

COMMONWEALTH OF PENNSYLVANIA

HOUSE OF REPRESENTATIVES

HUMAN SERVICES COMMITTEE

ROOM 60, EAST WING

HARRISBURG, PENNSYLVANIA

WEDNESDAY, APRIL 11, 2018

9:30 A.M.

BEFORE:

HONORABLE GENE DIGIROLAMO, MAJORITY CHAIRMAN  
HONORABLE ANGEL CRUZ, MINORITY CHAIRMAN  
HONORABLE ALEXANDER CHARLTON  
HONORABLE BUD COOK  
HONORABLE CRIS DUSH  
HONORABLE JONATHAN FRITZ  
HONORABLE RICH IRVIN  
HONORABLE AARON KAUFER  
HONORABLE TOM MURT  
HONORABLE ERIC NELSON  
HONORABLE TOM QUIGLEY  
HONORABLE ERIC ROE  
HONORABLE JUDY WARD  
HONORABLE MICHAEL DRISCOLL  
HONORABLE STEPHEN KINSEY  
HONORABLE MAUREEN MADDEN  
HONORABLE JOANNA MCCLINTON  
HONORABLE DANIEL MILLER  
HONORABLE PERRY WARREN

*Pennsylvania House of Representatives  
Commonwealth of Pennsylvania*

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SUBMITTED WRITTEN TESTIMONY

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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.

If I could ask everyone to take a seat. Perfect timing, Angel.

Good morning. Welcome to the Human Services Committee. We are very, very excited about everyone being here this morning. If we could start out by asking everyone to stand for the Pledge of Allegiance to the flag.

(Pledge of Allegiance was recited.)

MAJORITY CHAIRMAN DiGIROLAMO: Before we get to our first testifier, I thought I might just take a minute and allow the members that are present today just to say hello and let you know who they are. I am first.

I'm Gene DiGirolamo from Bucks County. I am the Republican Chairman of the Committee.

Representative Cruz.

MINORITY CHAIRMAN CRUZ: I'm Representative Cruz from Philadelphia. I am the Minority Chairman of this Committee. Thank you.

Welcome, everyone.

REPRESENTATIVE DRISCOLL: Mike Driscoll,

1 I represent northeast Philadelphia.

2 REPRESENTATIVE KINSEY: Good morning.

3 Stephen Kinsey from the city of  
4 Philadelphia.

5 REPRESENTATIVE MADDEN: Good morning.

6 Representative Madden from the Poconos,  
7 Monroe County.

8 REPRESENTATIVE DUSH: Good morning.

9 Representative Cris Dush, the 66th  
10 District, out of Indiana and Jefferson Counties.

11 REPRESENTATIVE MURT: Tom Murt, I  
12 represent Montgomery County and part of  
13 Philadelphia.

14 REPRESENTATIVE CHARLTON: Alex Charlton,  
15 I represent Delaware County.

16 REPRESENTATIVE QUIGLEY: Representative  
17 Tom Quigley from Montgomery County.

18 REPRESENTATIVE IRVIN: Good morning.

19 Rich Irvin, representing all of  
20 Huntingdon County, parts of Centre and Mifflin  
21 Counties.

22 REPRESENTATIVE ROE: Good morning.

23 Representative Eric Roe, I represent the  
24 158th District in Chester County.

25 REPRESENTATIVE KAUFER: Aaron Kaufer,

1 120th District, Luzerne County.

2 REPRESENTATIVE COOK: 49th District, the  
3 Mon Valley, Bud Cook.

4 REPRESENTATIVE FRITZ: Good morning,  
5 friends.

6 Jonathan Fritz, representing the 111th,  
7 comprising Wayne and Susquehanna Counties.

8 MAJORITY CHAIRMAN DiGIROLAMO:  
9 Representative Miller, just say hello.

10 REPRESENTATIVE MILLER: (No microphone.)  
11 Hello. Dan Miller.

12 MAJORITY CHAIRMAN DiGIROLAMO: Okay.  
13 Before we get to the first testifier, just a couple  
14 of ground rules. The cameras are on, so we are  
15 being -- I believe PCN is televising this. So just  
16 to remind everybody, the cameras are on.

17 Also, we have a little glitch this  
18 morning. We've been called into session at 10:30.  
19 We usually start at 11:00. So we are going to have  
20 to be finished with the hearing today at 10:30. Our  
21 rules do not allow us to have a hearing when the  
22 House is in session.

23 So I think we very easily will be able to  
24 work around this. At the end of the meeting, we're  
25 going to open it up for questions. So if we have

1 any time before 10:30, we will have some questions  
2 for our testifiers.

3 And with that, just a couple of comments.  
4 You know, I believe we're going to learn a lot today  
5 about the challenges of people who face and have a  
6 combined vision and hearing loss. I don't believe  
7 anyone would argue that they do not need and deserve  
8 our support. We expect to hear about ways to  
9 increase independence and self reliance, so the  
10 folks who are deafblind may achieve their goals of  
11 education, employment, raising a family and  
12 contributing to society.

13 Also, just to mention, next week, we do  
14 have a voting meeting. We're going to be taking up  
15 a bill, HB 2069, which is Representative Miller's  
16 bill, that will provide grants and money that will  
17 help fund some of the services that are very justly  
18 need.

19 So with that, Representative Cruz, do you  
20 have anything that you want to add?

21 MINORITY CHAIRMAN CRUZ: No.

22 MAJORITY CHAIRMAN DIGIROLAMO: Okay.

23 With that, we're going to call our first testifier  
24 up. From the Center for Independent Living of  
25 Central Pennsylvania, Marsha Drenth, who is the

1 Program Manager for DeafBlind Living Well Services.

2 Marsha, welcome.

3 MS. DRENTH: Thank you.

4 MAJORITY CHAIRMAN DiGIROLAMO: You can  
5 begin whenever you're ready.

6 MS. DRENTH: Good morning, Committee  
7 members and audience. Thank you for giving me this  
8 opportunity to speak on behalf of persons who are  
9 deafblind. I'm going to speak on behalf of me as a  
10 person who is also deafblind, with a hearing and  
11 vision loss.

12 To give you a bit of information about  
13 myself, I'm a wife, a mother of three grown  
14 children. I work in the nursery at my church. I'm  
15 an advocate. I work full-time. I have many  
16 hobbies. I'm a daughter. I'm a sister, and many  
17 other characteristics.

18 I graduated from Temple University with a  
19 social work degree. Originally, I was born as a  
20 person with a visual impairment. At one point, I  
21 could read print and actually was able to drive with  
22 normal vision.

23 In November of 2007, after learning to be  
24 a visually-impaired person and using my hearing to  
25 the best of my ability, I was diagnosed with a mild

1 hearing loss. This was devastating. I was in  
2 complete and utter denial.

3 In 2009, I moved to Pennsylvania, where I  
4 married my husband and began a new life. In 2007,  
5 while enrolled as a student at Temple University, I  
6 experienced another major hearing loss episode. I  
7 no longer could hear the person sitting next to me  
8 speaking. I could no longer hear the professors at  
9 the front of the room.

10 I became very depressed, isolated and  
11 lonely. I asked many, many questions and no one had  
12 answers, answers I wanted about how to live as a  
13 person with both hearing and vision loss. I was  
14 fortunate enough to be able to attend the  
15 Helen Keller National Center in 2014. There I  
16 learned what an SSP was, a support service provider.

17 I became independent and knowing how to  
18 communicate with sign language and other adaptive  
19 technology, as a person with both hearing and vision  
20 loss. I graduated from Temple University in 2015.

21 I now use support service providers in  
22 both my professional and personal lives. For  
23 example, in my personal life, I use an SSP to go to  
24 workshops. In my personal life, I attend church  
25 retreats. I'm a lucky one. Many of the consumers



1 that I provide services to don't have the  
2 opportunity to know what's going on in their lives,  
3 make informed decisions and get out into their  
4 community.

5 But what about all of those that we have  
6 not found out about?

7 What about those that have no one or have  
8 ailing family and friends that are helping take care  
9 of those persons with hearing and vision loss?

10 Those are the persons that we need to  
11 find and that need services, just like myself and  
12 many of the others that are in this room. It's  
13 those that are important for us to find and to be  
14 able to provide services to.

15 Support service providers provide me the  
16 access to my community, personal life, professional  
17 life and everything in between. I'm now able to  
18 live independently because of an SSP. This is an  
19 important program. I have the opportunity and the  
20 pleasure to provide services to those folks all over  
21 the State.

22 Many of you, I have met with in person.  
23 I urge you -- if you've heard my story before,  
24 you're about to hear other stories of deafblind  
25 persons who will also share how they've become

1 independent and able to live their lives with the  
2 use of an SSP -- please do not let those people who  
3 are deafblind in the State of Pennsylvania go  
4 without services.

5 Thank you.

6 MAJORITY CHAIRMAN DiGIROLAMO: Thank you,  
7 Marsha, very, very much. Very terrific testimony.

8 Also on the panel, we have Renee Fisher,  
9 who is a support service provider; and Zenola Tyson,  
10 who is a patron of SSP. If they are here, they  
11 could both come up.

12 MS. FISHER: (Communicating via ASL.)

13 Hello, everyone. My name is Renee  
14 Fisher, and I'm from the Pittsburgh area.

15 I am deaf. I work as a support service  
16 provider, an SSP, for people who are deaf and blind.  
17 So people who are deafblind, I work with them. It's  
18 of severe critical importance to have SSP services  
19 for deafblind people throughout the State of  
20 Pennsylvania. HB 2069 is of critical importance for  
21 them to continue.

22 People who are sighted are able to drive,  
23 to go out, watch TV, do different activities, try  
24 different things, but with deafblind people, it's  
25 not that way. It's the opposite. They often depend

1 on family and friends just for basic life  
2 information, so their independence is very limited.  
3 They become isolated, lonely and depressed. It also  
4 causes many mental health issues among this  
5 population, as well.

6 If you could just imagine being deaf and  
7 blind, how would you go to the grocery store?

8 Right now, you get in your car, you  
9 drive, you go, you pick out what you want, you pay,  
10 you find the shortest line, you know, pay, then go  
11 home, but with a person who is deaf and blind, their  
12 experience is completely different. They have to  
13 find someone who will help support them, like an  
14 SSP.

15 They have to plan the trip in advance.  
16 They have to get somebody to pick them up to take  
17 them to the store, to guide them throughout the  
18 store, to explain what the products are. That  
19 friend or family member may have limited time, so  
20 they might want to hurry and rush the deafblind  
21 person or just leave them in the car and say, I'll  
22 go pick it up for you and I'll be right back. So  
23 it's very unfortunate for them because they have  
24 limited experiences.

25 With a support service provider, they

1 provide attention to detail. They guide the  
2 deafblind person throughout the store. They tell  
3 them about the different products that are there.  
4 If there are new products maybe the deafblind person  
5 hasn't known about, the SSP will take time to tell  
6 them about that.

7           For example, maybe they prefer Charmin  
8 toilet paper over Cottonelle or you know, Northern  
9 or whatever, and they don't know that there's that  
10 different type of toilet paper out there because  
11 somebody has always picked it out. Or different  
12 types of fruits and vegetables, you know, canned  
13 fruits and vegetables, we let them know all the  
14 different brands and the types.

15           Also, there are free samples. Maybe they  
16 never knew that there might be free samples out  
17 there, so they could try that. And they might not  
18 know the nutritional information on these products,  
19 so we can let them know the nutritional information,  
20 as well.

21           So again, just imagine, if a deafblind  
22 person only has five hours of access to a support  
23 service provider, that's really rough for them.

24           How are they going to find time for  
25 enjoyment, for socialization, to work?

1           It's hard for them. Sighted people don't  
2 have to worry about that. They're not limited to  
3 just five hours. We don't want deafblind people to  
4 live like that, so this is a huge concern.

5           Another huge concern that we have is  
6 safety. Some people walk around with a cane and  
7 they think that they might be okay, but if there's  
8 some kind of roadblock, they might not see that and  
9 they might fall down. One of my friends actually  
10 fell down a hole. It was at a construction site.

11           Deafblind people have also been killed  
12 with a car hitting them. Again, having an SSP is  
13 important. Having those services statewide is  
14 really important. That would reduce the problems  
15 that they've experienced.

16           In Seattle, Washington, they have a big  
17 deafblind population there. So there are different  
18 expectations and accommodations for deafblind people  
19 because of the large population that they have  
20 there.

21           Deafblindness varies. The communication  
22 style of deafblind people varies. Some people use  
23 tactile tracking, print on palm, FM systems, people  
24 that have maybe a mild hearing loss, et cetera.

25           The regular public, when they see someone

1 who is deafblind, they get nervous and they don't  
2 know what to do. They often back away, whereas an  
3 SSP can help bridge that communication and make the  
4 person who is not familiar with deafblind people  
5 become comfortable.

6 I want to be clear that we're not  
7 personal care attendants. Deafblind people can do  
8 those types of things on their own. They're very  
9 independent, but we are there for safety issues, for  
10 environmental cues, et cetera.

11 If SSP services were terminated, I can't  
12 even imagine what would happen to people who are  
13 deafblind in the State of Pennsylvania. I can't  
14 even imagine the depression, the struggle that these  
15 people would go through. So I'm hoping that you  
16 will continue with the SSP services.

17 I want to thank you for your time and  
18 your attention today. Thank you all.

19 MAJORITY CHAIRMAN DiGIROLAMO: Zenola  
20 Tyson, who is a patron of SSP.

21 MS. TYSON: (Communicating via ASL.)

22 Are we ready?

23 My name is Zenola Tyson. I live in Camp  
24 Hill, and I'm deafblind myself. Thank you so much  
25 for the ability to utilize SSP services.

1           You know, they're able to help me go to  
2 my doctor's appointments, for food shopping,  
3 finding, you know, clothing that I like, and to be  
4 able to interact and participate in the community.  
5 You know, if I possibly need physical therapy, that  
6 SSP can actually come and provide, you know, sign  
7 interaction with me.

8           Also, to be able to go out and  
9 socialize -- you know, food shopping, many, many  
10 things are in that food store. Think of the size of  
11 that store. There are so many different items in  
12 that store that I have no idea that are there. And  
13 one person needs to be able to explain that to me.  
14 You know, you have no idea just how many salad  
15 dressings and cereals there are. It's such a  
16 challenge for a deafblind -- it's not easy to live  
17 with this disability.

18           It's very frustrating. There are many  
19 barriers. So please, please continue to support the  
20 deafblind in our lives and to support DeafBlind  
21 Living Well Services. You know, we really need the  
22 program. We need SSPs to help us to live a normal  
23 life, so that we can live in peace and we can be  
24 calm with what we have in our lives.

25           Thank you very much.

1 MAJORITY CHAIRMAN DiGIROLAMO: (No  
2 microphone.) Zenola, thank you very, very much. To  
3 the three testifiers, Marsha, Renee, Zenola, that  
4 was really very, very compelling testimony. Thank  
5 you. Thank you so much for being here today.

6 I will tell you what, I think the three  
7 of them deserve another round of applause.

8 Good job.

9 Next, we have the Department of Labor &  
10 Industry, Office of Vocational Rehabilitation. We  
11 have David DeNotaris, who is the Executive Director.  
12 Dave, welcome.

13 We have Ryan Hyde, who is the Director of  
14 the Bureau of Central Operations. Welcome, Ryan.

15 Both of you can begin whenever you're  
16 ready. Oh, one minute. Some other members have  
17 come in since we've first started. I would like to  
18 give them an opportunity to say hello.

19 REPRESENTATIVE McCLINTON: (Speaking and  
20 using ASL.)

21 Good morning, Chairman. My name is  
22 Joanna McClinton. I'm a State Representative in the  
23 191st Legislative District.

24 Thank you.

25 REPRESENTATIVE WARREN: Good morning.



1 I'm Perry Warren. I represent the 31st  
2 District in Bucks County.

3 REPRESENTATIVE NELSON: Good morning.

4 I'm Eric Nelson. I represent  
5 Westmoreland County.

6 MAJORITY CHAIRMAN DiGIROLAMO: Okay,  
7 gentlemen, you can begin when you're ready.

8 MR. DENOTARIS: Yes. This is on?

9 MAJORITY CHAIRMAN DiGIROLAMO: Yes.

10 MR. DENOTARIS: Good morning. Good  
11 morning, Mr. Chairman DiGirolamo, Chairman Cruz,  
12 Representative Miller, and to the Committee.

13 My name is David DeNotaris, and I am  
14 privileged to serve as the Executive Director of the  
15 Pennsylvania Department of Labor & Industry's Office  
16 of Vocational Rehabilitation, OVR. OVR is the lead  
17 agency for residents of Pennsylvania with  
18 disabilities.

19 Last year, OVR staff assisted over 6,000  
20 employers in accessing the most untapped talent  
21 pool, individuals with disabilities. OVR assisted  
22 over 9,300 individuals with disabilities in  
23 obtaining real jobs with real pay in their  
24 communities. I truly believe in the potential of  
25 individuals with disabilities, for I am one myself.

1 I went totally blind from a rare  
2 degenerative eye condition, Retinitis Pigmentosa,  
3 RP, when I was 19 years old and attending East  
4 Stroudsburg University. After significant  
5 challenges, setbacks and struggles, I realized that  
6 if I could access the same information as my  
7 classmates, colleagues and peers, that I would be  
8 able to access the same educational training,  
9 independent living and employment opportunities as  
10 my neighbors.

11 I learned and truly believe that access  
12 equals success. When an individual with a  
13 disability can access a positive philosophy about  
14 their disability, access community services and  
15 access professionals that can provide necessary  
16 environmental information, an individual with a  
17 disability can avoid isolation and identify and  
18 build upon their skills and abilities and be  
19 successful contributing members of their community.

20 I was appointed as the Director of the  
21 Bureau of Blindness and Visual Services in August of  
22 2007. Soon after, individuals began to ask about  
23 SSP services, which are services that are being  
24 addressed today in HB 2069. Similar services are  
25 available in other surrounding states. And then we

1 began considering how Pennsylvania can meet these  
2 consumers' requests.

3 In 2012, OVR partnered with the Statewide  
4 Independent Living Council, S-I-L-C, SILC, and the  
5 Office for the Deaf and Hard of Hearing, ODHH, to  
6 build support service programs in the State Plan of  
7 Independent Living, SPIL. We also consulted with  
8 the Advisory Committee for the Blind and Advisory  
9 Committee for the Deaf and Hard of Hearing regarding  
10 these services.

11 The SSP project was then put into the  
12 centers -- the State Plan and awarded to the Centers  
13 for Independent Living of Pennsylvania, CILCP. In  
14 the first year of the partnership, we held three  
15 forums to learn what services consumers would  
16 benefit from. The forums were in Philadelphia,  
17 Pittsburgh and Harrisburg. The meetings were rich  
18 with information regarding what customers, parents,  
19 family members were requesting and advocating for.

20 We heard things like: I need to get to  
21 the doctors; I want to go to the pharmacy and not  
22 have to ask the 16-year-old young man where to  
23 purchase feminine products; my son needs help  
24 getting to the supermarket, and I'm not going to be  
25 around forever; I'd like to go outside by myself and

1 take my dog for a walk; I'd like to go to church  
2 again; I'd like to go Christmas shopping and get my  
3 family members presents. The stories were humbling.

4 The requests were real, and the need was  
5 great. We had the opportunity, like all of us, to  
6 be difference makers. Our workshop began training  
7 SSPs by the Helen Keller National Center in Sands  
8 Pint, New York. Over 85 individuals were trained  
9 statewide as support service providers.

10 In year two, SSP service providers worked  
11 with 35 customers who benefitted from the program.  
12 In year three, 50 deafblind individuals benefitted  
13 from the initiative. In the past five years, OVR  
14 has invested nearly \$700,000 in this life changing  
15 initiative.

16 Though OVR's primary mission is  
17 employment-related, we realize value and encourage  
18 independence. Our vision was and is to develop and  
19 sustain an accountable and meaningful project that  
20 will inspire and empower residents we are so  
21 privileged to serve.

22 I am so honored for this opportunity to  
23 address you. When the time is right, I'd be happy  
24 to answer any questions.

25 Thank you, sir.

1 MAJORITY CHAIRMAN DiGIROLAMO: Ryan, do  
2 you have anything you would like to add?

3 MR. HYDE: Nothing at this time. I'm  
4 happy to answer questions at the appropriate time.

5 MAJORITY CHAIRMAN DiGIROLAMO: (No  
6 microphone.) Okay. We have one more testifier, and  
7 then we're going to open it up for questions at the  
8 end.

9 Next, we have Tom Earle, who is the  
10 Executive Director of Liberty Resources, Inc. Tom,  
11 welcome.

12 MR. EARLE: Good morning, Committee  
13 members. My name is Thomas Earle, and I'm the Chief  
14 Executive Officer of Liberty Resources, which is the  
15 Center for Independent Living that serves the  
16 Philadelphia area. I'm also the Treasurer of the  
17 Pennsylvania Council on Independent Living and the  
18 Chairperson of the Philadelphia Commission on Human  
19 Relations.

20 Through these roles in my work and  
21 career, including my legal career, I have often seen  
22 the challenges that people with disabilities, in  
23 particular, people with sensory disabilities, face  
24 in enjoying the everyday aspects of living in a  
25 community that able-bodied, able-sighted and

1 able-hearing people get to enjoy and take for  
2 granted. I am here this morning to offer my full  
3 support for HB 2069 in an attempt to secure  
4 permanent future funding for the support service  
5 programs for people who are deafblind in the  
6 Commonwealth.

7           There are currently over 509,000  
8 Pennsylvania residents who have some form of deaf,  
9 hard-of-hearing, and blind, visually-impaired  
10 disabilities. For those who are completely deaf and  
11 blind, they often lead lives of deep isolation for  
12 many aspects of life in the communities, including  
13 communication, social interaction, employment  
14 opportunities and other activities of daily living  
15 that many non sensory-impaired individuals enjoy  
16 every day.

17           As the Center for Independent Living is  
18 serving thousands of disabled individuals in the  
19 Philadelphia region, many of whom have physical  
20 disabilities, we continue to be understaffed,  
21 underfunded and ill-equipped to effectively serve  
22 the unique independent living needs of people who  
23 are deaf and blind. Currently, Liberty is working  
24 with seven deafblind consumers.

25           The services support program, developed

1 by our sister, CIL, Center for Independent Living of  
2 Central Pennsylvania, is an innovative and  
3 well-designed model that has successfully begun the  
4 specialized training and capacity to better serve  
5 this most vulnerable group of Pennsylvania citizens.

6 Pennsylvania can and must do more. Act  
7 139 should be amended to establish appropriate  
8 funding levels that will ensure that the SSP can be  
9 sustained on an annual basis across all counties in  
10 Pennsylvania. The Pennsylvania Council on  
11 Independent Living and the network of 17 CILs  
12 strongly supports HB 2069 as an effective resource  
13 to address the independent living needs of this  
14 underserved and often isolated community.

15 In the future, this may provide us with  
16 another opportunity to revisit Act 139, which has  
17 been in place for a long time, and assess what other  
18 aspects of it need to be updated to meet the growing  
19 needs of seniors and people with disabilities who  
20 would like to live independently in Pennsylvania.  
21 In conclusion, as an individual who is legally blind  
22 from a progressive form of blindness called  
23 Retinitis Pigmentosa, I am especially sensitive to  
24 the needs of children, adults and seniors who are  
25 afflicted with sensory disabilities.

1           Accordingly, I implore this Committee and  
2 the leadership of the State Legislature to swiftly  
3 pass this simple amendment to sustain this vitally  
4 important program for the deafblind community.  
5 Thank you very much for allowing me to testify  
6 today.

7           MAJORITY CHAIRMAN DiGIROLAMO: Tom, thank  
8 you very much.

9           Tom, why don't you just stay right there  
10 because we're going to open it up for some  
11 questions. Before I do that, I'll give  
12 Representative Miller an opportunity to explain  
13 HB 2069 that many of the testifiers were talking  
14 about today, and that we're hopefully going to move  
15 out of Committee next week.

16           REPRESENTATIVE MILLER: Thank you,  
17 Mr. Chairman. Thank you so much for your and your  
18 office's support of my and Tom's bill.

19           I do appreciate seeing so many friends  
20 here, by the way. Several people were at our  
21 Disability Summit that we did just a couple of weeks  
22 ago. Tom and a bunch of -- Jason Ortitay have  
23 always been supportive of our discussions there.

24           This bill came out of their advocacy.  
25 And I thought the Chairman did a great job of sort



1 of giving the personal stories right in the  
2 beginning. I'll tell you, they brought my  
3 Disability Summit to a halt with their stories of  
4 the impact that SSPs have at sort of opening up  
5 opportunity.

6 One of the reasons I think a lot of us  
7 spend time on disability and mental health issues  
8 is, I just love touching that sort of shared  
9 humanity that we all have, and they brought that to  
10 the forefront. The bill, obviously -- I know,  
11 perhaps, we'll find an aspect here or there to make  
12 it better -- but the bill looks to cement a program  
13 that was started with a grant funding, that  
14 originally, as far as I know, allowed for 15 hours  
15 of SSP services. That was a month.

16 So that was 15 hours for the month that  
17 someone had assistance in connecting with the  
18 outside and the rest of the world. Over time, I  
19 heard of some ebbs and flows in the program, where  
20 that was cut down for at least a period to five  
21 hours. So imagine, for us, to think about if  
22 somebody would tell you, you have five hours for 30  
23 days to do or connect in any way that you want to,  
24 yet think of what you have to prioritize, and think  
25 of what you have to push together to have that

1 limited window.

2 So thankfully, from what I understand,  
3 there have been some extensions here or there that  
4 have allowed the program to continue. I'll tell you  
5 what -- and thank you, Chairman -- just to summarize  
6 with it, what we're looking for here in the bill is  
7 a permanent ongoing commitment.

8 The language currently is at \$250,000. I  
9 would say to us that I don't think we could find a  
10 better bang for the buck in our budget that means  
11 more to individuals than this \$250,000 that is  
12 there. We did hear a couple of comments, where some  
13 people said that, perhaps, by expanding the reach of  
14 some things, it's possible we may find some other  
15 people who are deafblind in other areas of the  
16 State, who are still in isolation without access to  
17 these services.

18 Theoretically, it's possible, and we'll  
19 hopefully find them. If they are there, I hope we  
20 will find them and assist them to get this window --  
21 limited window of opportunity, but the reality of it  
22 is, the ballpark we're talking about is very small,  
23 with a tremendous benefit to these Pennsylvanians.  
24 So I really thank you for putting -- both  
25 Chairmen -- for putting the effort together, and

1 your staff, to bring us here today.

2 I'm confident that we will have a bill on  
3 the House floor that we can all stand up together on  
4 and be proud of. Thank you.

5 MAJORITY CHAIRMAN DiGIROLAMO: Okay.  
6 I'll open it up for questions.

7 Representative Cruz, do you have any  
8 questions?

9 Do members have any questions for any of  
10 the testifiers today?

11 Okay. Representative Fritz.

12 REPRESENTATIVE FRITZ: Thank you,  
13 Mr. Chairman.

14 I want to thank our testifiers today.  
15 They did a wonderful job and just brought a great  
16 energy to this room.

17 Representative Miller and  
18 Representative Murt, I want to thank you for your  
19 work on this legislation.

20 I represent a rural area. And my  
21 curiosity is this, how does this program manifest in  
22 a rural area?

23 Do you dovetail with the counties?

24 How do we provide those services?

25 MAJORITY CHAIRMAN DiGIROLAMO: Maybe Dave

1 could come up and answer the question.

2 MR. DENOTARIS: Thank you, sir.

3 So the question is, how does the program  
4 dovetail in rural areas?

5 So the Center for Independent Living of  
6 Central Pennsylvania, it's a local CIL here in  
7 central PA, but it's certainly a statewide program  
8 that, you know, reaches all of the -- does our best  
9 to reach all of the counties. We see a high  
10 population in the Pittsburgh area and the  
11 Philadelphia area.

12 One of the ways that we certainly have --  
13 I think the Centers for Independent Living have done  
14 a tremendous job of using technology, sharing  
15 videos, social media, stories, successes about the  
16 program. So you know, with some really limited  
17 resources, I think they've done a tremendous job of  
18 connecting with providers, other support groups, to  
19 educate people regarding the services.

20 REPRESENTATIVE MILLER: I apologize for  
21 jumping in, if I could.

22 Thank you, Dave.

23 Chairman, my quick suggestion -- I know  
24 Marsha could be very quick with it, but she is  
25 responsible directly for accessing this program.

1 And I think a quick moment from here would help even  
2 flush out more of the good gentleman's question.

3 MS. DRENTH: Thank you.

4 Yes, I'm the Program Manager for the  
5 program. So yes, we do try very hard to really get  
6 into the counties in which we have either Centers  
7 for Independent Living, other Pennsylvania  
8 Associations for the Blind. And then also, what has  
9 happened a lot of times over the past three or four  
10 years, is that the program and information about the  
11 program travels by word of mouth.

12 So when we also do support service  
13 provider trainings, we are also getting into the  
14 community and getting to know the landscape of that  
15 community. So we take people that are in that  
16 county and in that area, so that those persons who  
17 are deafblind not only can get out into their  
18 community, but also work with people that are in  
19 their community.

20 And so, as David was saying, we really  
21 try very hard to have -- we've had great social  
22 media campaigns. And technology has been a big part  
23 of that, but also, that means that I also have to go  
24 out and do a lot of presentations and I have to  
25 travel to some very rural areas. I admit that there

1 are rural areas in which we have not really gotten  
2 to, as of yet. I know that there's a huge need in  
3 Erie County, for example, that we have been paying  
4 attention to and will continue to, and increasing  
5 support service providers to help persons who are  
6 deafblind in that area, but there are others.

7           You know, unfortunately, with  
8 Pennsylvania being a large State, there are 67  
9 counties. So I'm trying very, very hard to get into  
10 every one of the 67 counties. And as I've gone to  
11 every Representative's meeting, I've left my  
12 information and given information to those  
13 Representatives and staffers, so that if they get  
14 calls, they can also pass that information along.

15           REPRESENTATIVE FRITZ: Thank you, Marsha.  
16 Thank you, David.

17           MR. DENOTARIS: Yes, sure.

18           MAJORITY CHAIRMAN DiGIROLAMO:  
19 Representative Dush.

20           REPRESENTATIVE DUSH: Hello.

21           Thank you, Chairman. I thank all of you,  
22 the testifiers, Marsha, Renee, Zenola, David,  
23 Thomas, what you've done with your lives is just a  
24 fantastic testament to what can be done when we  
25 provide the type of services that allow you to have

1 a more full life.

2 My dad worked for OVR. He broke his back  
3 and OVR put him through college. And he ended up,  
4 instead of going to work as a teacher, OVR offered  
5 him a job. He was a placement counselor. I'm  
6 sitting here -- I can't stop smiling because of the  
7 testimonies that you folks have provided and the  
8 types of things that you've overcome.

9 My question is for Dan. Because it  
10 hasn't been addressed here, as far as the testimony  
11 today, the \$250,000 solidified, what exactly will  
12 that entail?

13 What will it provide, in specificity, if  
14 you could?

15 REPRESENTATIVE MILLER: As far as my  
16 knowledge, the reality of it is that the current  
17 grant program has helped fund the direct service  
18 providers themselves. So it's a personnel cost, in  
19 essence, with some administration that is done, as  
20 well.

21 So these are the moneys that are used to  
22 make it so that when, for example, someone similar  
23 to Marsha may have a need, that SSP comes up there  
24 and has his or her time, obviously compensated in a  
25 way that 's appropriate for the profession. So it's

1 an almost entirely pure personnel cost.

2 REPRESENTATIVE DUSH: And \$250,000, is  
3 that going to cover the entire Commonwealth?

4 That's what I was getting at. I think  
5 that needs clarification.

6 REPRESENTATIVE MILLER: I appreciate the  
7 question, Representative.

8 From my information, I do think it takes  
9 us into a variety of some other questions with it.  
10 Listen, the SSP profession itself is rather new and  
11 we are still trying to establish what is an  
12 appropriate level of reimbursement for their key  
13 services. One could say that in the relatively near  
14 future, at some time when Act 139, perhaps, is  
15 further flushed out, that we could come back here  
16 and say, here's the issue of what we're finding  
17 regarding having personnel available to provide  
18 those key services.

19 There's also the chance that, as the good  
20 Representative had mentioned regarding some access  
21 questions, that as more and more work is done, we  
22 will hopefully -- I would admit to you that it is my  
23 goal that everyone who is in this Commonwealth who  
24 would qualify for these services has access to them.  
25 So there is the chance that, whether it be, you know



1 in a year or three years, that our numbers will come  
2 back and say, we have identified hopefully everyone  
3 in the Commonwealth, and instead of \$250,000, it's  
4 \$310,000.

5 But somewhere in that ballpark, I expect  
6 both of those questions are ripe. They are things  
7 that we should keep in mind. And I think that more  
8 information will come as hopefully this gets  
9 cemented into law.

10 REPRESENTATIVE DUSH: Thank you. I  
11 agree. It's excellent bang for the buck.

12 Again, I want to applaud you folks  
13 because, far too often, as was testified to earlier,  
14 people do tend to withdraw from people with  
15 disabilities. When you take the time to get to know  
16 them, and if you are out there doing the things that  
17 you're doing and involved in the way that you are,  
18 those barriers are going to start dropping. I  
19 applaud you for what you've done.

20 MAJORITY CHAIRMAN DiGIROLAMO:  
21 Representative Nelson.

22 REPRESENTATIVE NELSON: Thank you,  
23 Mr. Chairman. Thank you, Representative Miller, for  
24 helping to set this stage.

25 Looking forward -- and again, I'm in a

1 semi-rural area -- I recognize the challenge that  
2 five hours a month creates in a  
3 seven-day-a-week-24-hour-a-day life.

4 How is this program -- or is there an  
5 opportunity for this program -- to connect with  
6 other church and volunteer organizations to be able  
7 to, you know, really cast a broader net, to reach  
8 areas like ours that, you know, whether it's from  
9 the grass cutting or the, you know, is there an  
10 effort to be able to build on, you know, the good  
11 faith that's existing in our communities to help  
12 increase awareness?

13 How do we achieve economy of scale by  
14 maintaining, you know, a budget?

15 REPRESENTATIVE MILLER: My first  
16 suggestion would be for a quick moment from Marsha  
17 regarding those questions, Representative.

18 MS. DRENTH: Thank you again.

19 Yes, you're very correct in the sense  
20 that deafblind folks have many needs that all  
21 individuals have. And when I bring a deafblind  
22 individual into the program, I sit down with them.  
23 I have a one-on-one chat with them about, not only  
24 support service providers, but other resources and  
25 things that are in their community. And if that is

1 something that they need help with, especially with  
2 transportation and other services, then a lot of  
3 times what happens is, that once they begin to use  
4 an SSP, then they are connected with other  
5 resources, not only just through myself, but other  
6 folks in that community. Because again, that SSP is  
7 in that community and they know the resources.

8 I take support service providers and I  
9 train them, that have already been in the community,  
10 that have already worked with the folks that are  
11 deafblind, blind and deaf. And so they are  
12 sometimes familiar with the resources. In some  
13 cases, they are not, so I can pass along that  
14 information, you know, whether it be for technology,  
15 which is moving at a very fast pace.

16 So that is something that is absolutely  
17 in the scope of my knowledge base. I don't know  
18 about every single resource in every single county,  
19 but I try very hard to work so that all consumers  
20 have access to everything. So if they were to  
21 present me with a need, I could definitely go the  
22 mile for them.

23 MR. EARLE: Mr. Chairman, if I could just  
24 add to that question about sort of connecting people  
25 with disabilities with services, that's one of the

1 primary, or what we call core functions, of Centers  
2 for Independent Living. They are, whether they're  
3 funded by the State or are Federal counterparts like  
4 Liberty, we are specifically funded to provide five  
5 core services, one of which includes information and  
6 referral.

7           So an individual who is deafblind, who  
8 begins to participate in an SSP program, will often,  
9 as Marsha mentioned, be connected to other aspects  
10 of the Center for Independent Living, skills  
11 training, learning to ride the public transportation  
12 system in their area or rural transportation options  
13 in rural areas, English as a second language, ASL,  
14 many skills training options.

15           So it really, as the title of these  
16 operations, Center for Independent Living, really  
17 provides the resources and staff. Of course, we  
18 face financial challenges and the growing need in  
19 Pennsylvania, as more people grow older, with  
20 age-related disabilities, including macular  
21 degeneration and hearing loss, the need for these  
22 programs is just going to continue to grow.

23           We are fortunate to have a Commonwealth  
24 that is taking the proactive steps, like this  
25 amendment, to really move that process forward.

1                   REPRESENTATIVE NELSON: Thank you.

2                   REPRESENTATIVE MURT: Yes.

3                   MR. DENOTARIS: Chairman DiGirolamo, this  
4 is David DeNotaris. I would like to also, just to  
5 piggyback on that, one of the things that was  
6 provided to you today is a copy of the OVR Annual  
7 Report. In the back of that Annual Report, there  
8 are a lot of interesting programs in there that,  
9 certainly, I think you and certainly your  
10 constituents would like to be aware of.

11                   But in the back of the Annual Report is a  
12 list of all of our 21 district offices. If that  
13 would be of use for people to make sure that they're  
14 connected, I wanted to bring that resource to your  
15 attention, as well.

16                   REPRESENTATIVE MURT: Thank you.

17                   Are there any other questions from any of  
18 our members?

19                   Representative Quigley.

20                   REPRESENTATIVE QUIGLEY: Thank you. I  
21 just wanted to share a brief experience I had about  
22 seven or eight years ago. I conduct constituent  
23 breakfasts on a regular basis, and we had been  
24 contacted by a service provider, saying that a  
25 husband and wife who were constituents of mine were

1 both deafblind and wanted to attend the constituent  
2 breakfast. So my staff and I were, you know, sort  
3 of taken aback. We had never encountered this  
4 before.

5           So we contacted a service provider, and  
6 we had to actually pay for two hours of service for  
7 them to come to the breakfast and allow this husband  
8 and wife team to participate in the breakfast. So  
9 it was a very, you know, enlightening experience for  
10 myself, my staff, as well as, and most importantly,  
11 I think, for the other constituents who were also in  
12 attendance to the breakfast, because I think what,  
13 you know, Representative Miller is trying to do is  
14 educate the rest of the Commonwealth of Pennsylvania  
15 to the need for these types of services.

16           So I appreciate his work and look forward  
17 to voting for that bill next weekend. As I said, it  
18 was a very enlightening experience for me and my  
19 staff, and again, most importantly, for the rest of  
20 the people at that breakfast and the rest of the  
21 people in the Commonwealth, that they understand the  
22 importance of providing these services to our fellow  
23 citizens.

24           Thank you.

25           REPRESENTATIVE MURT: Are there any

1 additional questions or comments?

2 Chairman Cruz, anything?

3 MINORITY CHAIRMAN CRUZ: No, not at this  
4 time.

5 REPRESENTATIVE MURT: I want to thank all  
6 of our testifiers and all of our members for  
7 attending today. As Chairman DiGirolamo mentioned,  
8 we are have having a voting meeting next week, where  
9 we will vote on some legislation that's pertaining  
10 to some of the issues, the concerns that were raised  
11 today.

12 We want to thank Representative Miller  
13 for his work on those issues. If there are no other  
14 questions, we will adjourn today's meeting.

15 Thank you.

16 (Whereupon, the hearing concluded at  
17 10:21 a.m.)

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CERTIFICATE

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.

*Tracy L. Markle*-----

Tracy L. Markle,  
Court Reporter/Notary