just wait. It's first come, first serve. I get that, except for the family where someone is hurting others or injuring themselves, wanders, is victimized, and is highly likely to end up in mental institutions, jail, or worse, and was not being treated for autism and how to fix the situation.

First come, first serve is a nice idea, but I seriously don't want my son to get supports before someone who is at risk of institutionalization.

I was pleased to hear Nancy Thaler say today that changes are coming and that people could be assessed and maybe even categorized by need, but still be on a first come, first serve basis? That could be good. That way, we could still unlock the potential of higher functioning adults who can get some services right away and go to work, pay taxes, and live independently with minimal support but know and identify and prioritize adults with significant needs in their category. If it's truly first come, first serve, I want my son to know what his number is, and I want to know so I can sleep at night.

I would personally like to see more county-based systems set up, and if it's already a success, an expansion of the ACAP, Adult Community Autism Program Waiver, that is only in four counties right now. It appears everyone who is on that waiting list is getting served. Could such a system support those on the waiver but also provide drop-in support or counseling to those who are waiting?

Could base funds support critical needs like respite care for families who need it so desperately?

There should be a significant investment in resources, training, and supports for families to understand what they can do while they're waiting. Perhaps this would prevent an immediate need for full-blown waiver services until later in life -- connections, starting at 18 while they're still in school, to work, like OVR; connections to social supports; behavioral health, et cetera.

At least when you sign up for the intellectual disability, you are assigned a supports coordinator and have at least one annual meeting -- a relationship of assessment, support, connections. Treating people with autism with less is not fair nor appropriate.

I echo my colleagues. We want more and we want more long-term structure to know how people are going to get off the waiting list. The Governor's budget this year proposes 100 additional slots for autism while the numbers of people in need are growing exponentially. We need to be more creative to ensure that those who can be served will be served. We need a plan of support for autistic adults who are going to be waiting, especially recent graduates. They can still make progress and not regress with your support.

I know you want to do what's right and I know you can't do everything. I just would like to ask you to do three essential things right now that ensure more autistic adults can get what they need:

- One, use resources more effectively to help more people.
- Two, fix the intake system for the Adult Autism Waiver, and I do have additional suggestions not listed here.
- Three, create a plan that supports autistic adults and their families while they wait, or if they never get access to services.

Thank you.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Mary, and thank you, testifiers.

PANEL FIVE

ACTING MAJORITY CHAIRMAN MURT: Our final panel this morning will be Shirley Walker.

Sheila?

MS. STASKO: I don't need to come back up.

ACTING MAJORITY CHAIRMAN MURT: Okay.

Good morning, Shirley.

MS. WALKER: Good morning. Or good afternoon.

ACTING MAJORITY CHAIRMAN MURT: Also, before you testify, I just wanted to recognize that my colleague, Representative Joe Emrick, is here. Joe represents part of

Northampton County. Good morning, Joe.

MS. WALKER: Before I begin, I wanted to make sure that you have this chart which was on the last page of my testimony.

And I'll say good afternoon, Representative Murt, Representative Miller, and Members of the Human Services Committee.

I am Shirley Walker, President and CEO of PAR. PAR is the only statewide provider association whose mission is solely to provide services and supports to people with autism and to people with intellectual disability.

Our members provide the full range of services and supports, from residential services to in-home services, from day services to employment. We provide services to tens of thousands of individuals in Pennsylvania who have an intellectual disability or autism.

I welcome this opportunity to appear before the Committee. PAR strongly supports the request for funding that is needed to enable individuals on the waiting list and their families to have the services that they truly need.

I am here today to add some facts for your consideration that have not yet been mentioned during the hearing and I do not believe are well understood.

But first, I want to acknowledge and express PAR's sincere appreciation to DHS Secretary Ted Dallas and Deputy Secretary Nancy Thaler for the time and attention that they have devoted during the past year to not merely listening to the concerns we have expressed to them regarding the punishing and irrational payment policies and practices that were enacted prior to their coming to DHS, but also for being willing to consider potential short-term and long-term remedial actions.

But as willing as Secretary Dallas and Deputy Secretary Thaler may be to consider changes in DHS policy, they are severely constrained by the persistent lack of sufficient funding available to DHS to support these services. It takes political will, legislative will, to ensure sufficient funding for what is needed.

As the statewide association whose focus is to ensure that our members who provide these services can continue to provide the services that our waiting list families are seeking, we come to you to make you aware of factors and misperceptions that we believe have contributed to the current difficult situation.

In 2011, you are aware that regressive payment policies were imposed by DHS only on providers of services to people with disabilities, not on any other Medicaid service providers. Why was that?

What happened in 2011, however, is only an exacerbation of the disparity that has impacted services for people with intellectual disability or autism over many years.

On the last page of my testimony is a chart. The chart graphically and sadly depicts the wide and glaring disparity in rate increases for intellectual disability and autism service providers versus the routine annual funding of rate increases that has been appropriated to other Medical Assistance providers like hospitals, nursing homes, and MCOs.

To better understand the chart before you, please note that there is a difference between funding increases that are needed to address increased utilization of services and funding that is needed for rate increases.

This chart depicts funding that has been made available by the Legislature for rate increases over the years -- flat-lined in comparison to other Medicaid providers.

Funding for increased utilization is the funding that is needed to support people who are receiving services, and as people grow older and other things happen, perhaps a medical problem occurs that causes the need for additional support, then it clearly takes more funding to support them. That requires funding that is generally referred to as “increased utilization funding.” Funding for increased utilization also is the funding that is used to get people off the waiting list into services.

On the other hand, funding for rate increases is what is required to pay the workforce that provides these services. The wages for this valued work need to be at a level that the worker can support his or her own family without having to have a second job or needing a hand-up in government-funded food assistance for their families.

Rate increases have fallen so far behind that we now have over 3,500 vacancies that are being so-called “filled” by temp agencies or regular staff on overtime. Both are bad options.

The Office of Developmental Programs noted recently that 85 percent of the dollars we receive in rates are spent on staffing. So when there aren’t rate increases, you can easily see who gets it in the neck: it’s the individual receiving services. Because if direct-support professionals are forced to leave their jobs as soon as they find a better paying job so that they can support their own family, the individual being supported is turned over to another and another and another person to support them.

Discontinuity does not result in a quality service. It takes a direct-support professional considerable time and experience with an individual to understand how to provide the best support for that individual.

As you can imagine just from your experience this morning observing, these are not easy jobs. They are jobs that require consistency and experience.

The disparity in funding for rate increases that you see in the chart is creating the crisis that is stemming from not being able to adequately pay our workforce, which means our workforce has to leave when they find better paying jobs.

We have been asking a lot of people why this disparity exists. We were surprised by their responses. For example, we were told that other Medical Assistance programs are mandatory and services for people with intellectual disability are optional, and that's the reason stated for the disparity. But that is not accurate. That is a perception I want to dispel today.

Intellectual disability services are covered services under the 1966 Mental Health and Intellectual Disability Act passed by the Pennsylvania General Assembly in its good wisdom and signed into law.

And intellectual disability and autism services are subject to the same funding requirements under Federal law as are, for example, hospitals and nursing homes. But they are not treated the same when it comes time to consider rate increases. Why is that?

Payments for these services, as with payments to hospitals, MCOs, and nursing homes, must be consistent with efficiency, economy, and quality care and be sufficient to assure the availability of providers competent to provide quality care. Quality starts with the direct-support professional.

These rules apply to all Medical Assistance providers. So why is there a disparity for people with intellectual disability or autism?

And unlike MCOs, hospitals, and nursing homes, Medical Assistance essentially is the sole payer for intellectual disability services. Families and we, the providers, don’t have any third-party pay available for intellectual disability services.

Further, unlike nursing homes and hospitals, intellectual disability and autism service providers receive no disproportionate share payments, even though nearly every person with intellectual disability served by our members is 100 percent Medical Assistance eligible.

We have also noted on the chart the annual supplemental disproportionate share payments made to hospitals. They have a much smaller percentage of persons they support who are on Medical Assistance than we have.

The financial assistance to help them with their Medicaid population is a large number. Why don't providers of services to people with disability who are 100 percent Medical Assistance eligible get disproportionate share payments or the equivalent in rate increases?

In addition to these disparities, we are still subject to numerous regressive payment policies that are impacting the availability and the quality of home and community-based services.

I will give you three examples of rules that no other Medical Assistance provider type is subject to. These rules went into effect in 2011 before this current Administration, who I believe is trying to change all of that.

The first example:

Community-based service providers, unlike every other Medical Assistance provider of services, cannot retain any earnings. If a provider experiences any savings in a fiscal year to try to be more prepared for emergencies or even to build a small capital base for extenuating circumstances such as, for example, a budget impasse, it's taken from them dollar for dollar in their future rates. Why is that?

The second example:

If an individual being served in a residential program is away with his or her family on weekends or for a vacation, under the current payment policies and procedures, a provider may not be reimbursed for the costs that it must continue to incur to maintain the residential support for the person. We can’t lay off staff. We can’t shut off the electricity or quit paying the mortgage. And if an individual returns unexpectedly from a planned trip with family or a weekend, we have to be staffed and ready. We cannot say no. Our costs remain, yet the fiscal policies that are currently in place will not reimburse those required costs.

If an individual is away from their residence, their home, for any reason outside of the control of a provider, why is the provider, and by extension the consumer, penalized?

We are in a single-payer system. We are unique in that we are the only service that is in a single-payer system. So how does a provider ever deal with loss in revenue? They have no way to recover lost funds.

The third example:

For residential services, the allowable costs reported by providers to DHS are typically 2 years old when used for rate-setting purposes with no adjustment to account for basic cost-of-living increases like utilities, not to mention increases in health-care costs or for other mandated costs. Why is this? Why are these providers of services to people with disabilities treated differently?

We're very aware of the stresses and demands on the State budget. We ask that as you confront the budget, that you prioritize the waiting list and a rate increase for intellectual disability and autism services that is sufficient to start closing the gap that the chart shows. Rate increases that directly impact the workforce that supports people with disabilities should be valued at least in the same way as rate increases for other Medicaid providers.

These services for people with intellectual disability and autism are no more optional and no less mandated by law than the other Medicaid provider types that you see in the chart. So why are services to people with disabilities treated differently?

We want to work together with you on solutions. We are currently working with Members of the House Intellectual Disability and Autism Caucus on legislation to address the funding and rate-setting issues. When the legislation becomes a reality, we ask for your active support. The legislation is being written to help close the gap through a thoughtful, planful correction of the longstanding disparity.

Thank you for your consideration of my testimony. Please use me as a resource for any questions you have.

ACTING MAJORITY CHAIRMAN MURT: Thank you, Shirley.

Thank you, Secretary Thaler, for staying with us.

At this time, we'll entertain some questions. Please bear in mind that we have to be up on the Floor at 1 o'clock, so.

Representative Miller.

REPRESENTATIVE MILLER: Thanks, Tom.

I think you mentioned the time issue to me on purpose.

You know, I just first want to say thank you to everyone who spoke today. I think Tom did a great job keeping us all on target, and obviously the chair people who are not here today did a fantastic job being sure we hear from a diverse group of people who are involved.

I also want to thank some of the young people who testified. I think, is that Glenn in the back? I think I see Glenn still back there. So we appreciate hearing from all of the young people, in particular, who came today.

You know, obviously it's kind of funny at the end to be sitting here with Tom. I feel like the two of us spend a lot of time talking about these types of issues. I will tell you, though, your stories at times were, well, impactful and difficult. The only thing, of course, is they are nowhere near as difficult as living these stories that you all shared with us today.

These are things here that we need to hear about, and although some people aren't behind us here today, obviously this whole thing will be recorded, and the Committee, of course, I think will look to take action. People know a little bit of some of the work that Tom and I are trying to do on the caucus, and that's fantastic.

But I will tell you, though, I appreciate the Administration staying the whole time. I appreciate where we were, and I appreciate people referencing where the State has been, in my opinion, which had been at the forefront of a lot of these movements. Many of you, as previously referenced, have been here for a couple of decades leading that fight.

I'll be honest with you, though. I don't feel like we are at the forefront of it anymore. I feel like we're living off of an old reputation, one that has been dismantled rather quickly. At the same time, we are seeing large increases of need.

I know some people mentioned the age of our care -- the amount of people in Pennsylvania who are being cared at home. That's fantastic, and it's great to see in some ways, I guess, that we're about the same, the typical State, but we're not the typical when it comes to the age of the caregivers, especially in some of our counties like Allegheny County.

Our caregivers are up there in age. This is a big issue. We had grandparents here today talking about caring for their adoptive son now. These are big, massive issues. And I'll be honest with you, I don't believe we are operating with enough urgency as we need to, and I don't believe that we have put forth a plan that would appropriately move on these issues with it.

I'll be honest: I am embarrassed by the waiting list. As a State Representative, someone who has some degree of a vote up here, I'm embarrassed that we have it, and I think that everybody who understands a little bit of this issue should understand why it's an embarrassment to our State.

We can and should be doing better. It's a massive problem.

I would also want to just kind of speak about school, why we're not doing a better job of transitioning our kids to adulthood. We know where the kids are. We know where the kids are.

The families, most of them, generally will come to the IEP meetings, okay? The school is there. There's a transition coordinator of some type that is there. Why there is any delay or why there is any confusion as to what happens at the end of that 18, 19, 20, 21st year when they are graduating, I don’t get. I don’t get. I don’t understand.

Everything we need is at that table to be able to push us forward with maybe one other phone call. So I’m very lost and confused by that aspect, just as I am embarrassed by the state of our State in relation to the issues that you brought up here today.

I know that Tom mentioned questions. I have a lot, to which I’ll look to get back to everybody with. But what I will tell you is, your testimony here was definitely important to us.

And while I appreciate many things that we have to talk about with that budget, there is somebody who mentioned a moral and a fiscal responsibility here in relation to the needs that you expressed, and we have to do better. We have to demand that all of our Representatives and our Governor and our Senators all do better with a sense of urgency, not an urgency in how to pick between who gets in and who gets out; an urgency in the fact that people need help now, and waiting to just see how long you live is not a good option, and it’s, as I said, very troubling to hear that today.

Thank you, Tom, Mr. Chairman, for the courtesy of the time.

ACTING MAJORITY CHAIRMAN MURT: I just want to make a couple of comments also.

Obviously, thank you to our testifiers. Representative Miller and myself have done our very best to coordinate the Intellectual Disability Caucus and rally our colleagues and so forth. But I still believe that the best advocates are you, our family members, the caregivers, the people that really know the issues.

I have only been in Harrisburg 10 years, and really, one of my first days here I met Sheila Stasko, and I have really been -- that was a good day. That was a good day; yeah. And I have really tried my hardest to learn as much as I can about these issues and their challenges and so forth. And even after 10 years, I still hear things that I don't understand and I need clarification on, so this is really a very, very complicated issue.

And one of the examples that I always use to illustrate these challenges to our colleagues that still are learning about intellectual disabilities is the fact that there are literally parents that are in their 80s, and I bet there are some in their 90s.

Bernie O'Neill, my colleague from Bucks County, says he has a family where the mother and father are in their 90s, and they are caring for a son or daughter at home, and the son or daughter is in their 60s. And the parents are struggling with age-related issues, and their son or daughter is struggling with their disability, as well as their own health issues. And that is really the example that I like to use to illustrate what these challenges are like to our colleagues, and that really seems to hit home.

And something else Representative Miller mentioned was about, down in my part of the southeastern part of Pennsylvania -- I represent Philadelphia and Montgomery County -- we have some just outstanding school districts, and they do a great job working with the special education students, training them to a very, very high level of readiness, working on cognitive skills and being on time, being dependable, being reliable. We have students from three different school districts that work in my district office, and it has been a great program.

And the issue is that when they graduate, they're ready to go to work. They want to work. They want to pay taxes. There are no supports for them, and that is a really sad situation when these students will graduate in June and will leave our office and then they will not have any kind of transition place to go. And it's called graduating to the couch, I guess, but that's really kind of a sad, sad commentary, and we're really fighting for more funding for all of these services.

And I meant what I said. This is, in my world, I feel like this is the biggest priority there is in State Government. This is all about people. And, you know, I get testy sometimes, and we haven't done this in a couple of years, but when they have money to build a soccer stadium and things like that, I love soccer, but they can snap their finger and that money appears, but try and find money for people with disabilities and it's like we're pulling teeth, pulling someone's teeth.

But we're going to keep fighting with the mission, and we hope that you will join us. We're very fortunate to have a leader in Secretary Thaler that gets it and is just as compassionate as they come, and we're very, very grateful, Secretary, for your commitment to this mission.

Okay?

REPRESENTATIVE MILLER: Hey, you're the boss.

ACTING MAJORITY CHAIRMAN MURT: Okay. I'm going to conclude our hearing because we have to get to the Floor.

And Secretary, can you stay for a few minutes if someone needs to talk to you?

DEPUTY SECRETARY THALER: Absolutely.

ACTING MAJORITY CHAIRMAN MURT: Okay. We'll conclude the hearing. Thank you.

(At 12:53 p.m., the public hearing concluded.)

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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Transcriptionist

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