

COMMONWEALTH OF PENNSYLVANIA
HOUSE OF REPRESENTATIVES

HUMAN SERVICES COMMITTEE

WORKFORCE ISSUES RELATED TO
CARE FOR PEOPLE WHO HAVE DISABILITIES

HARRISBURG, PENNSYLVANIA
60 EAST WING, MAIN CAPITOL BUILDING

WEDNESDAY, DECEMBER 6, 2017

BEFORE:

HONORABLE GENE DIGIROLAMO, MAJORITY CHAIRMAN
HONORABLE ANGEL CRUZ, MINORITY CHAIRMAN
HONORABLE ALEXANDER CHARLTON
HONORABLE BUD COOK
HONORABLE MICHAEL CORR
HONORABLE CRIS DUSH
HONORABLE JONATHAN FRITZ
HONORABLE RICH IRVIN
HONORABLE AARON KAUFER
HONORABLE NICK MICCARELLI
HONORABLE TOM MURT
HONORABLE ERIC NELSON
HONORABLE ERIC ROE
HONORABLE JUSTIN SIMMONS
HONORABLE TARAH TOOIL
HONORABLE JUDY WARD
HONORABLE JASON DAWKINS
HONORABLE MICHAEL DRISCOLL
HONORABLE STEPHEN KINSEY
HONORABLE MAUREEN MADDEN
HONORABLE JOANNA McCLINTON
HONORABLE DANIEL MILLER
HONORABLE MARK ROZZI
HONORABLE MIKE SCHLOSSBERG
HONORABLE BRIAN SIMS
HONORABLE PERRY WARREN

*Pennsylvania House of Representatives
Commonwealth of Pennsylvania*

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P R O C E E D I N G S

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MAJORITY CHAIRMAN DiGIROLAMO: Good morning, everyone. Good morning and welcome.

I would like to call this meeting of the Human Services Committee to order. Good to see everybody. Welcome.

For the first order of business, I would ask everyone to stand for the Pledge of Allegiance to the flag.

(Pledge of Allegiance was recited.)

MAJORITY CHAIRMAN DiGIROLAMO: If I could ask Pam to take roll call.

(Roll call was taken.)

MAJORITY CHAIRMAN DiGIROLAMO: Okay. A quorum being present.

Before we commence with our very important hearing today, we have one bill that we want to move out of Committee. That is SB 728, which is Senator Yaw's bill.

Do I have a motion and a second to move the bill?

Motion by Representative Murt; second by Representative Nelson.

Just for the information of the members,

1 this is a bill -- it was my bill. It's exactly
2 the same language in the bill that we moved out
3 of the Committee a while ago. We brought it up
4 for a vote on the House floor. It passed out
5 unanimously and went over to the Senate.

6 I've been working with Senator Yaw. He
7 had the bill in the Senate. He sent it over
8 here. This is the easiest way to get this bill
9 done, so I'm going to bring his bill up. It's a
10 very important bill for people that have
11 epilepsy.

12 It removes the two or three drugs that
13 are in the database, our prescription drug
14 database. They are schedule 5 drugs. They are
15 non-addictive and non-narcotic. The only use of
16 it is to treat epilepsy. The Epilepsy
17 Foundation and many of the families around the
18 State would like to have those drugs removed
19 from the database, and I agree wholeheartedly
20 with them. I think it's a good idea.

21 If we can get this bill out of
22 Committee, onto the floor and to the Governor's
23 desk, that would be the final stage, without any
24 more amendments.

25 Any questions or concerns on the bill as

1 it is?

2 Representative Dush.

3 REPRESENTATIVE DUSH: Thank you,
4 Mr. Chairman.

5 Just a quick clarification. This is
6 just removing the requirement for the physicians
7 to check the database, correct?

8 MAJORITY CHAIRMAN DiGIROLAMO: Correct.

9 This removes --

10 REPRESENTATIVE DUSH: The pharmacists
11 still have to --

12 MAJORITY CHAIRMAN DiGIROLAMO: This
13 removes the requirement of the physicians
14 entering this information or -- it's not the
15 physicians; the pharmacists have the requirement
16 of entering the information in the database.

17 REPRESENTATIVE DUSH: Yes.

18 MAJORITY CHAIRMAN DiGIROLAMO: So this
19 removes the requirement for the pharmacists to
20 enter these three drugs in the database when
21 they fill the prescription.

22 REPRESENTATIVE DUSH: Okay. I was under
23 the impression it was the doctors, rather than
24 the pharmacists.

25 MAJORITY CHAIRMAN DiGIROLAMO: Go ahead,

1 Melanie.

2 UNIDENTIFIED SPEAKER: The bill actually
3 removes the requirement for the physician who
4 wants to write one of these three drugs from
5 checking the database for that patient before
6 they write it.

7 The medication will still be one of the
8 scheduled drugs that the pharmacist will input.

9 REPRESENTATIVE DUSH: Thank you.

10 That's what I -- that's the way I
11 understood it.

12 Thank you.

13 MAJORITY CHAIRMAN DiGIROLAMO: Any other
14 questions?

15 Representative Kaufer.

16 REPRESENTATIVE KAUFER: Thank you,
17 Mr. Chairman.

18 I just wanted to make a couple of
19 comments. I think this is a very good bill. I
20 think this is something that we have to move
21 forward.

22 In talking with some of the lobbying
23 community, yourself and others, I know we've
24 been asked to move this forward without
25 amendment. I do believe that there are other

1 changes that we need to do to our ABC-MAP
2 Program.

3 Out of respect to that, and trying to
4 get this done for the epilepsy and our seizure
5 community, people that suffer from seizures, I'm
6 going to move this forward. But I think we need
7 to have a broader discussion on other changes
8 that we need to be doing to our ABC-MAP Program.

9 With that said, I will support the bill
10 today. Thank you.

11 MAJORITY CHAIRMAN DiGIROLAMO: Thank
12 you.

13 Any other questions or comments?

14 Okay. Seeing none.

15 Are there any negative votes on the
16 bill?

17 Seeing no negative votes, the bill is
18 then reported out of Committee unanimously.
19 Congratulations to the individuals that are here
20 that find this bill very, very important, as I
21 do.

22 So with that, we're going to move on to
23 our very important hearing agenda today. The
24 hearing is related to care for people who have
25 disabilities and the people who give that care.

1 This has been an issue that has been out there
2 for a very, very long time.

3 The caregivers of these people who have
4 disabilities do an incredible, amazing job in
5 taking care of these individuals. The pay has
6 not been that good. We would like to see the
7 pay for these people, these direct support
8 professionals -- we want to see that their wages
9 go up. That's important to me, and I think
10 important to a lot of other people in the
11 General Assembly.

12 I mean, it's sad to think that some of
13 these direct support professionals actually have
14 to go on welfare or Medicaid to make sure that
15 they can support their families. That should
16 not happen because the work that they do is
17 incredible; it's extremely valuable. It's
18 important to the families who have people with
19 disabilities. So that is the focus and the
20 reason of our hearing today.

21 Representative Cruz, do you have any
22 comments before we get started?

23 MINORITY CHAIRMAN CRUZ: No. I'm fine,
24 Mr. Chairman.

25 MAJORITY CHAIRMAN DiGIROLAMO: Okay.

1 Seeing none, I'm going to call our first panel
2 up, Study Presentation by authors.

3 We have Nicholas Torres, who is the CEO
4 of Social Innovations Partners. If you would
5 just come right up to the desk.

6 And also, Scott Spreat, who is the
7 President of Woods Research and Evaluation
8 Institute at Woods Services, which is located
9 right next to my legislative district in
10 Bucks County.

11 Gentlemen, welcome. Just a couple of
12 ground rules. First, I know some of you are
13 still standing. There are some chairs off to
14 the side there, if you would like to grab a
15 chair, get a seat and come around the side of
16 the room.

17 Also, I remind everybody that we are
18 being filmed. I believe this is going to be on
19 PCN, maybe live, and then replayed later.

20 Just to set the ground rules, we have to
21 be done with this hearing by 11 o'clock,
22 according to our House Rules. We are in session
23 at 11 o'clock.

24 I know a lot of you have traveled a long
25 distance. So we're going to take testimony from

1 all of the people who are here to testify first.
2 I know we have a film at the end, which is very
3 important. I want to see it.

4 If there is any time at the end, I will
5 open it up for questions from the members.

6 Okay?

7 With that, gentlemen, you can begin
8 whenever you would like.

9 DR. SPREAT: Well, good morning and
10 thank you very much for allowing us to address
11 the Committee today.

12 We're here today to summarize results
13 and implications of a study that we conducted
14 regarding wages for direct support
15 professionals. These are the individuals who
16 work directly with people with intellectual
17 disabilities, providing them with care and
18 training and the basic support needed to become
19 part of the community.

20 We're going to describe current
21 conditions, and I'm going to review the impact
22 of increasing their compensation. Over the last
23 35 years, there have been a number of studies on
24 compensation for direct support professionals
25 done at different times and in different States

1 by different researchers. They came up with a
2 uniform similar answer, they're not paid all
3 that well.

4 Now, that's not too surprising. There
5 are always going to be jobs at the low end of
6 the wage spectrum. The difference that we see
7 now is coming from the subjective reports of the
8 providers who hire these individuals.

9 The providers say they can't hire enough
10 direct support professionals. They say the
11 staff turnover is too great. They say that
12 overtime is killing them. They say that many
13 new hires are not sufficiently qualified to do
14 the job.

15 These concerns characterize the staffing
16 crisis that currently besets the field of
17 intellectual disability. It's also compounded
18 by the fact that a recent study that was
19 published showed that one-third of providers in
20 Pennsylvania lose money each year.

21 Now, Nick and I are both researchers.
22 We've learned to question anecdotes and
23 subjective reports of what's going on. In fact,
24 there's an old scientific adage that says the
25 plural of anecdote is not evidence.

1 So we're interested in how we go about
2 quantifying the staffing crisis that is going on
3 in Pennsylvania now. Fortunately, a number of
4 provider associations were willing to allow us
5 to do that.

6 Through the cooperation of, initially,
7 seven provider organizations and then three
8 separate provider organizations that funded a
9 further analysis, we were able to get 121
10 provider agencies in Pennsylvania to voluntarily
11 provide us data on direct support professional
12 compensation and retention.

13 Now, while 121 is a pretty good number
14 for a study -- that's unbelievable for the
15 number -- but the bigger number and the more
16 important number is that these 121 agencies
17 employ over 34,000 direct support professionals.
18 So the numbers that I'm going to give you in a
19 minute have a pretty good basis, if we're
20 dealing across 34,000 direct support
21 professionals.

22 This study was a basic survey. It just
23 asked for a variety of information. We learned
24 the following.

25 Median salary for direct support

1 professionals in Pennsylvania is \$11.50 an hour.
2 It ranged from \$8.23 an hour, up to \$19.24 an
3 hour.

4 Now, the \$19.00 is a real outlier.
5 That's why I used median instead of mean for --
6 it's one agency. I actually went and checked to
7 see if they really were paying it, and they
8 were, but they're an outlier.

9 Ninety-six percent of the direct support
10 professionals in Pennsylvania get health care
11 through their job. It's a shared process. They
12 pay part and their provider -- their employer
13 pays part. Ninety-five percent have dental
14 care. And it's, similarly, a joint funded
15 service.

16 Paid time off averages about 20 days per
17 year. Sixteen percent had pension plans,
18 probably less now because my employer just froze
19 its pension plan. So that will take it down to
20 14 percent, probably.

21 Ninety-five percent have defined
22 contribution plans, 403(b)s, things of that
23 sort. These are almost always a joint funded
24 sort of process, where the employer puts some
25 money in and the employee does, as well.

1 Key figures: turnover, 26 percent per
2 year. That's actually lower than what had been
3 reported in the literature prior to the 2008
4 recession, still pretty high, though.

5 Vacancy rates, about 12 percent; sixteen
6 percent for part-time employees. It's really
7 hard to find part-time employees in the field.

8 Now, think about the 12 percent. On one
9 hand, that doesn't sound all that horrible.
10 It's not unusual to be asked to reduce a budget
11 by X percent, and we're able to do that.

12 But you've got to remember that in the
13 intellectual disability field, every direct
14 support professional slot has to be filled that
15 day. If somebody -- if I call out sick today or
16 tomorrow, it doesn't matter. I just have more
17 work to do when I come back the next day, but a
18 direct support professional has to be there. If
19 the person is not there, we have to find
20 somebody else to take his spot because they're
21 providing care for people.

22 So think of it this way, a 12-percent
23 vacancy rate, 8-percent of time for paid time
24 off, vacation or sick leave, 2 percent for
25 required training per regulations, maybe 3

1 percent for holidays and some unknown amount for
2 family medical leave.

3 The typical first line supervisor who's
4 trying to staff his program for a given day,
5 about one out of every four slots is a zero,
6 it's an empty. He's got to find some way to
7 fill it, whether it's overtime or whether it's
8 hiring an agency staff to come and do that.
9 It's a big challenge.

10 Picture also the consumer, the
11 individual who's receiving the services, because
12 with that, many people are being pulled to do
13 overtime, agency staff coming in -- one of our
14 agencies conducted a study last year of how many
15 people a given consumer might experience working
16 with them over the course of the year. The
17 number was over 300.

18 So Nick will probably talk a little bit
19 about program continuity, but you can see, if
20 I'm dealing with 300 people in a year --
21 admittedly, that's an extreme number -- that's
22 not program continuity.

23 Eleven dollars and fifty cents an hour,
24 roughly \$24,000 a year, isn't a living wage.
25 Even if you're living in your mother's basement,

1 it's not a living wage.

2 The MIT living wage calculator suggests
3 that a living wage for a Philadelphian with one
4 child is about \$23.00 to \$24.00 an hour. Our
5 most typical employee is a single parent that
6 fits into that category.

7 So I'm going to turn the microphone over
8 to Professor Torres, and he's going to talk
9 about social implications of low wages and the
10 likely impact of increasing DSP salaries.

11 MR. TORRES: Good morning.

12 So I think what -- in terms of a number
13 of people we're talking about, my understanding
14 is that we're talking about a half percent of
15 the population of Pennsylvania, which is -- so
16 we're talking about affecting the lives of about
17 600,000 people in terms of the quality of care.

18 We're looking at that as, if we care
19 about these most vulnerable people, we have to
20 care about the services that we provide. So
21 when you're talking about that 12 percent
22 vacancy rate and the turnover rate, we're
23 saying, when you have those rates of turnover,
24 we can't provide quality care because it affects
25 their networks, the program continuity and their

1 ability to provide those services.

2 But before we went into the financial
3 implications of it, what we realized is that we
4 needed to look at sort of who are these people
5 and how do they support their families. That
6 took us into public benefits.

7 What we realized is that there is this
8 phenomenon that's well-known as the benefits
9 cliff. So as your wages go up, your benefits
10 decrease. So when we're looking at what we're
11 paying now, which is about \$12.00 an hour, you
12 know, most of these individuals in direct
13 support services are both participating in the
14 workforce, but they are also participating in
15 public benefits. So society is paying for these
16 costs on both sides of the spectrum.

17 So it kind of led us to this idea, which
18 was a reinforcement of the Economic Policy
19 Institute, that says, you know, for every dollar
20 increased for workers earning up to \$12.16 an
21 hour, the share relying on public assistance is
22 predicted to decline. So we kind of took this
23 approach and said, you know, we either pay on
24 the front end or we pay on the back end.

25 But in the middle, we're sacrificing

1 quality of care for why we're all here today,
2 which is really looking at those services for
3 people with intellectual and developmental
4 disabilities.

5 What we also realized is that if they
6 don't participate in public benefits, that's
7 because they're working time and a half.
8 They're working overtime, which again decreases
9 quality of care because they're working too many
10 hours.

11 So the number of people we're talking
12 about -- we're talking about the 600,000 people,
13 approximately, that receive our services, but
14 then we're talking about 74,000 people who
15 provide these services. Then we looked at
16 another study that actually said, because we
17 can't provide them a quality of work -- there
18 are additional repercussions on them, which are
19 their families and their children.

20 So we also saw that children of low wage
21 parents are more likely to face educational
22 difficulties and a lot of other repercussions
23 out there that we did not calculate in the
24 study, but that are considered, so 74,000 people
25 and their families.

1 Then we took the approach and said,
2 well, ultimately, what are the implications for
3 the State of Pennsylvania and the taxpayers?

4 So we played out the scenario and said,
5 what if we increased the wages to \$15.00 an hour
6 from the average of around \$12.00 an hour?

7 That would cost an additional \$475
8 million, but we have to consider that half of
9 that would be paid by Medicaid Waiver work so
10 the actual cost for Pennsylvania would be about
11 \$237 million to increase the wages to an average
12 of \$15.00 an hour. But those costs, those
13 additional costs, are offset by savings.

14 So we looked to sort of literature and
15 said, where are the savings?

16 Well, the providers save about \$43
17 million in recruitment and training costs
18 because of that 26 percent vacancy or attrition
19 and 12 percent vacancy, there are a lot of costs
20 that are related to getting the quality of care.
21 Then we looked at, there's a large amount,
22 \$187 million, that is paid for overtime. So
23 again, we're playing with these different
24 scenarios, but that's a direct savings to the
25 provider network also.

1 But ultimately, when you take and
2 consider public benefits -- and although it's
3 not an exact science because public benefits are
4 a complicated issue, we worked with a benefits
5 data trust to actually find out what they look
6 like. And then, in this study, we gave three
7 case scenarios.

8 But we're estimating about \$260 million
9 would be saved on the public benefits side. So
10 again, that is almost equal to -- so it's almost
11 a zero-out for the State of Pennsylvania in
12 terms of how much we're paying by just raising
13 it to \$15.00 an hour.

14 So again, you know, the benefits again
15 are the taxpayer savings, as we just listed.
16 The employee pride and the ability to provide
17 quality services is important, but also to their
18 families and the people they serve, which are
19 74,000 people, plus their families. And then
20 ultimately, why we're here is to increase the
21 quality of care for the individuals we care
22 about most.

23 In conclusion, you know, we recommended
24 that we should move towards \$15.00 an hour, just
25 because it makes economic sense; it makes

1 quality of service sense; and it affects the
2 families that we serve. Nobody really loses.
3 It's a win-win situation for everybody.

4 Ultimately, we would like to see it move
5 up to \$18.00 an hour because we also noticed
6 that, you know, the State-run developmental
7 centers, that's about what they're paying and
8 they don't have, necessarily, the same attrition
9 or the same vacancy rates.

10 So again, we have a model out there that
11 actually shows that it does work, so we should
12 take the consumer -- or the direct providers
13 into that network also. Thank you very much.

14 MAJORITY CHAIRMAN DiGIROLAMO: Okay,
15 gentlemen. I appreciate your testimony.

16 If you're able, if you could stay till
17 the end in case some questions come up, we would
18 really appreciate it.

19 We have the second panel. We actually
20 have three people that are going to testify in
21 the second panel from SpArc, a service provider
22 and direct support professional. Mia McGuire,
23 who is the Director of Admissions; and Samira
24 Gray, who is a direct support professional; and
25 also, Ray Jefferson, who is a direct support

1 professional in the mental health field.

2 Is Ray here?

3 I think we're going to get started.

4 Welcome.

5 Good morning. You can begin whenever
6 you're ready.

7 MS. MCGUIRE: Thank you. Good morning.

8 Thank you for having me here today. The
9 reason I'm here is because it is of the utmost
10 importance that we fix the DSP crisis in
11 Pennsylvania. Without highly trained
12 professional staff in these crucial roles, the
13 quality of life for people with disabilities will
14 suffer.

15 My name is Mia McGuire, and I am here
16 from SpArc Services. We are a provider
17 organization that supports nearly 500 people
18 with intellectual disabilities and autism. We
19 are located in North Philadelphia and support
20 people within our own neighborhood and the
21 entire southeast region.

22 To best serve the participants in our
23 programs, SpArc Services employs 80 direct
24 support professionals. Each DSP is responsible
25 for anywhere from one to 15 people at a given

1 time and is responsible for providing support
2 services for individuals across all types of
3 programs.

4 The job of the DSP is multi-faceted.
5 Not only are DSPs responsible for providing a
6 safe environment for the people that they
7 support, but they are also charged with knowing
8 and understanding the individual's health-care
9 needs, their dietary restrictions, their
10 medication needs, the risk factors that they
11 have, personal care needs and behavioral
12 concerns and triggers of the people that they
13 support.

14 And if that isn't enough, DSPs also
15 implement the strategies that have been
16 developed to help people obtain their outcomes
17 and goals in multiple settings, and within the
18 greater community. The job of the DSP does not
19 end when the participants go home. DSPs are
20 also responsible for reporting on daily progress
21 of goals, participating in meetings for the
22 people that they support and completing the
23 multitude of training requirements to ensure
24 that people in these roles feel knowledgeable
25 and confident in their abilities.

1 As a provider who recruits and needs to
2 retain qualified staff to continue providing
3 support to the participants in our programs, the
4 challenge to maintain staff seems
5 insurmountable, primarily due to the salary,
6 which is tied to the rates set forth by the
7 State.

8 In addition, the people who live and
9 work in Philadelphia -- sorry.

10 It is these rates, based on State
11 appropriations, that pay poverty level wages in
12 our system. In addition, the people who live
13 and work in Philadelphia have an added burden,
14 due to higher cost of housing, higher cost of
15 basic necessities and an added city wage tax.

16 The job responsibilities for the DSP
17 positions are great. It is unfortunate that the
18 salary is low and inequitable to the value they
19 add to the lives of so many.

20 All of these factors contribute to the
21 high turnover rate that plagues this role and
22 the industry as a whole. We can talk about the
23 cost that it has on the organization, but the
24 highest cost is the effect that it has on the
25 people who are supported firsthand by DSPs.

1 The keystone to health and safety for
2 individuals with disabilities is consistency.
3 Consistency of staffing is of the utmost
4 importance.

5 I have seen the agony firsthand when a
6 DSP has to make the decision between staying at
7 a job they love and supporting the people they
8 care about, so that they can provide for their
9 families. The true losers of this occurrence
10 are the individuals they support.

11 It is unfortunate that it is a regular
12 occurrence and happens so often that the people
13 we support, their families and the teams of
14 support professionals have become accustomed to
15 progress and regression due to changing in
16 staffing. This shouldn't be the case.

17 I could go on about the challenges that
18 DSPs face within this field and when they leave
19 to go home, but I think it's more important that
20 you hear about it firsthand from someone who
21 lives it every day.

22 Samira Gray, who is sitting right next
23 to me, is one of the dedicated staff who works
24 at SpArc. She's here to tell her story.

25 Thank you.

1 MS. GRAY: Good morning.

2 A day in the life of a Direct Support
3 Professional has many challenges. To
4 effectively do my job, it requires patience,
5 determination and perseverance. The
6 objective is to create a therapeutic learning
7 environment and to influence the
8 participants' independence.

9 Each participant attempts to convey
10 their independence in different ways.
11 Difficulties arise when a DSP has to discover
12 what those indicators are. Direct Support
13 Professionals are not psychologists. Patience
14 is the one essential characteristic that aids
15 the DSP and the participant on a personal level.

16 I have a passion for this line of work
17 because I believe it's essential to convey to
18 the world that people with any form of
19 disability are human, too. While I'm at work, I
20 am happier than when I am at home alone.
21 Because while at work, I feel no different than
22 I do with my family and friends.

23 Working with people with disabilities
24 opens my mind to a world that most people
25 overlook because they're afraid of the unknown.

1 I do not fear the unknown. For me, knowledge is
2 power.

3 The people that I work with have vibrant
4 and witty personalities that make working with
5 them like a home away from home. Individuals
6 with disabilities are not easily accepted in the
7 community. Oftentimes, while working as a DSP,
8 I've felt alienated and prejudged.

9 People look at people with disabilities
10 and act like they're abnormal. This is very
11 upsetting and is why I chose this profession.
12 It is my role to help integrate people with
13 disabilities into the community so that all
14 people are more comfortable.

15 DSPs are the frontline people who work
16 to instill independence within participants'
17 daily lives by redirecting when things are done
18 improperly, by teaching morals and values and
19 explaining things that one does not understand.
20 With the aid of a DSP, participants become more
21 independent and we are able to accomplish goals
22 that are important to them.

23 I have a client by the name of Joe, who
24 is non-verbal and deaf, which makes it hard to
25 convey things to him. Prior to me working with

1 Joe, others had to help him transition from one
2 task to the next very often. Now, he's more
3 aware of the transitions and can do them with
4 little or no assistance. To many, that may seem
5 minute, but it's a huge step towards Joe's goal
6 and means that I am doing my job well and
7 helping him gain his independence.

8 Each DSP has a different ratio of
9 participants whom they're expected to know all
10 about. They have to know the needs and the
11 goals of each person that they serve, knowing
12 their risks, their healthy history, their health
13 needs, their behavioral health needs, how to
14 deescalate situations and what to do in the case
15 of an emergency. This is a lot of information
16 and work.

17 Also, it is required that DSPs complete
18 daily progress notes for each participant.
19 Daily notes account for their attendance, units
20 of service, and what progress they have made
21 toward their goals. Although the daily
22 struggles of a DSP are abundant, I still would
23 not choose any other profession.

24 However, when I return home, I'm faced
25 with life's most difficult challenges. I have

1 rent, utilities, cell phone bills, toiletries,
2 food and clothing expenses, all accounted for on
3 a DSP's salary. The hourly wage isn't enough
4 for me to sustain life's daily necessities. My
5 rent alone is \$650, and I haven't made that in
6 one check.

7 I'm in school furthering my education in
8 this field because of my commitment to my
9 clients. However, this is an expense, since I
10 do not have a car and I must use money on public
11 transportation to and from school.

12 On a DSP's salary, I have to sometimes
13 decide what will and what will not get paid
14 monthly. I may have to do my homework in the
15 dark one month just to be able to maintain the
16 roof over my head.

17 I am thankful for the Federal
18 Supplemental Nutrition Assistance Program
19 because I am able to receive food stamps. In
20 order to qualify for SNAP benefits, one must
21 prove that they are unable to feed themselves.
22 I have to provide proof: bills, statements,
23 lease, et cetera, things that I am unable to
24 meet, the basic needs to get through a month
25 without borderline being homeless.

1 We also pay for our own health care. If
2 we aren't healthy, who is going to take
3 care of the participants?

4 I believe in this line of work. It
5 should not be so hard to stay in a job that you
6 love, and you should not have to choose to stop
7 serving people who need you so that you can have
8 a roof over your head.

9 This struggle is not mine alone. Almost
10 every one of my coworkers is in the
11 same situation of having to decide which bill
12 gets paid and which does not. This is not a
13 good way to live, especially since you work hard
14 doing the right thing every day for people with
15 disabilities.

16 MAJORITY CHAIRMAN DiGIROLAMO: Samira,
17 that was terrific testimony.

18 Thank you.

19 MS. GRAY: Thank you.

20 MAJORITY CHAIRMAN DiGIROLAMO: Next we
21 have Ray Jefferson.

22 MR. JEFFERSON: Yes.

23 MAJORITY CHAIRMAN DiGIROLAMO: He is
24 also a direct support professional.

25 You can begin whenever you would like.

1 MR. JEFFERSON: Good morning -- good
2 afternoon, rather.

3 My name is Raymond Jefferson. I am 23
4 years old, and I live in West Philadelphia with
5 my mother. I have worked in the mental health
6 profession for about two years. I'm a mental
7 health direct support professional working and
8 assisting COMHAR Corporation in North
9 Philadelphia.

10 I work in a program that is called CRR,
11 Community Rehabilitation Residents.

12 Can you hear me now?

13 I work in a program that is called CRR,
14 Communication Rehabilitation Residents, for
15 people who live with mental health illnesses.
16 CRRs are specifically designed to assist people
17 with chronic psychiatric disabilities to live as
18 independently as possible through the training
19 and assistance and the skills of communication
20 for living and by serving as focus for
21 rehabilitation.

22 The illnesses of our consumers include:
23 psychiatric bipolar disorder, major depressions
24 and psychosis. My job duties include monitoring
25 consumers' medication. This involves making

1 sure that they are taking their medication and
2 that they are in adequate supply of their
3 medication. I complete the program medication
4 records for each client as their medication is
5 given.

6 My other duties include: crisis
7 prevention; leading our consumers in learning
8 skills, such as cooking nutritious meals; making
9 sure that their hygiene is maintained; making
10 sure that their rooms and everything else is
11 clean and safe.

12 I complete daily documentation, in which
13 I record behavior of our consumers and
14 assignments of their status. I have to make
15 sure that their medication needs are addressed
16 as they arise. I drive our consumers in our
17 15-passenger van to community outings and
18 medical appointments.

19 I run AA meetings with our clients, as
20 well as community meetings. I provide our
21 consumers with counseling when they are in need,
22 and emotional support.

23 The requirements for this job include a
24 tremendous amount of training, including
25 training in CPR and first aid, crisis control,

1 confidential control, management, deescalation
2 and many more. I also have training in the
3 medical terminology field.

4 In addition to these trainings, to do
5 the work that I have just described for you, it
6 also requires: patience, stability,
7 dependability, good judgment and willingness to
8 work very hard. Although I have tremendous
9 respect for our consumers because of their
10 ability to maintain a positive outlook despite
11 all of the problems that they may face, this
12 work can also be very challenging due to their
13 symptoms.

14 Our clients can become agitated,
15 suicidal, dangerous to others or can present as
16 intoxicated. This requires a great deal of
17 knowledge, cool-headedness and skills to manage.

18 As I previously stated, I perform this
19 challenging work in Philadelphia, where the
20 average salary for a direct service provider,
21 DSP, is often between \$12.00 to \$14.00 per hour.
22 My hopes for myself are like those of any other
23 American. I would like to have, at some point
24 in my life, a nice house, a wife and kids, a
25 nice car and to take care of my responsibilities

1 to a family and my community. I would also like
2 to have an opportunity to help those who are
3 less advantaged than me.

4 I am now working to achieve these goals
5 by taking college courses within criminal
6 justice. The cost of my education, along with
7 everyday costs, such as gas, phone, utilities,
8 food -- excuse me -- medical expenses and
9 helping my family's expenses, can be difficult
10 to cover.

11 My salary now is just enough to make
12 ends meet. My wage would not provide me with
13 the resources to meet the unexpected expenses or
14 to afford anything beyond.

15 I have a certain consumer who I work
16 with that I would like to tell you about. I
17 call him Red. Red, no matter what his condition
18 is, no matter what he has been through, he
19 always finds the ability to just smile, glow and
20 make a joke.

21 I taught Red how to cook as well as
22 dealing with his other people skills. It is
23 great to see how much he interacts with other
24 people and how much he has grown.

25 In order to help other people like Red,

1 it is important that DSPs are available to meet
2 their needs. In order to ensure the abilities
3 of a DSP, it is necessary to pay a salary that
4 attracts the best people in this field. It
5 would make me very sad to think of one of the
6 others like Red to not have the help that he
7 needs.

8 I, therefore, respectfully request that
9 you offer more for the people in this field.

10 Thank you.

11 MAJORITY CHAIRMAN DiGIROLAMO: Okay,
12 Ray. Good job.

13 To the three of you, really good job.

14 If I could ask you just to stick around
15 at the end in case there are some questions that
16 come up, we would appreciate it.

17 With that, I'm going to bring up the
18 next panel, the third panel, family members.

19 First, Cheryl Dougan, who is a parent;
20 M.J. Bartelmay, Jr., who is a parent and the
21 past president of The Arc of PA.

22 To the both of you, welcome. Please,
23 you can start whenever you would like.

24 MS. DOUGAN: Thank you,
25 Chairman DiGirolamo, Minority Chairman Cruz and

1 Committee members for your time today -- we
2 really appreciate it -- on this issue.

3 My name is Cheryl Dougan. I am a
4 resident of Bethlehem, Northampton County. I'm
5 honored to speak with you today about
6 Pennsylvania's direct support professional
7 workforce crisis. It is affecting our
8 Commonwealth's most vulnerable citizens,
9 including our son, Renzo.

10 There was a really blissful time of life
11 when I was oblivious to this critical and often
12 invisible workforce; no more. My son's life
13 depends upon direct support professionals, DSPs,
14 every hour of every day.

15 Our story begins on May 21st, 1998. It
16 was the first really beautiful spring day. I
17 mean, the skies were pure blue and everything in
18 life just seemed to be going our way. We were
19 just beginning to feel secure about our future.
20 My husband, Tony, had received tenure the month
21 before at Lehigh University, and I had begun
22 work on my Master's degree.

23 Our only child, Renzo, was fourteen and
24 already taller than both of us. He relished in
25 that achievement. We, on the other hand, were

1 proud of his more hard-won accomplishments.

2 He was about to graduate tenth in his
3 eighth grade class. He loved playing jazz on
4 his saxophone, but was quickly becoming enamored
5 with the guitar, so he could set his poetry to
6 music, like his idol, Bob Dylan. He loved
7 playing soccer and lacrosse. He just loved
8 life. He was an amazing, amazing son.

9 I received a phone call from Renzo's
10 school around 2:30 that afternoon, telling me
11 that he had been rushed to the emergency room.
12 I was there within minutes. Renzo was
13 unconscious, his body writhing in seizures.

14 Medical personnel surrounded him, one
15 rhythmically pumping air into his lungs through
16 a ventilation mask. His clothes were cut away,
17 right through his leather belt. His chest was
18 wired with electrodes.

19 I clutched at his bare feet, the only
20 space left unattended, and really struggled to
21 remain calm so they wouldn't throw me out.

22 I learned that Renzo had suffered a cardiac
23 arrest while undergoing presidential fitness
24 testing in gym class.

25 His coach and a police officer had

1 attempted CPR, but not until the EMTs arrived to
2 use an electronic defibrillator did his heart
3 regain its beat. It was too late to prevent a
4 severe anoxic brain injury.

5 Renzo was medevaced to a Philadelphia
6 hospital, where he remained in a coma for nearly
7 one month. His prognosis, likely to remain in a
8 persistent vegetative state.

9 After nearly three months of
10 hospitalization, we brought Renzo home. Our
11 dining room was transformed with a hospital bed
12 and an array of medical equipment. Our son
13 could no longer walk, talk, eat or control any
14 of his bodily functions. He couldn't even
15 smile. He didn't have the muscle tone, the
16 control; neither could we.

17 Friends and community rallied to see to
18 our every need. They not only raised enough
19 money to build an accessible addition and to buy
20 a van, but they even delivered meals for
21 the next year, allowing us time to construct
22 Renzo's room and adjust to circumstances.

23 Weighed down by immeasurable sorrow, we
24 turned to face the future. Renzo's care became
25 my full-time job. I sought out and secured the

1 right medical specialists to support Renzo's
2 long-term needs and accompanied him to all of
3 his appointments.

4 I struggled to make sense of the
5 fragmented service system upon which our son's
6 future would now depend. I felt compelled to
7 learn everything that I could about special
8 education, health and social services, legal and
9 financial implications and resources,
10 employer-based and Medicaid-based health
11 insurances and so on.

12 It was years before I realized that I
13 had taken on the impossible challenge.
14 Government systems are inherently subject to
15 radical change as political administrations
16 shift. They will never be stabilized or
17 understood.

18 I know now that Renzo's well-being does
19 not rest in the fluctuating budgets,
20 regulations, program silos with their separate
21 requirements or a plethora of services
22 requiring endless and often redundant paperwork;
23 rather, Renzo's life depends upon a competent,
24 ethical and compassionate direct support
25 professional workforce. They have made all the

1 difference.

2 Eventually, Renzo regained his smile.

3 It speaks volumes, while his speech remains
4 still difficult to understand. His smile does
5 not always tell the truth. In fact, his
6 perpetual smile is part of his brain injury. He
7 can no longer cry.

8 As Renzo continued to heal, he felt the
9 loss of all that he had been. Through that
10 really beautiful smile, he begged for nearly two
11 years, kill me, kill me, I can't
12 think. Renzo has survived those years of
13 depression, as have we, largely because of some
14 remarkable DSPs who gave him reason to live.

15 Renzo's dearest DSP, Jenn O'Brien, has
16 remained committed to him for seventeen years.
17 Jenn began supporting Renzo when her own two
18 children were two and four years old. Her
19 youngest, Keegan, just graduated from high
20 school. Already, he has a part-time job earning
21 more per hour than his mother, whose salary has
22 remained relatively stagnant.

23 There has been no increase in pay to
24 reward Jenn for her long tenure, no merit pay
25 for the invaluable work she does or even a

1 cost-of-living raise. It's wrong.

2 Jenn is a skilled worker, credentialed
3 in medication management, CPR with AED. To
4 maintain employment, she completes a number of
5 annually required training courses. Jenn
6 competently assists Renzo at medical, dental and
7 therapy appointments, monitors his health and
8 cares for him when he is sick.

9 In warm weather months, she assists him
10 at equine therapy. He regained his balance with
11 horseback riding in three weeks' time. It's an
12 amazing therapy. In the winter, she helps him
13 to exercise in a warm water therapy pool.

14 Jenn tends to all of Renzo's personal
15 needs, including showering and toileting,
16 trimming his beard, cutting his nails, arranging
17 hair cuts, maintaining his dental hygiene. Jenn
18 even helps Renzo shop for his clothes on sale or
19 secures barely worn hand-me-downs.

20 After my husband's unexpected open heart
21 surgery in 2005, it seemed more urgent that we
22 secure Renzo's living situation for the long
23 term. We decided to withdraw the equity from
24 our home in order to purchase a little house for
25 our son around the corner.

1 At age 34, he relishes his sense of
2 independence. Renzo returns to our house every
3 Sunday evening. He's sweet, and he loves my
4 cooking, but he's always happy to get back to
5 his house and to his cherished DSPs.

6 Renzo's DSPs make it possible for him to
7 live on his own. They take him grocery
8 shopping, cook his meals, do his laundry, keep
9 his house clean. When needed, they even shovel
10 snow in the winter, so they can get him into his
11 wheelchair-accessible van and to work or other
12 appointments on time.

13 Renzo has become a valued and
14 contributing citizen of our community, only
15 because of innovative DSPs who have supported
16 him to seek his potential. Renzo -- and this is
17 a kid with the prognosis likely to remain
18 persistently vegetative; I just want you to
19 reflect on that -- he has received awards for
20 his volunteer work with children at Easter Seals
21 Preschool Program and for vocational achievement
22 as a dedicated employee of Martin Guitar & Co.
23 -- remember that guitar he loved -- where he has
24 worked for over 15 years.

25 Renzo also shows up to vote in most

1 elections. The poll workers know him by name.
2 His vote canceled mine out in a recent
3 election. Somehow, amid the DSPs' busy and
4 physically demanding day supporting Renzo's
5 every need, they now must carve out time to
6 complete an absurd amount of documentation that
7 is required by the system.

8 As recordkeeping moves to electronic
9 verification, this profession is growing even
10 more complex. This work has become far more
11 demanding, while wages have not only stagnated,
12 but have actually decreased, when calculated
13 with the cost of living.

14 Renzo lost several good DSPs this past
15 year due to crisis, burnout or the need to make
16 a living wage. Since fewer quality people are
17 applying to do this demanding work without
18 commensurate pay, there are a lot more open
19 shifts at Renzo's.

20 Jenn is doing her best to maintain a lot
21 of overtime. Several weeks lately, she has done
22 more than 80 hours a week. Too often, Tony or I
23 are called to cover open shifts. Honestly, as
24 we near age seventy, it's becoming difficult for
25 us to give our son the level of physical support

1 that he needs. We collapse in exhaustion and
2 unbearable sadness after spending an eight-hour
3 shift with him.

4 Not all that long ago, Renzo had a
5 dynamic team of DSPs who cared not only about
6 Renzo, but also each other. Joe was a member of
7 that team for seven years. He shares his story
8 in a video that you will see shortly.

9 Jenn is the only remaining member of
10 that team. She is able to continue this job
11 that she loves -- that pays too little -- only
12 because her husband is able to help support
13 their family needs and to provide health
14 insurance.

15 Sadly, Renzo is experiencing more bouts
16 of depression. It seems he is having trouble
17 adjusting to so many new people as they orient
18 to doing his most intimate care. Imagine the
19 number of people in his life who have seen him
20 naked and in the shower and helped with -- I
21 mean, it's heartbreaking.

22 They don't yet know how to assist him at
23 medical visits, support him to do volunteer
24 work, to meet up with friends in the community,
25 to work out in the pool, to help him work on

1 walking, talking or feeding himself. They can't
2 understand his speech patterns, his non-verbal
3 communication.

4 Renzo's life is falling apart at the
5 seams, and I feel really powerless to help. I
6 am so tired. It will be 20 years May 21st,
7 2018. This isn't the life that we dreamed for
8 our son.

9 Simply put, people with disabilities
10 need a stable and secure direct support
11 professional workforce in order to survive and
12 to take their rightful place as contributing
13 members of our communities. The best way to
14 establish system-wide security for lifetimes --
15 my concern, as all parents of children with
16 disabilities -- is what happens to our son when
17 we die?

18 My son's life is dependent upon his
19 DSPs. It is not dependent upon the government
20 as it shifts and changes and goes through,
21 always, the unexpected.

22 The people who are there on the
23 frontline every day, those are the people that I
24 trust and believe in, that they will nurture and
25 support my son for the long term. They need to

1 be provided a living wage. I need them to be
2 there for years to come.

3 As a mother, I sincerely thank you for
4 your time and consideration of this issue that
5 is so dear to my heart and so critical to my
6 son.

7 Thank you. Thank you. Thank you.

8 MAJORITY CHAIRMAN DiGIROLAMO: Cheryl,
9 thank you for that very, very powerful
10 testimony.

11 MR. BARTELMAY, JR.: Good morning,
12 Chairman DiGirolamo, Chairman Cruz, Committee
13 members and guests.

14 I'm also here to share how direct
15 support professionals have had an impact on my
16 family, and in particular, my son.

17 I'm a single father of two children,
18 ages 23 and 25. Our oldest child, MJ, III -- I
19 call him M or M-er -- has the
20 diagnosis of down syndrome and is on the autism
21 spectrum.

22 My ex-wife, Theresa, and I share joint
23 guardianship and co-parent M. His disability
24 creates significant challenges and barriers to
25 living the normal independent life of a

1 25-year-old man.

2 He is non-verbal, has virtually no
3 self-help skills and no self-preservation or
4 safety skills. He requires 24/7 care and
5 support.

6 Standardized testing categorizes him as
7 having no measurable IQ. In reality, he is a
8 bright, engaging young man that requires
9 specific and different interactions to develop a
10 relationship. That said, he's a healthy, happy
11 member of our society and is active in his
12 community.

13 He attends church with his family, shops
14 for groceries and household items, practices
15 pre-vocational skills and continues to
16 develop the life skills that will allow him to
17 be as independent as possible.

18 He has friends and enjoys bowling and
19 swimming with them. None of this would be
20 possible without the support of his family and
21 DSPs.

22 We have been beneficiaries of various
23 DSP services throughout his life. It began with
24 early intervention as an infant and continues
25 today with habilitation aide and companion

1 services through a local provider of Medicaid
2 Waiver services in Mercer County.

3 Unquestionably, he would not be where he
4 is today without the involvement of these
5 professionals in his life. Over the course of
6 the past 25 years, he has had in excess of 20
7 different DSPs working with him. This doesn't
8 include school personnel, such as teachers and
9 aides. Much of the reason for the large number
10 of staff has been related to the high turnover
11 rate.

12 By far, the vast majority of these folks
13 have been outstanding in their ability to work
14 with M. They have all been minimum wage or
15 slightly above minimum wage employees.

16 Fortunately, we have been able to find
17 great people to work at this wage.
18 Unfortunately, we have been unable to keep these
19 folks on board for any length of time.

20 The impact of staff turnover cannot be
21 overstated. Because of my son's lack of
22 communication skills, a great deal of time is
23 required to build a relationship and establish
24 the trust that allows progress to occur. High
25 turnover is the enemy of this process.

1 Each time that a new person begins a
2 relationship with my son, the long process of
3 developing trust starts over. Initially, he
4 will resist being left in a one-on-one situation
5 with new staff. Like many individuals with
6 autism, trust is something that comes with great
7 difficulty. We're currently experiencing this
8 struggle.

9 Over the course of a couple years, M had
10 developed a great relationship with a young
11 woman named Heather at Professional Habilitation
12 Services, a local provider agency. We watched
13 our son grow and thrive in this relationship.
14 We saw it reflected in his behavior at home and
15 in community situations. He was as happy as we
16 had seen him since he left the Hickory High
17 School system four years ago -- the Hickory
18 School System.

19 This was also the longest continual
20 relationship with a staff person that he had
21 enjoyed. Unfortunately, she felt it necessary
22 to find other employment to allow her to provide
23 for her family.

24 While employed at PHS, Heather was paid
25 slightly more than minimum wage. PHS is an

1 outstanding organization that we could not speak
2 more highly of. We understand that the salary
3 rates are constrained by the rate a provider can
4 bill for Medicaid Waiver services.

5 Our son's normal week consists of
6 approximately seven hours a day of pre-voc.
7 training with his hab. aide. These activities
8 occur Monday through Friday.

9 Additionally, he works on life skills,
10 such as shopping, toileting, laundry and other
11 personal care skills. All of these are done in
12 conjunction with my ex-wife and myself. It is
13 critical that we are consistent in the care and
14 training that our son receives.

15 We have worked closely over the years in
16 developing his individualized service plan to
17 ensure that all parties involved in his life are
18 on the same page. Again, for the most part,
19 this has been very successful, but problems
20 occur with staff turnover when we have to begin
21 anew each time new staff comes on board.

22 It is very difficult, if not impossible,
23 for M.J. to understand why turnover occurs. He
24 doesn't just experience a new staff member; he
25 experiences the breaking of a bond of trust that

1 has taken time to develop. The impact that this
2 has on his development has been enormous. It is
3 not unusual for us to see him regress in some of
4 his skill development.

5 Additionally, we can see changes in
6 behavior. He will not leave home or work with
7 new staff until the relationship is developed.
8 This is a time-consuming process for him, as it
9 is for all of us. Trust does not come
10 overnight.

11 On a more positive note, relationships,
12 such as the one he has had with Heather, have
13 been a blessing to my family in more ways than I
14 can share in our limited time. He has had the
15 opportunity to experience life in the community
16 to the fullest possible extent because of these
17 relationships.

18 He has had the opportunity to develop
19 friendships, not only with peers from the
20 agency, but with community members at large.
21 The impact on him directly, and my family
22 indirectly, cannot be adequately conveyed. Had
23 we not had quality staff to work with our son,
24 we would not even have been able to experience
25 everyday activities as a family.

1 I wanted to share a couple more positive
2 aspects. As I mentioned, Theresa and I are
3 divorced. We would both not be able to work or
4 manage our homes, if not for direct care
5 support. It is during the hours that support is
6 provided that we are able to work, see
7 health-care providers and take care of other
8 necessities of life.

9 Furthermore, we would have missed out on
10 activities involving our son, Charley. That
11 support and care has allowed us to attend events
12 and activities that would have been virtually
13 impossible with our other son's limited mobility
14 and self-help skills.

15 Additionally, they've been invaluable in
16 helping us to create the skills necessary for
17 our son to thrive in the community. Social
18 skills and appropriate behavior are just one of
19 the many benefits we've received.

20 I want to close with the statements from
21 the Office of Developmental Programs document
22 entitled Everyday Lives: Values In Action.

23 1. We value what is important to people
24 with disabilities and their families who are
25 striving for an everyday life. An everyday life

1 is about opportunities, relationships, rights
2 and responsibilities. It is about being a
3 member of the community, having a valued role,
4 making a contribution to society and having
5 one's rights as a citizen fully respected. It
6 is a vision that we should all be working toward
7 together.

8 2. People with disabilities have a right
9 to an everyday life, a life that is no different
10 than that of all other citizens. This continues
11 to be the truest statement on which we can
12 build our work.

13 These statements are the embodiments of
14 everything we hope for and desire for our son.
15 Quality direct service professionals have
16 allowed us to work towards an everyday life
17 for M.

18 Thank you for your time and
19 consideration as you weigh the impact of the
20 salary of direct support professionals, and more
21 importantly, the people that are served, like my
22 son.

23 MAJORITY CHAIRMAN DiGIROLAMO: Thank you
24 both.

25 M.J., did I hear -- where's home at,

1 Mercer County?

2 Is that where you live?

3 MR. BARTELMAY, JR.: Pardon me?

4 MAJORITY CHAIRMAN DiGIROLAMO: Where's
5 your home at, in Mercer?

6 MR. BARTELMAY, JR.: Mercer County,
7 Hermitage.

8 MAJORITY CHAIRMAN DiGIROLAMO: Cheryl,
9 Bethlehem, is that where you're from?

10 MS. DOUGAN: Yes.

11 MAJORITY CHAIRMAN DiGIROLAMO: Okay.
12 Welcome.

13 Maybe I could ask -- we're going to go
14 to the video now. Maybe the both of you could
15 just stay right there.

16 MR. BARTELMAY, JR.: Certainly.

17 MS. DOUGAN: Yes.

18 MAJORITY CHAIRMAN DiGIROLAMO: After the
19 video, we are going to open it up for questions
20 and answers from members of the Committee.

21 So with that, Judy, I think you're ready
22 to start the video.

23 (Video was played.)

24 REPRESENTATIVE MURT: Good morning,
25 everyone.

1 Chairman DiGirolamo had to leave and --
2 he might be back -- he has asked me to run the
3 meeting in his absence.

4 If you're a direct support professional,
5 could you raise your hand, please?

6 Could we give these people a round of
7 applause?

8 (Applause.)

9 I just want you to know that both myself
10 and my colleagues that are here, we are very,
11 very grateful for your devotion and your
12 dedication to your mission and to the clients
13 whom you serve.

14 Yesterday there was a direct support
15 professional here at the Capitol. She was
16 responsible for two middle-aged men. The two
17 men were in the restroom right down the hall.

18 She was a female. Her clients were
19 males, and they were using the lavatory. They
20 were struggling, and she could not go in to
21 assist them. She asked me to go in, just to see
22 if they were okay.

23 We had to close the restroom so she
24 could go in and assist them. I know this is not
25 an unusual event if you're a direct support

1 professional; this is a struggle that you face
2 every day. I just want you to know how grateful
3 we are for the great work that you do.

4 This is a crisis. This is a tragedy
5 that we are paying these professionals a salary,
6 a wage, that's not a whole lot higher than what
7 they might get at Burger King or McDonald's.
8 That is -- that is just shameful.

9 We are going to commence with some
10 questions. So to the panel members that have
11 spoken thus far, if you don't mind coming
12 forward and maybe sitting at the end of the
13 table there, so you're close to a microphone in
14 case there is a question for you.

15 I just have a couple of questions. I'm
16 going to ask Representative Kinsey to ask a few,
17 if he doesn't mind.

18 I think I know the answer here, but for
19 the direct support professionals that work for
20 the various agencies, this position does require
21 comprehensive background checks; is that
22 correct?

23 UNIDENTIFIED SPEAKER: Yes.

24 REPRESENTATIVE MURT: In addition to
25 that, we heard about a great deal of training

1 that is required for this position, very, very
2 comprehensive training. I do have a question
3 about the various agencies.

4 For a direct support professional who
5 wants to go to college or get a graduate degree,
6 is there any kind of tuition remission or
7 tuition payment that is afforded to the direct
8 support professionals?

9 DR. SPREAT: Tom, it depends on the
10 provider agencies. Some providers do provide
11 tuition remission. Some have instituted
12 unanimous collaboration with universities,
13 specifically to provide additional training, but
14 it is not a uniform situation at all.

15 REPRESENTATIVE MURT: Doctor, would you
16 say it's half of the agencies?

17 DR. SPREAT: I would probably say it's
18 less than half. Yeah.

19 REPRESENTATIVE MURT: Okay. I'm going
20 to recognize Representative Kinsey for some
21 questions.

22 REPRESENTATIVE KINSEY: Thank you,
23 Mr. Chairman.

24 I want to first thank each and every one
25 of you for coming up and sharing what you shared

1 this morning. It's very touching to hear some
2 of these stories.

3 Mr. Torres, I wanted to start with you.

4 When you talked about increasing the
5 minimum wage, I think in your testimony, you
6 mentioned going to \$15.00 per hour and then
7 increasing it up to \$18.00 per hour.

8 This particular legislature has had some
9 problems with even discussing an increase of
10 minimum wage, raising the minimum wage. We're
11 going to continue to work on that, but you know,
12 we recognize that there are some problems in
13 trying to get folks to understand the purpose of
14 it.

15 So in your testimony, I took it that you
16 were talking about raising the pay wage to
17 \$15.00 immediately, but even when you talked
18 about the \$18.00, how did you -- like, in your
19 mind, when did you foresee that coming on board,
20 the increase from \$15.00 to \$18.00?

21 MR. TORRES: I mean, we looked at the
22 situation and we just wanted to provide two
23 different scenarios. So we did provide a \$15.00
24 scenario and an \$18.00 scenario.

25 Again, the logic kind of goes into this

1 that the public either pays at the front end or
2 they pay at the back end through public
3 subsidies. I know there are different pots of
4 money of how this is; it's not an exact
5 correlation in terms of that, but either way,
6 it's public tax dollars.

7 We originally thought that \$18.00 an
8 hour would be the ideal situation. We actually
9 compared it to the State-run agencies, which
10 don't have as high of an attrition and turnover
11 rate or vacancy rate.

12 So I mean, ideally, we said \$18.00 an
13 hour would be great, but you know, we also
14 looked at things incrementally and said, okay,
15 maybe we start with \$15.00 an hour. We landed
16 at \$15.00 an hour because of the similar
17 legislation that we're looking at for nursing
18 assistants, and they were recommending the
19 \$15.00 an hour.

20 So we kind of went along with that,
21 saying that, you know, they're also in the same
22 situation. So that was sort of our logic for
23 that.

24 REPRESENTATIVE KINSEY: Great. Thank
25 you.

1 Mia, in your testimony, you talked about
2 the need to retain and recruit qualified staff.
3 I think I knew some of this, you know, back in
4 my previous life, but I know that things have
5 changed over the course of time.

6 What are the basic qualifications when
7 you interview somebody, a prospective individual
8 who wants to be employed?

9 What are the basic qualifications that
10 the individual has to have, you know, when they
11 come to you looking for employment?

12 MS. MCGUIRE: So to be a DSP, I mean,
13 there are some qualifications that are regulated
14 by --

15 REPRESENTATIVE KINSEY: Is that on?
16 Push the button.

17 MS. MCGUIRE: Hi. Sorry.

18 REPRESENTATIVE KINSEY: That's okay.

19 MS. MCGUIRE: There are some
20 requirements for that position, the DSP
21 position, that are required. So like through
22 the State, you need to have a high school
23 diploma. Then there are some other
24 qualifications.

25 When we hire, we look for people who

1 are, you know, who can do the job. So there are
2 some physical things you would have to be able
3 to do to get that job.

4 You also need to be able to complete
5 some training requirements, as well. You have
6 to be kind and open-minded. And really, we look
7 for people who are dedicated.

8 It's not an easy job. Being a DSP is a
9 really difficult job. It requires a lot. So I
10 don't know if there are -- if there is any set
11 of requirements that we're always looking for.
12 I mean, there are some basic ones that people
13 have to fulfill.

14 The biggest thing is we need people who
15 are really willing to do the job, who are
16 willing to do it well because they're taking --
17 DSPs take care of people with disabilities.
18 They are supporting them. They have to help
19 them with their goals.

20 REPRESENTATIVE KINSEY: Right.

21 MS. MCGUIRE: You have to be able to do
22 that.

23 REPRESENTATIVE KINSEY: So the
24 individuals, at the very minimum, must have at
25 least a high school diploma?

1 MS. MCGUIRE: They must have at least a
2 high school diploma, yes.

3 REPRESENTATIVE KINSEY: All right.

4 Also, the next part of my question is,
5 the hours of required training -- I think I used
6 to know that it used to be 24 hours.

7 Has that changed, or is it still 24
8 hours?

9 MS. MCGUIRE: It is still 24 hours.

10 REPRESENTATIVE KINSEY: Annually?

11 MS. MCGUIRE: Annually.

12 REPRESENTATIVE KINSEY: And in most
13 cases, the agencies pay for that out of their
14 budget or do you outsource for training, as
15 well?

16 MS. MCGUIRE: We -- I don't know what
17 other organizations do. My assumption would be
18 that organizations pay for the training. We, at
19 SpArc, pay for the training for the people who
20 are -- for the 24 hours of training.

21 Some of the training we provide
22 in-house, other training opportunities we might
23 send someone for. And there are 24 hours of
24 training.

25 REPRESENTATIVE KINSEY: Samira -- just

1 my last question, Mr. Chairman.

2 Samira, when you testified -- again, I
3 appreciate all that you shared in regards to
4 your commitment and dedication.

5 How long have you worked in this
6 particular arena?

7 MS. GRAY: For the past two and a half,
8 almost three years.

9 REPRESENTATIVE KINSEY: About three
10 years?

11 MS. GRAY: Yes, about three years.

12 REPRESENTATIVE KINSEY: Have all of your
13 years been with SpArc or have you gone and --

14 MS. GRAY: No, I used to work for a
15 company called Devereux.

16 REPRESENTATIVE KINSEY: Yes.

17 MS. GRAY: Yeah, I used to work for
18 Devereux.

19 REPRESENTATIVE KINSEY: In your case --
20 and maybe when you talk among your peers -- are
21 folks leaving one company to go to another
22 company because one company pays higher?

23 I mean, there might be other factors,
24 such as location and so forth, but --

25 MS. GRAY: Well, in my case, leaving

1 Devereux, I took a pay cut.

2 REPRESENTATIVE KINSEY: Took a pay cut?

3 MS. GRAY: I took a pay cut.

4 REPRESENTATIVE KINSEY: Okay.

5 MS. GRAY: However, I left Devereux
6 because I was in school and the commute was too
7 costly for me.

8 REPRESENTATIVE KINSEY: All right.

9 MS. GRAY: However, transitioning from
10 Devereux to SpArc, I chose to take a different
11 pathway coming to SpArc because of me having to
12 leave my client at Devereux. It was kind of
13 like heartbreaking for me.

14 REPRESENTATIVE KINSEY: Okay.

15 MS. GRAY: So I chose to do it with a
16 community of people at their workforce, rather
17 than on a personal level at home. Because in
18 the event that I have to leave SpArc, God
19 forbid, for whatever reason, I would rather it
20 be from a colleague standpoint versus like a
21 personal, brother, sister, daughter, son view.

22 REPRESENTATIVE KINSEY: Thanks.

23 I know I said last one, but, Ray, I want
24 to just congratulate you also.

25 You're 23 years old. You live in West

1 Philly, but you travel to North Philly?

2 MR. JEFFERSON: Yeah.

3 REPRESENTATIVE KINSEY: I'm from
4 Germantown, so I'm familiar with the city of
5 Philadelphia.

6 I think you said you've worked in this
7 field for how long?

8 MR. JEFFERSON: Two years, but I was
9 trained in this field for the past three years
10 in high school prior.

11 REPRESENTATIVE KINSEY: What high school
12 did you go to?

13 MR. JEFFERSON: Paul Robeson High School
14 for Human Services.

15 REPRESENTATIVE KINSEY: Great. And you
16 worked in there for how long?

17 MR. JEFFERSON: Two years.

18 REPRESENTATIVE KINSEY: But you started
19 in, you said, criminal justice?

20 MR. JEFFERSON: Previously -- yeah, I'm
21 in school for criminal justice.

22 REPRESENTATIVE KINSEY: All right.

23 MR. JEFFERSON: But I previously was
24 trained in this field three years prior, before
25 I started working here.

1 REPRESENTATIVE KINSEY: Right.

2 So let me just ask you this question.

3 And this is, you know, coming from Philadelphia,
4 you know, just asking this question. So you're
5 studying criminal justice.

6 Do you plan to continue to work in this
7 field, I mean, or are you going to get involved
8 in --

9 MR. JEFFERSON: Yeah, it was like a
10 juggle. I went from -- I originally wanted to
11 go to school for criminal justice, but then I
12 went to high school and developed in the program
13 for human resources, which taught me everything
14 in this field.

15 Then going towards college, my college
16 that I got chosen to play football at, they
17 didn't have human resources, so I took criminal
18 justice.

19 REPRESENTATIVE KINSEY: What school are
20 you at?

21 MR. JEFFERSON: I went to Cheyney.

22 REPRESENTATIVE KINSEY: I went to
23 West Chester.

24 MR. JEFFERSON: For real?

25 REPRESENTATIVE KINSEY: I just want to

1 let you know that, okay.

2 All right. But listen, I want to thank
3 you all for being up here this morning.

4 Thank you, Mr. Chairman.

5 REPRESENTATIVE MURT: Before we
6 recognize Representative Rozzi, I just wanted to
7 remind the members that Kathy Brown McHale,
8 President and CEO of SPIN, Special People in the
9 Northeast, has submitted written testimony,
10 which is very powerful. So if you get an
11 opportunity, read it.

12 Representative Rozzi.

13 REPRESENTATIVE ROZZI: Thank you,
14 Representative Murt.

15 I just want to thank all of the DSPs
16 here for coming here today and supporting your
17 speakers and hearing these powerful stories.

18 Cheryl, that was amazing, bringing tears
19 to my eyes.

20 I guess I have a question that's going
21 to go back off of Kinsey's \$15.00-\$18.00 an hour
22 question, but before I start that, I just want
23 to say that, you know, I come from the business
24 sector. You know, my father started his own
25 business in 1969.

1 One of the things that -- and he was
2 very fiscally conservative, very fiscally
3 conservative. In fact, he said when I went to
4 college that I came back a bleeding heart
5 liberal. I'm proud of that, and I know he's
6 proud of that.

7 Even though he was fiscally
8 conservative, he was very smart and realized
9 that if he would spend the money up front, that
10 you're not going to spend that money on the back
11 end to constantly keep training employees over
12 and over and over. Your business just does not
13 function properly if you're constantly bringing
14 in new people.

15 We talked about the \$15.00 an hour. And
16 you gave amounts of what that would cost. But
17 to be honest with you, \$15.00 an hour is still a
18 disrespect for the people in this room and the
19 work that they are doing.

20 Eighteen dollars an hour, what is the
21 cost?

22 Did you work up those numbers at all,
23 what the cost would be?

24 MR. TORRES: Yeah. So the \$18.00 an
25 hour, we have basically said, it's the same

1 amount -- so you're paying the \$18.00 an hour --
2 so \$467 million in taxpayer cost versus the
3 \$237 million. The savings remains the same
4 because we assumed \$43 million in recruiting and
5 training.

6 We assumed that was about a 60-percent
7 decrease, that attrition. There's -- so \$187
8 million dollars in overtime savings.

9 REPRESENTATIVE ROZZI: Right. That's
10 because of the crisis, right?

11 MR. TORRES: Right. That crisis, it's
12 interesting to note, you know, why does a DSP,
13 you know -- why do we pay so much in overtime
14 costs?

15 Well, one is, they don't have enough
16 people, so they have to, you know, put that
17 opportunity out. But on the other side, why do
18 DSPs take advantage of that overtime costs?

19 Because they have to pay their bills.
20 So it's this catch-22 situation.

21 REPRESENTATIVE ROZZI: So the numbers
22 you did give were for the \$18.00 an hour earlier
23 in your presentation?

24 MR. TORRES: Right.

25 REPRESENTATIVE ROZZI: I just thought

1 they were for the \$15.00.

2 MR. TORRES: Well, the ultimate -- so at
3 the end of the day -- and then it's in the
4 report that there's \$109 million for the
5 \$15.00-an-hour savings to the taxpayers. And
6 then, ultimately, there's a \$31 million cost
7 to the taxpayers if you went to the \$18.00 an
8 hour.

9 REPRESENTATIVE ROZZI: You know, to me,
10 this is just sad for Pennsylvania. It seems
11 like, I mean, I go from hearing to hearing and I
12 just sat through the State-Of-The-Job report for
13 Pennsylvania, where it's the exact same thing.

14 You know, the people who are taking care
15 of our most vulnerable, we are paying nothing,
16 you know. And up here, us legislators up here,
17 we're making \$86,000 a year. To me, that is
18 sick that the people that are doing this kind of
19 work, that are putting, you know, their life on
20 the line, going into situations that are
21 dangerous, you know, putting their life and love
22 into their job, and the amount of money they're
23 making is so disrespectful, you know.

24 I just want you guys to know that I know
25 this Committee will work hard to make sure that

1 we do the right thing here for you guys.

2 Thank you, Mr. Chairman.

3 REPRESENTATIVE MURT: Thank you,
4 Representative Rozzi.

5 Representative Kaufer.

6 REPRESENTATIVE KAUFER: Thank you,
7 acting-Chairman Murt.

8 Let me just say, credit to the
9 Committee, because for once -- this is the only
10 time I ever think a committee schedule actually
11 ran ahead of time. Congrats to
12 Chairman DiGirolamo who got this moving.

13 But let me just say thank you to all of
14 the DSPs that are here.

15 I did want to ask a couple of questions
16 in regards to the study, gentlemen. And I
17 appreciate you coming up with it.

18 So I'm looking at it and you're showing
19 that, overall, there is a benefit to taxpayers
20 if you're looking at the \$15.00-an-hour
21 scenario. There is a \$31 million cost if we're
22 looking at the \$18.00-an-hour scenario.

23 So I know you're saying that this is
24 strictly Pennsylvania dollars, right, so that's
25 not taking into account any Federal money. This

1 is specific Pennsylvania moneys/savings that
2 we're looking at.

3 So in that regard, why do you think that
4 -- so now that this is out there and we're
5 talking about this, you know, obviously we are
6 in a cash-strapped State and we are looking at a
7 way of raising wages for people in this room and
8 all across the Commonwealth that would actually
9 be a way of saving money to the taxpayers of
10 Pennsylvania.

11 What hurdles do you see there being in
12 implementing this or what do you guys -- why
13 wouldn't we implement this today?

14 What are the shortfalls that I'm missing
15 of just looking at this dollars and cents-wise,
16 why it doesn't make sense?

17 MR. TORRES: Well, I think we're arguing
18 it does make sense, but sometimes you have to
19 take the risk. You know, I have a colleague who
20 runs an anti-poverty organization. He said, how
21 can we pay people poverty wages when we're
22 running anti-poverty?

23 So he said, we're going to take a risk.
24 We're going to pay people \$15.00 an hour. And
25 on the back end, I'm going to save all my money

1 on attrition and retention. Ultimately, he was
2 right, but he had to put the money up front.
3 It's a risk.

4 So we provided the logic of why it will
5 make sense and why it will benefit the
6 taxpayers, but the State of Pennsylvania does
7 have to take that first step forward to take
8 that risk to put the money up front.

9 Based upon these projections and
10 assumptions, the money will come back to the
11 taxpayers on the back end. So we're -- we don't
12 think there are barriers. It's really people's
13 fear that they won't get paid back in the end.

14 REPRESENTATIVE KAUFER: So the devil's
15 advocate of this is the risk on the front end is
16 really what you foresee there being the problem?

17 MR. TORRES: Correct. I think, you
18 know, even provider agencies are afraid to take
19 that risk, too, because they're looking at their
20 bottom line, too. Let's say a provider agency
21 put out \$15.00 or \$18.00 an hour with the idea
22 that they were going to save on overtime costs
23 or so. It's a risk; and people are risk
24 adverse.

25 But, you know, the best place to start

1 with the risk is with the state of the -- you
2 know, who is funding these provider agencies.

3 REPRESENTATIVE KAUFER: I wanted to get
4 back to one other question. You guys mentioned
5 that you had an outlier in what you were looking
6 at with the \$9.24 an hour, when you were talking
7 about the median versus the mean.

8 I was wondering if that model that you
9 looked at had a remarkably different model than
10 other programs in the State or why they would be
11 so much different than other programs.

12 DR. SPREAT: Afraid I can't give you
13 that detail. It came up as, what's your average
14 salary, and we saw the number, questioned it,
15 called to find out is it real, and it was real,
16 but we didn't explore what they were doing
17 differently.

18 REPRESENTATIVE KAUFER: Just as a way of
19 following up, obviously, I'm curious to see what
20 they're doing in a sense of how they're able to
21 raise wages for their workers. I'm very curious
22 to see how they got to those numbers and --

23 DR. SPREAT: That's probably a good
24 idea. We could do that because I can identify
25 who it was, but --

1 REPRESENTATIVE KAUFER: I would love if
2 you could follow up with our --

3 DR. SPREAT: Yeah.

4 REPRESENTATIVE KAUFER: -- Committee and
5 give that information. I think that's
6 worthwhile information, to know what people are
7 doing.

8 Just in -- and Mr. Chairman, I will
9 finish up my thoughts here. But, you know, one
10 of the big initiatives that our Caucus has been
11 doing within our Policy Committee over the last
12 -- our last three policy chairs have been trying
13 to address the cycles of poverty. It started
14 with who's our current Speaker, Speaker Turzai.
15 He talked about some programs we could look at.

16 Our Majority Leader currently,
17 Dave Reed, looked at how we can do sort of more
18 of a softer angle on breaking that cycle of
19 poverty, addressing the benefits cliff here in
20 Pennsylvania.

21 Our current Policy Chairman,
22 Kerry Benninghoff, has put a focus on this, on
23 how we can tie those two perspectives together.
24 This is something we have been working on,
25 something that I had been involved in

1 spearheading within our Caucus and something
2 that we are getting ready to talk about and make
3 some announcements policy-wise here over the
4 next month.

5 I really believe this is something that
6 should absolutely be tied into this program. I
7 see this as being something that does develop
8 the cycle of poverty amongst people within the
9 DSP community.

10 Just in saying that, I just -- this is
11 such an issue that I hear back at home. And I
12 know I have people here from my home area.
13 Thank you, Don, for being here.

14 But I know there are people that are
15 here from northeastern Pennsylvania. This
16 couldn't have been a bigger issue to address in
17 our community, not only statewide, about getting
18 people to be self-sufficient. I think you hit
19 the nail on the head, to be able to speak within
20 our Caucus about how we can move an initiative
21 like this forward. I appreciate the work and
22 testimony of everyone that is here today.

23 Thank you, Mr. Chairman.

24 REPRESENTATIVE MURT: I want to recognize
25 Representative Mark Longietti, who joined us.

1 I have a couple of questions, if the
2 testifiers don't mind.

3 What is the best way to do this?

4 Do we need to do it legislatively?

5 Do we need to do it administratively?

6 Do we need -- is the call made by the
7 Secretary of Human Services?

8 Is the call made by ODP?

9 How do we do this as quickly as
10 possible?

11 MR. BARTELMAY, JR.: I'm not professing
12 to be an expert, but having served as president
13 of the Arc of Pennsylvania in the past, most of
14 the DSPs in the State are paid through the
15 Medicaid Waiver Program. As you folks are well
16 aware, that's a partnership with Federal
17 dollars, CMS dollars.

18 Rates are set by ODP for what can be
19 charged for the service. Units are arrived
20 at -- most of the units of service that my son
21 receives are measured in 15-minute increments.
22 I believe -- and I'm working from memory; and I
23 haven't looked at these numbers in quite some
24 time -- but I believe, for example, the one
25 category of DSP, it's charged at a rate of \$6.37

1 a unit. So if we extrapolate that, we're
2 somewhere around \$25.00 an hour. We've got to
3 cover all of the various overhead that's related
4 to it.

5 So really, it's through what's set by
6 ODP. It kind of trickles down to, here's what's
7 left after we do administrative costs. I did
8 serve as the president of the board of directors
9 of a provider agency a number of years ago, and
10 this was a constant battle. We were a union
11 shop. The DSPs were unionized, but they were
12 well aware of the battle.

13 REPRESENTATIVE MURT: Where was that?

14 MR. BARTELMAY, JR.: Mercer County,
15 Pennsylvania.

16 REPRESENTATIVE MURT: And what was
17 that --

18 MR. BARTELMAY, JR.: The agency was
19 MCAR.

20 REPRESENTATIVE MURT: Okay.

21 MR. BARTELMAY, JR.: They're a
22 subsidiary agency of the Arc of Mercer County.
23 And it's a challenge, it remains a challenge.
24 This is not a new problem, the high turnover
25 rates. It's been forever.

1 As minimum wage is increased, we haven't
2 even necessarily -- we've seen the salaries draw
3 closer to minimum wage, not even increase in a
4 proportionate amount. And that's hurt us with
5 turnover, it's been my experience.

6 But as I said, I stepped away from that
7 role for a couple of years now, a few years, but
8 I don't think things have materially changed.

9 REPRESENTATIVE MURT: Scott and
10 Mr. Torres, do you concur with that?

11 MR. TORRES: Go ahead.

12 DR. SPREAT: Well, let me give you a
13 little context, as well.

14 About 80 percent of any provider's
15 budget is spent on employees. So agreeing
16 entirely with what the gentleman said, there is
17 not a lot of money left over to play with
18 because you're already spending 80 percent of
19 it. Included in the compensation -- we talked
20 about a mean/median wage of about \$11.50 --
21 there's also about 28 percent that goes to
22 employee benefits, not necessarily great
23 benefits, but benefits.

24 So there is not a lot of blood left in
25 the stone is the problem. The rates are set by

1 ODP. If they went up -- I wouldn't recommend a
2 specific rate, a salary for DSP, I'd say raise
3 the rates so that we can afford to pay people
4 better salaries.

5 REPRESENTATIVE MURT: I guess my
6 question is, is that something that's best
7 accomplished administratively by ODP or do we
8 have to pass a law?

9 What is the best way to make that
10 happen?

11 MR. TORRES: So without answering that
12 question, you know, in this study, we also noted
13 that, you know, roughly two-thirds of the DSPs
14 in the non-profit sector, the provider makes
15 about two-thirds of what is paid by the State
16 centers. So you know, when you look at those,
17 there's already a precedent set about we should
18 be paying them \$18.00 an hour, so I'd say, maybe
19 look into that.

20 But the other idea is, you know, before
21 answering the question, is it a law or is it
22 administratively, because that actually
23 increases then the State budget in terms of
24 going to that. You could also, you know, do a
25 pilot or a few pilots and structure it like a

1 pay for success bond. So if one of the
2 providers said, you know what, let's take this,
3 let's take this recommendation. Let's pay
4 people \$15.00 or \$18.00 an hour, it would play
5 itself out. And if they're successful, by
6 decreasing the amount they pay out in overtime
7 and the decrease of retention/attrition, then
8 the government pays back the investor. So it
9 could be structured like that, in a pilot type
10 of scenario, like it pays for success. There's
11 precedent in terms of that.

12 I'm not an expert of whether it should
13 be a law or whether it should be handled
14 administratively because, ultimately, it is a
15 paying out of the State to -- but if the State
16 assumes the risks, then the providers are more
17 likely to do it, as long as they are not going
18 to lose their shirt in terms of trying to
19 understand sort of how this would go through.

20 REPRESENTATIVE MURT: Before I recognize
21 Representative Kinsey, I want to mention to
22 everyone, we're currently debating HB 1401,
23 which is a tax on the extraction of natural gas
24 in Pennsylvania. If that bill comes to
25 fruition, some of that funding will go to help

1 this mission. We wrote that in there. So we're
2 hopeful that comes to fruition.

3 Representative Kinsey.

4 REPRESENTATIVE KINSEY: Thanks again,
5 Mr. Chairman.

6 For the parents, again, your stories are
7 touching. And we receive a lot of information
8 as parents start to age, you know, and have the
9 concern for the care of their sons or daughters.

10 What options have been presented to you,
11 like lifesharing? Is that an option that has
12 been discussed among family groups?

13 You know, again, I know you talked about
14 the house around the corner from you, but like
15 is lifesharing an option that might be of worth
16 to families and/or are there other options that
17 parents might be looking at as you talk about
18 the future of your child and as you become older
19 and not able to provide the care that you deem
20 necessary for the individual that you love?

21 MS. DOUGAN: There are a lot of options.
22 And this past year, more options have been added
23 by the Office of Developmental Programs. It
24 really is unique to the individual, to the
25 family.

1 For our son, to place him in a
2 lifesharing situation would mean moving him out
3 of the community where he grew up, you know, so
4 much a part of everyday lives and playing a part
5 in the community. So if the lifesharing
6 situation might be a long-term commitment to
7 community, great; but if it takes him out of
8 community -- or I've known parents who've, you
9 know, lifesharing works over here for a while
10 and then the lifesharing -- it's the same thing
11 with the family, they age, whatever, so they get
12 put in an another place. So for us, it was
13 about consistency.

14 There is also the self-direction model,
15 where a parent, family member or somebody can
16 become the employee of record. I did that for
17 almost five years. It's an unpaid position.
18 Under that, you're able to pay higher wages to
19 DSPs, but you are not able to provide them with
20 insurance, benefits, overtime, you know, all of
21 the other perks that you get through an agency.
22 And it was well over 40 to 60 hours a week for
23 me, at times.

24 When I looked at that option, it sort of
25 -- if I drop off the face of the earth tomorrow,

1 it's not sustainable. So for us, the choice
2 was, how do we make our son's life the most
3 sustainable if I got hit by a truck tomorrow;
4 and it's keeping him in community where people
5 know him.

6 I mean, his neighbors came and gardened
7 for him this summer. I mean, they are still
8 really involved. If there's a crisis, they are
9 all right there. So there are options.

10 I think -- I also, on just a side note,
11 since I have the microphone. I really
12 personally -- and I don't want to go against my
13 colleagues. As a parent, I really do want the
14 rate of pay to be focused on DSPs, an increase,
15 and not necessarily at the determination of
16 different provider agencies.

17 It's been a problem in the past -- I
18 know years ago, the last cost of living, which
19 was -- when was that, 2008 or something, that
20 they were even given a cost of living?

21 Some agencies chose to give that on to
22 direct support people, other agencies didn't.
23 And my primary advocacy in order of importance
24 is my son; second are the DSPs. I really -- I
25 want there to be some insurance to them that

1 their rates will be increased in this discussion
2 across the State, maybe other options
3 considered. I don't know if our State
4 universities can do something with tuition that
5 allows DSPs to -- I mean, it's so much bigger
6 than just the money.

7 How are we treating these people, this
8 workforce? Is there a career ladder?

9 You know, is it, welcome to the dead-end
10 job; we'll get this raise for you, but you may
11 not get another raise in two years, three years,
12 four years?

13 So this is just the beginning, I think,
14 to increase the wage. And then next is to look
15 to how we professionalize this workforce and
16 give them a code of ethics, give them the tools
17 to stay in this as a chosen profession for a
18 long time. The people who work at Burger King,
19 Walmart, I don't know that they see that as a
20 profession, their service.

21 This is not a service, although it's in
22 the service industry. It's human beings and the
23 need to keep people alive and have good lives.
24 I wanted to also add that the rate of pay in our
25 State centers is higher. The DSPs in those

1 State centers do not have the level of
2 responsibility that they do have in community,
3 where they are making so much less money.

4 People in the State centers -- there is
5 someone else measuring the medication, someone
6 else doing the housekeeping, someone else --
7 they are just doing -- and if someone is sick,
8 there is an automatic replacement.

9 If you're in home and community -- and
10 in my son's case, vulnerable -- you really need
11 a well-trained, well-paid workforce, at least on
12 par with our State centers.

13 REPRESENTATIVE KINSEY: Mr. Chairman, I
14 think State centers are State employees, though,
15 is that correct?

16 Is that what it is?

17 REPRESENTATIVE MURT: That's correct,
18 the five State centers, yes.

19 REPRESENTATIVE KINSEY: Well, again,
20 thank you.

21 MR. BARTELMAY, JR.: I'd like to -- I
22 couldn't agree more with Cheryl's comments.
23 Lifesharing certainly presents an option, but on
24 the other side of this, from the family
25 perspective, we still have a waiting list in

1 Pennsylvania. There are literally thousands of
2 families waiting to receive any services. Many
3 won't receive services for their loved one until
4 they pass, themselves. So it's not simply the
5 options. We have a tiered system.

6 You can receive services at the PFDS,
7 Person Family Directed Supports Waiver; and
8 that's capped at thirty-some-thousand dollars a
9 year. That doesn't go very far in providing the
10 level of care somebody like our children need.

11 There's a middle waiver and then
12 there's, of course, the consolidated waiver, but
13 that is -- that is not an easy thing to achieve,
14 unfortunately. So that plays a big impact on
15 it, but we have -- I agree with Cheryl, we have
16 a plethora of options, but you have to remember,
17 we're taking very vulnerable people -- and I
18 can't speak highly enough for these folks.

19 My son has had over 20 different people
20 bathe him, care for him, the most intimate
21 things imaginable, and he can't communicate
22 back. It's scary. It's something we live with
23 every day. The quality of the people that we
24 have just amazes me because it's far beyond the
25 job.

1 You don't do what these folks do because
2 you want a job or a paycheck, because quite
3 frankly, they could go to Walmart, they could go
4 to Burger King. They could go to many places
5 and do just as well without changing the diaper
6 of a 170-pound man and cleaning him and some of
7 the things that folks do. I can't speak highly
8 enough. I just can't imagine why we -- sir,
9 what you said about the most vulnerable; that
10 just staggers me.

11 And I am a -- I am also a fiscal
12 conservative and have been my whole life, but
13 you know, there are times that we just have to
14 take a look at who we are as a society, who we
15 are as a community and step forward and do
16 what's right.

17 REPRESENTATIVE MURT: I want to
18 recognize Representative Warren for rejoining
19 us.

20 I'm not the chairman, and I'm going to
21 conclude the meeting, but I'm going to ask
22 Chairman DiGirolamo and Chairman Angel Cruz to
23 draft a letter to ODP to address some of these
24 issues that were raised today.

25 Mr. Bartelmay made a good point about

1 the people on the waiting list. There are
2 people on the waiting list -- there are
3 families, literally, where there are parents
4 both living, 90 years old, caring for a son or
5 daughter, with some of our DSPs, that might be
6 60 or 65 years old.

7 The parents are struggling with their
8 own age and health-related issues, and here they
9 are caring for a son or daughter on a daily
10 basis, on the emergency waiting list for a
11 waiver.

12 I will be very honest with you, my blood
13 pressure goes up when I see someone can snap
14 finger and build a soccer stadium someplace in
15 the Commonwealth and they make these families
16 wait years, sometimes decades, for this funding
17 that they need. This has to be addressed.

18 We've been making some progress, but not
19 enough. It's been underfunded for literally
20 decades. We'll try it again during the
21 Appropriations hearing.

22 Any of my colleagues have anything to
23 mention?

24 DR. SPREAT: Mr. Murt, one more thing --

25 REPRESENTATIVE MURT: I want to thank

1 our testifiers.

2 Yes.

3 DR. SPREAT: I understand that this
4 Committee will be considering a set of
5 regulations coming to this Committee and that
6 it's an opportunity to look at how those
7 regulations would impact pay rates and funding
8 rates for people working as direct support
9 professionals, so that's something to keep in
10 mind as you guys are reviewing it.

11 REPRESENTATIVE MURT: It would be a good
12 idea to check in with Gene DiGirolamo about
13 that.

14 DR. SPREAT: I will. I will bring it to
15 his attention.

16 REPRESENTATIVE MURT: Okay. That will
17 conclude our meeting.

18 Thank you, everybody, for attending.
19 Keep up the great work. God bless you.

20 MR. BARTELMAY, JR.: Thank you.

21 (Whereupon, the hearing concluded 10:44 a.m.)

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C E R T I F I C A T E

I hereby certify that the proceedings
are contained fully and accurately in the notes
taken by me on the within proceedings and that
this is a correct transcript of the same.

Tiffany L. Mast
Tiffany L. Mast, Reporter

Notary Public