

HUMAN SERVICES COMMITTEE

HOUSE OF REPRESENTATIVES
COMMONWEALTH OF PENNSYLVANIA

PUBLIC HEARING ON SERVICES AND ISSUES FOR
INDIVIDUALS WITH AUTISM

Public Hearing held at SPIN, Inc.,
Norcom Community Center, 10980 Norcom Road,
Philadelphia, Pennsylvania, held on Thursday, May 21,
2015, commencing at 10:00 a.m., before Joanne Rose, a
Registered Professional Reporter, Registered Merit
Reporter, Certified Realtime Reporter and Notary
Public.

APPEARANCES:

Chair Gene DiGirolamo

Representative Craig T. Staats

Representative Thomas P. Murt

Representative David H. Zimmerman

Representative Leslie Acosta

Representative Michael J. Driscoll

Representative Martina White

Representative John Sabatina

Valerie Barowsky, Research Analyst,

Human Services Committee

INDEX OF SPEAKERS

BY MS. McHALE	4
BY MS. WALL	10
BY MS. SHEA	24
BY MS. KAPLAN	30
BY MR. JUNOD	35
BY MS. McHALE	44
BY MS. BAROL	51
BY JJ COSTELLO	58
BY MS. COSTELLO	58
BY MS. CLARKE	65
BY MS. WALL	71
BY MS. TOWNSEND	81
BY DR. HUREWITZ	83
BY MS. WALL	88
BY MS. BAROL	93
BY MS. WALL	94

1 REPRESENTATIVE DiGIROLAMO: Good
2 morning. If I can get everybody's attention and ask
3 everyone to find a seat, we'll get this hearing
4 underway.

5 And, again, welcome to the hearing of
6 the Human Services Committee and, as we always do, I
7 would ask everyone to stand for Pledge of Allegiance
8 to the flag.

9 (Pledge of Allegiance)

10 REPRESENTATIVE DiGIROLAMO: Welcome to
11 SPIN and welcome to this public hearing. I think it's
12 an extremely important issue. And to start out I
13 might just let the members of the Committee just say
14 hello. I'll let you know who they are and where they
15 come from.

16 I'm State Representative Gene
17 DiGiolamo. I'm from the 18th Legislative District in
18 Bucks County and the Republican chairman of the
19 Committee. Craig?

20 REPRESENTATIVE STAATS: Good morning.
21 My name is Craig Staats and I represent the 145th
22 District, which is in Upper Bucks County.

23 REPRESENTATIVE MURT: Representative Tom
24 Murt. I represent part of Northeast Philadelphia and
25 part of Montgomery County.

1 REPRESENTATIVE WHITE: I'm State
2 Representative Martina White. I represent the 170th
3 Legislative District, which encompasses Northeast
4 Philadelphia, neighborhoods of Somerton, Bustleton,
5 and Parkwood.

6 REPRESENTATIVE ZIMMERMAN: I'm
7 Representative David Zimmerman representing the 99th
8 District, which is in the northeast part of Lancaster
9 County and New Holland, that area.

10 REPRESENTATIVE DiGIROLAMO: Okay. With
11 that I'd like to ask Kathy Brown McHale, who is
12 president and CEO of SPIN, to come up to the table and
13 maybe just give us a welcoming, a few opening and
14 welcoming remarks.

15 MS. McHALE: Hi. Good morning,
16 everybody. I just wanted to take the opportunity to
17 thank the Human Services Committee today for coming
18 out to SPIN and all of our distinguished guests in the
19 audience today for coming today as we shine a
20 spotlight on the serious issues of autism services and
21 the gaps in services in Pennsylvania.

22 And I thank you all for being here and
23 welcome to SPIN and our award-winning Norcom Community
24 Center. Hope to have a good hearing.

25 REPRESENTATIVE DiGIROLAMO: Okay, Kathy.

1 Thank you. Just a few brief remarks. Today's hearing
2 is about services with individuals who have autism,
3 and I think we've got a pretty good system in place in
4 Pennsylvania.

5 I think they do really, really good work
6 and provide an awful lot of services, but there are
7 also -- as we hear from around the state, there are
8 also many challenges that we're going to have, not
9 only today but moving forward in the future. And
10 that's why we're here today, to get an idea of what
11 some of those challenges are and how we can better
12 improve the system.

13 So, again, welcome to everybody. Just a
14 couple ground rules. We are being televised so we're
15 on camera. I'm not sure if PCN is going to pick us
16 up, but they very well might pick it up.

17 Also, we have a lot of testifiers today.
18 I thought the way we might do this, we have to be
19 finished by 12 o'clock. So I thought we'd let all the
20 people testify first. And then if they would please
21 stick around and then afterwards if we have some time,
22 which we should, before 12 o'clock, we might ask them
23 to come up and answer a few questions. Okay?

24 With that, I'm going to introduce first
25 my good friend Representative Tom Murt, who is going

1 to make a brief presentation on one of his initiatives
2 with the Legislative Budget Finance Committee.

3 REPRESENTATIVE MURT: Thank you,
4 Mr. Chairman, and thank you to SPIN for having us here
5 today. SPIN just does an outstanding job serving the
6 communities here in Northeast Philadelphia. And we're
7 just so lucky to have you here with this important
8 mission. So thank you.

9 One of the things that we have restarted
10 this session is the Intellectual Disabilities Caucus.

11 And we have combined the former Autism
12 Caucus with the Intellectual Disabilities Caucus
13 because many of the members in the House were actually
14 members of both caucuses, so we thought that we would
15 have some synergy by bringing the two groups together
16 and we have.

17 My colleague from Pittsburgh,
18 Representative Dan Miller, is very committed to this
19 mission and he has really done some really great work
20 with leadership thus far.

21 There is a House resolution on which we
22 are working right now. It's House Resolution 183.
23 And I just wanted to give you a little bit of
24 background about this house resolution.

25 At the present time we have 22

1 co-sponsors and that's significant because it's a very
2 bipartisan mix. But essentially the resolution is to
3 manifest and we're preparing to reintroduce House
4 Resolution 948 from last session, which directs the
5 Legislative Budget and Finance Committee to conduct a
6 survey of the current programs for adults with Autism
7 Spectrum Disorders to receive assistance with housing,
8 employment, transportation, financial management, and
9 health care.

10 And under current law there are two
11 programs for which autism or adults with Autism
12 Spectrum Disorders may qualify. That's the Adult
13 Community Autism Program and the Adult Autism Waiver.

14 And current data from our Department of
15 Human Services indicates that these programs are not
16 adequate. We know that. They are not adequate to
17 serve the large and growing numbers of adults with
18 Autism Spectrum Disorders across the Commonwealth of
19 Pennsylvania.

20 And just to give you a sense of what
21 we're talking about, by the year 2020 there will be
22 more than 36,000 adults, 36,000 adults with Autism
23 Spectrum Disorders. And in the fiscal year of
24 2014-2015 we had an estimated 518 slots. That's
25 5-1-8. That's how grossly underfunded this mission

1 is. And there are 146 slots for the Adult Community
2 Autism Program that were available.

3 So we really want to step up and we
4 really want to know what we're up against in terms of
5 the funding that's required to properly support this
6 mission, this program.

7 The process to qualify and receive
8 services through these waivers differs substantially
9 from the process to qualify and receive services
10 through the Intellectual Disability Waivers, creating
11 confusion and a lack of fair and consistent rules to
12 qualify for services.

13 Therefore, we are asking for an
14 evaluation of data from the Department of Education on
15 current students who will be future adults with Autism
16 Spectrum Disorders and for the Department of Human
17 Services to assess their own data on current and
18 future members of adults with Autism Spectrum
19 Disorders, including sources of this data which have
20 been excluded from past counts, and then to issue a
21 report on the plan to provide home and community-based
22 support and services to these individuals.

23 Last session, Representative DiGirolamo
24 was kind enough to pass this resolution out of the
25 Human Services Committee and we are hoping and we're

1 pretty confident we can do it again this session and
2 get it onto the floor.

3 But essentially what we really want to
4 know, we want to know what we're up against. We want
5 to know how many individuals we're talking about and
6 then we want to move ahead and to properly fund this.

7 One of the things that we're excited
8 about, you hear about the Marcellus Shale, all that
9 natural gas we have upstate. And there have been some
10 proposals to place tax on the extraction of that gas,
11 which some of us support, some of us don't.

12 But we are hopeful that some of the
13 funding that will be generated through that tax will
14 go to human services that will go for this mission.
15 So that is a cause for optimism and hope.

16 So, Mr. Chairman, thank you very much
17 for your leadership and your support on this agenda.
18 Thank you.

19 REPRESENTATIVE DiGIROLAMO: Thank you,
20 Tom. I want to recognize there's a group of students
21 here, I think, from Drexel University, nursing
22 students. So I want to welcome them. Good to see
23 you. Good to have you here.

24 And with that I'm going to introduce our
25 first testifier, Nina, Nina Wall, who is a director

1 for the Bureau of Autism Services in the Department of
2 Human Services.

3 And how nice it is to say Department of
4 Human Services, instead of the Department of Public
5 Welfare. And we have my good friend Representative
6 Murt to thank for that, for passing the legislation
7 the last session.

8 Nina, welcome. You can begin whenever
9 you're ready.

10 MS. WALL: Thank you so much. And it is
11 really a great pleasure to be here today and I want
12 to, of course, thank our host, SPIN, for bringing us
13 all together for this hearing.

14 And I'm certainly delighted to be here
15 with all of you today. So good morning, Chairman
16 DiGirolamo, Chairman Cruz, Committee Members and
17 Staff.

18 I am Nina Wall and I serve as the
19 director of Pennsylvania's Bureau of Autism Services,
20 which is housed in the Office of Developmental
21 Programs in the Department of Human Services.

22 The Bureau of Autism Services was
23 officially established in 2007, based on one of the
24 central recommendations of the Pennsylvania Autism
25 Task Force. This task force, comprised of 300

1 stakeholders, came together in 2003 to deliberate over
2 a mission, which was two-fold.

3 First, the task force had to identify
4 the gaps in Pennsylvania's autism service system.
5 Second, the task force needed to prioritize concrete
6 recommendations that would address these gaps and
7 spark efforts to build a system of care responsive to
8 the challenges faced by Pennsylvanians living with
9 autism.

10 The task force's recommendations both
11 accurately reflected the priorities and the hopes of
12 the autism community as well as established the
13 framework for discussions about autism at the national
14 level.

15 In essence, the work of the Pennsylvania
16 Autism Task Force became the national blueprint for
17 autism services. Autism, also referred to as Autism
18 Spectrum Disorder or ASD, is a complex, life-long,
19 brain-based neurological condition that involves
20 difficulties in social communication and behavioral
21 development.

22 It is a spectrum disorder, which means
23 that individuals are diagnosed sometimes with a wide
24 array of challenges. Many individuals with autism
25 have co-occurring intellectual disability.

1 In fact, thousands of individuals with
2 ASD are currently being served in our intellectual
3 disability system. Other individuals with autism
4 present with average to above average intellectual
5 ability but still may experience many of the social
6 and communication difficulties that, unsupported,
7 profoundly affect their ability to successfully live
8 in the community.

9 Along that continuum are individuals who
10 experience a wide array of trials. While ASD is not a
11 mental illness, it's important to remember that there
12 are individuals with autism who also experience mental
13 health challenges, as well as physical health
14 challenges.

15 Most, if not all, individuals with
16 autism require some level of support to address their
17 complex needs. Current research on the etiology of
18 autism tells us that it is a condition that an
19 individual is born with. It is not acquired.

20 While some individuals can make
21 tremendous gains, individuals do not outgrow autism.
22 Autism is optimally diagnosed before a child's third
23 birthday, but there are many individuals with autism
24 who are not diagnosed until adulthood.

25 It's important to emphasize that when an

1 individual's diagnosis is inaccurate or missed
2 entirely, that individual loses access to the benefits
3 of early and appropriate intervention. Experts are in
4 complete agreement that early and intensive
5 intervention is closely correlated with better
6 outcomes.

7 Though ASD is a life-long disability,
8 the introduction of evidence-based supports provided
9 by well-trained professionals have helped many
10 individuals make substantive progress, even well into
11 adulthood.

12 Last month was Autism Awareness Month
13 and it was created to raise awareness about the
14 disorder. While it is heartening to see attention
15 focused on individuals living with ASD, it is
16 disturbing that nationally there is still a minimal
17 focus on the needs of adults with autism.

18 People fail to make the connection that
19 children with autism become adolescents with autism,
20 young adults with autism, and then finally mature into
21 senior citizens living with autism.

22 As we consider the challenges ahead of
23 us in Pennsylvania, and indeed nationally, we cannot
24 forget that we spend 75 percent of our lives as
25 adults.

1 The Pennsylvania Autism Task Force had
2 great foresight and great vision when it directed us
3 to focus our priorities on the developments and
4 implementation of service models specifically designed
5 to address the unique needs of adult Pennsylvanians
6 living with autism.

7 When we began mapping out a plan for an
8 adult autism service model, we were keenly aware that
9 we were the first state attempting to do so. It was
10 both a tremendous challenge but also a tremendous
11 opportunity.

12 In 2003 when the Autism Task Force began
13 its most important work, there was emergent
14 understanding and information on how best to support
15 children with autism but minimal understanding of how
16 best to support adults with autism and models designed
17 to address their unique needs.

18 The Adult Autism Waiver and the Adult
19 Community Autism Program are models that were
20 developed by Bureau of Autism Services staff at DHS
21 and were approved by the Centers for Medicare and
22 Medicaid Services in 2008.

23 They are the first of their kind. Both
24 models were designed to meet the unique needs of
25 adults with autism with and without an intellectual

1 disability across the lifespan.

2 Both models were informed by a vision
3 that rested strongly on an assumption that all
4 individuals with autism are unique but can benefit
5 from supports based on assessment, measured by
6 outcomes, and provided by professionals who are
7 appropriately trained to understand and meet the
8 unique needs of this population.

9 Moving into our seventh year of
10 administering these two programs, we have seen some
11 impressive successes with our program participants.
12 But we are acutely aware that there is still much to
13 learn about how to respond to the very complex and
14 heterogeneous needs of an adult autism population.

15 We have drawn from our experiences of
16 providing services to create programs responsive to
17 the needs of the adults we serve, but we must continue
18 to ensure that our programs are adaptable to the new
19 knowledge we acquire from working with this community.

20 The Adult Autism Waiver is a 1915(c)
21 Home and Community-Based waiver designed to provide
22 long-term services and supports for community living,
23 tailored to the specific needs of adults with ASD.

24 Priority is given to adults not
25 receiving ongoing state or federally funded services.

1 Additionally, the Adult Autism Waiver is available
2 statewide and provides participants with the choice of
3 an enrolled provider for each service.

4 The Adult Community Autism Program or
5 ACAP is not a waiver. It's a managed care program
6 that offers an integrated model of care. ACAP is
7 currently available in four counties and serves 146
8 adults with ASD. It's administered by Keystone Autism
9 Services and offers a network of coordinated autism
10 specific services.

11 The Commonwealth makes a capitated
12 payment to Keystone, which is responsible for
13 developing a comprehensive and integrated provider
14 network that includes HCBS supports, as well as a
15 participant's primary medical and dental care.

16 The Adult Autism Waiver and ACAP were
17 developed with a focus on providing the necessary
18 supports to allow individuals with autism to
19 experience greater levels in independence.

20 These supports promote and emphasize
21 securing and maintaining employment and are structured
22 with an emphasis on meaningful community inclusion.
23 We have designed supports and person-centered services
24 to be informed by assessment.

25 When the system is not responsive to the

1 needs of individuals with autism, the resulting
2 outcomes may include protracted crisis
3 hospitalizations, overuse of physical and chemical
4 restraint, negative interactions with law enforcement,
5 and increased levels of family and caregiver stress.

6 Our programs have the challenging task
7 of providing appropriate assistance to a highly varied
8 and diverse population. The nature of the supports an
9 individual might require at the age of 21 are vastly
10 different from someone's needs perhaps at the age of
11 40 and at the age of 80.

12 In addition to understanding the unique
13 individual strengths and challenges for our program
14 participants, we must be equally vigilant in
15 understanding the needs that reflect developmental
16 changes and challenges across the lifespan.

17 Each person with autism is unique from
18 all others. An understanding encapsulated in the
19 frequently quoted statement, and many of you may have
20 heard this, "When you've met one person living with
21 autism, you've met one person living with autism."

22 From our work we have come to appreciate
23 that it is also accurate to say, "When you've met one
24 family of a person living with autism, you've met one
25 family of a person living with autism."

1 It is not possible to effectively
2 support our program participants in isolation from his
3 or her family or caregiver. Many parents,
4 grandparents, and siblings have served as their family
5 member's primary case manager and support and often
6 have a great deal of understandable anxiety, fear, and
7 concern about the future well-being of their loved
8 one.

9 Interacting compassionately and
10 responsibly with our program participants' family
11 members is critical in helping the individuals we
12 serve make progress towards their goals.

13 The Autism Services Education Resource
14 and Training Collaborative is central to the Bureau of
15 Autism Services' strategy to build capacity to assist
16 Pennsylvanians living with autism.

17 The ASERT Collaborative is comprised of
18 Pennsylvania universities, hospitals, medical centers
19 and private community providers. ASERT works closely
20 in partnership with the Bureau on efforts to improve
21 our adult programs.

22 It is conspicuously present in our
23 communities as the boots on the ground extension of
24 the autism bureau. ASERT's efforts are invaluable in
25 our work to design and provide resources that allow

1 the autism community access to good information and to
2 connect with resources at the state and local level.

3 Since 2009, in close partnership with
4 the bureau, ASERT has worked regionally and statewide,
5 spearheading a wide array of initiatives. ASERT has
6 focused on resource development, system-wide access,
7 training initiatives, family support, program
8 improvement, complex case consultation, and innovative
9 clinical and employment model development.

10 Through the ASERT Resource Center
11 website and local outreach efforts the ASERT
12 collaborative provides an invaluable resource to
13 individuals with autism, their families, private
14 community providers, and the community at large.

15 ASERT improves the lives of an estimated
16 40,000 individuals' families and professionals through
17 their clinical services, training and outreach
18 efforts. And their outreach continues to expand
19 significantly each year.

20 While it is always important for systems
21 to work collaboratively in order to address the
22 complex problems we are facing in the larger human
23 services discussion, going forward I'm firmly
24 convinced that there will be a need for innovative,
25 cross-systems partnerships in order to address the

1 overwhelming challenge we are seeing with the
2 exponential increase in the number of individuals with
3 autism.

4 My colleague, Dr. Lindsay Shea, will be
5 testifying today about the findings of the
6 Pennsylvania Autism Census Project and its profound
7 implications for our system.

8 Going forward, the need for cross-system
9 and cross-sector collaboration between government
10 agencies and the private sector will be foundational
11 to ensuring that we are leveraging all available
12 public and private resources.

13 We have seen that individuals with
14 autism impact every system. The Bureau of Autism
15 Services staff, and there are 38 of us statewide, is
16 often called upon to provide information and clinical
17 or technical support in every service system.

18 We routinely interact with the Office of
19 Developmental Programs' intellectual disability arm
20 and our colleagues in mental health, substance abuse,
21 child welfare, vocational rehabilitation, and
22 education.

23 Unfortunately, we have had to engage
24 with the juvenile justice and the criminal justice
25 systems as some individuals with ASD have experienced

1 some very sad, tragic, and problematic outcomes.

2 Given the influx of adults with autism
3 who are aging, we anticipate future collaboration with
4 our colleagues involved in the long-term living and
5 aging systems. Community and private sector
6 collaboration will be central to our work going
7 forward.

8 Awareness of autism in the community is
9 necessary to create a climate that promotes safe and
10 supportive inclusion of individuals with autism.

11 It will also be important to build
12 capacity and ensure that there are appropriately
13 trained clinical professionals to support the needs of
14 individuals with ASD and to emphasize to potential
15 employers that individuals with autism bring important
16 gifts, talents, and skills to the work environment.

17 Our work and strategic planning is
18 guided by data that we have gathered through the
19 Pennsylvania Autism Census Project initially reported
20 on in 2009 and updated in 2014, as well as the
21 Pennsylvania Autism Needs Assessment Project from
22 2011.

23 The original Pennsylvania Autism Census
24 Project identified nearly 20,000 Pennsylvanians with
25 autism who had impacted the Medicaid and educational

1 systems. In the 2014 Pennsylvania Autism Census
2 Update the number of children and adults in
3 Pennsylvania with autism had risen to over 55,000.

4 Data have shown that between the two
5 time points there was a 181 percent overall increase
6 in the number of individuals with autism touching our
7 service system and a 334 percent increase in adults at
8 or above the age of 21 with autism making adults the
9 fastest-growing group.

10 The findings of these studies are
11 informing service and program planning efforts. Our
12 Adult Autism Waiver is currently funded to support 518
13 adults with ASD, with capacity in the governor's
14 proposed budget to bring an additional 50 individuals
15 into the program.

16 ACAP is funded to support 146
17 individuals. There are currently 1400 individuals,
18 primarily adults and transition age youth, on the
19 interest list for the Adult Autism Waiver.

20 The adult community -- the autism
21 community in Pennsylvania, as well as nationally, is
22 facing many formidable obstacles. We are seeing an
23 exponential increase in the number of individuals with
24 autism across the lifespan who require services.

25 Programs must be designed to address the

1 very complex and fluid needs of the autism population
2 in an environment where there is very little research
3 specific to best practice to ensure good programmatic
4 outcomes for individuals with ASD.

5 The Bureau of Autism Services looks to
6 the future right now. And one of our main priorities
7 is to increase capacity in our adult programs and to
8 improve quality of services we provide.

9 The Bureau of Autism Services is right
10 now in the midst of an intensive strategic planning
11 effort focused on preparing for growth and integrating
12 what we've learned to ensure that program participants
13 achieve the best possible outcomes.

14 A key component of our planning process
15 includes gathering feedback from our program
16 participants, from their family members, our staff,
17 and from our program providers.

18 We are also engaging with adults living
19 with autism who may not be eligible for our programs
20 but who are able to offer a necessary perspective
21 regarding their needs.

22 Since the Bureau of Autism Services was
23 launched over a decade ago, and that is hard to
24 believe, we have learned to navigate and respond to
25 the significant challenges we face in our efforts to

1 build quality supports for individuals with autism and
2 those who love and support them.

3 We are indeed very fortunate to live in
4 a state that houses great autism expertise and a
5 resident autism advocacy voice. I look forward to
6 future opportunities to work with the House Human
7 Services Committee and members of the General Assembly
8 to ensure that Pennsylvania continues to lead the
9 nation in understanding and meeting the needs of
10 Pennsylvania's autism community.

11 Thank you.

12 REPRESENTATIVE DiGIROLAMO: Thank you,
13 Nina. That was terrific testimony. We hope you stick
14 around for a little bit.

15 MS. WALL: I will.

16 REPRESENTATIVE DiGIROLAMO: Next, we
17 have a panel. Next, Lindsay Shea, who is the
18 director, Eastern ASERT from Drexel University; Pam
19 Piscitelli from Drexel University, Eastern ASERT also;
20 and Katy McGinley Kaplan, who is the Director of Human
21 Services & Special Initiatives for Philadelphia City
22 Councilman Danny O'Brien.

23 Okay. We have two of the three.

24 MS. SHEA: Pam Piscitelli will not be
25 joining us. Katy will be representing the

1 Philadelphia Autism Project on her own.

2 REPRESENTATIVE DiGIROLAMO: Welcome.

3 MS. KAPLAN: Good morning.

4 REPRESENTATIVE DiGIROLAMO: And you can
5 begin whenever you're ready.

6 MS. SHEA: Can you all hear me? Good
7 morning. Thank you to Chairman DiGirolamo,
8 Representative Cruz, and the Members of the Human
9 Services Committee for drawing attention to the issue
10 of services for individuals with autism. Thank you
11 also to SPIN for hosting this event.

12 My name is Lindsay Shea and I direct the
13 ASERT Collaborative in the Eastern Region. We're
14 housed at A.J. Drexel Autism Institute at Drexel
15 University. Go Dragons.

16 The ASERT Collaborative is funded by the
17 Pennsylvania Bureau of Autism Services. You can learn
18 more about ASERT and our array of projects at
19 paautism.org.

20 I'm also fortunate to work closely with
21 Councilman O'Brien and his team on his initiative, the
22 Philadelphia Autism Project. This morning I'm going
23 to focus on my work through those initiatives to
24 describe the service needs of individuals with autism
25 in Pennsylvania and in Philadelphia.

1 Through the Pennsylvania Autism Census,
2 a hallmark ASERT project, we use data from multiple
3 systems to identify where people with autism are
4 receiving services and how those services are changing
5 over time.

6 This strategy helps to predict where
7 services will be needed in the future and to find
8 points where the systems could and should talk to each
9 other.

10 The autism prevalence in Philadelphia
11 and Pennsylvania, as Nina indicated, is reflective of
12 the increasing autism prevalence seen across the
13 United States. Through the Commonwealth the number of
14 people with autism receiving services has tripled
15 since 2005.

16 This indicates that more and more people
17 with autism need and are using services. And we can
18 expect that total number to continue to grow.

19 The data from the Pennsylvania Autism
20 Census extensively captures the experiences of
21 adolescents with autism as they transition into
22 adulthood and uses data from Medicaid, education,
23 vocational rehabilitation, child welfare and justice
24 systems in Pennsylvania to be the first effort of its
25 kind in the U.S. to capture all these groups across

1 rural, urban, underserved, and underrepresented
2 communities in every corner of the Commonwealth.

3 During the transition to adulthood,
4 approximately half of adolescents with autism are
5 likely to be diagnosed with ADHD, behavioral or
6 conduct disorder, or an anxiety disorder or
7 depression.

8 These additional diagnoses increase the
9 importance of understanding how to support adolescents
10 with autism to determine their needs and identify a
11 service team of supports specially during the critical
12 transition into adulthood.

13 The autism life care model and new
14 service approach through the ASERT Collaborative
15 considers exactly those needs and will roll out in
16 Philadelphia and other areas of the Commonwealth in
17 the 2015-2016 project year.

18 Pennsylvania Autism Census also found
19 that one in 10, about 8 percent, of adolescents and
20 adults with autism receiving services through the
21 Pennsylvania Office of Vocational Rehabilitation
22 successfully gained employment.

23 Employment is a critically important
24 component of the transition into adulthood, but the
25 specific communication and social support needs of

1 adolescents with autism require creative and
2 thoughtful approaches to helping adolescents with
3 autism gain and maintain the employment that helps
4 them succeed more independently in their communities.

5 To bolster this effort the ASERT
6 Collaborative and the Philadelphia Autism Project are
7 proud to be partnering with SPIN and CIS to generate a
8 best practices employment training for direct care
9 staff, providing services to individuals with autism.

10 Interactions with the justice system
11 through the Pennsylvania Autism Census Project, we
12 found also a spike during the transition into
13 adulthood, particularly among 15- to 18-year-olds.

14 From 2005 to 2011 the number of
15 pre-adjudicated charges for this group jumped from 436
16 to over 2500. And it's important to know that this
17 number is likely an underestimate.

18 In a statewide survey, justice system
19 personnel most commonly asked for tools on
20 communicating and interacting with individuals with
21 autism. The ASERT Collaborative and the Philadelphia
22 Autism Project use those survey results to provide
23 training of justice system personnel in the police
24 department, probation, parole, corrections, detention,
25 judge and court systems. And these trainings will

1 continue.

2 We're also working with the Philadelphia
3 Municipal Court to consider diversionary strategies
4 and programs. In both Pennsylvania and Philadelphia,
5 the Pennsylvania Autism Census found that adults with
6 autism were the fastest growing group.

7 Although historically there's been a
8 large focus on children with autism, those children
9 with autism, as Nina also said, grow into adults and
10 seniors with autism who have behavioral health and
11 physical health needs.

12 Adults with autism can flourish in
13 communities with appropriate services and supports
14 that are based on those needs. In fact, Pennsylvania
15 is home to two of the only programs for adults and
16 among the first programs for adults with autism, the
17 Adult Community Autism Program, or ACAP, and the Adult
18 Autism Waiver, which were developed and are run by the
19 Pennsylvania Bureau of Autism Services.

20 However, the current Pennsylvania budget
21 proposes only one slot for adults with autism for
22 every 43 slots for adults with intellectual
23 disability.

24 Adults with autism who lack the services
25 they need are less supported to succeed in their

1 communities and more prone to crises that traumatize
2 them and their families and are costly to systems.

3 Pennsylvania and Philadelphia are home
4 to unique and innovative initiatives that help
5 generate, replicate, and implement successful models
6 of supporting individuals with autism across lifespan,
7 in particular using data to identify how those models
8 can be most successful, efficient, and effective.

9 I encourage you all to visit
10 paautism.org to learn more about the ASERT
11 Collaborative and about the Pennsylvania Autism Census
12 with a clickable map by county to learn more about how
13 autism has grown in your backyard and
14 phillyautismproject.org to learn about the
15 Philadelphia Autism Project. Thank you for your time.

16 REPRESENTATIVE DiGIROLAMO: Thank you,
17 Lindsay.

18 MS. KAPLAN: Good morning. I would like
19 to thank Chairman DiGirolamo and Chairman Cruz and the
20 members of the Committee for holding this hearing on
21 services and issues for individuals with autism.

22 I'd also like to thank my colleagues at
23 SPIN for hosting us today. My name is Katy Kaplan and
24 I'm the Director of Human Services and Special
25 Initiatives for Councilman-At-Large Dennis O'Brien,

1 who I know you guys know pretty well.

2 I'm going to briefly talk about
3 Councilman O'Brien's initiatives for the Philadelphia
4 Autism Project.

5 The Philadelphia Autism Project was
6 designed to create an inclusive process that relied
7 upon self-advocates, family members, policy makers,
8 researchers, service providers, and other key
9 stakeholders to design a more effective, efficient,
10 and comprehensive system of care for individuals
11 living with autism and their families in Philadelphia.

12 Councilman O'Brien worked hard to
13 assemble a select, diverse, and powerful leadership
14 team and charged them with formalizing the project's
15 blueprint in early 2014.

16 Over the course of three day-long
17 meetings, stakeholders mapped out the current system
18 noting strengths, areas needing improvement, gaps in
19 services, and then they used this to generate a
20 comprehensive list of 119 initiatives that, if
21 implemented, will dramatically improve the quality of
22 life for individuals living with autism.

23 In January 2015 the final report, which
24 I brought with me so I have copies for you, the final
25 report was published providing a strategic plan for

1 how to improve services and supports in Philadelphia
2 and implementation of initiatives began immediately.

3 So just to give you a quick snapshot of
4 something we've been working on since the report has
5 been published, using input from stakeholders'
6 recommendations for top priorities. So stakeholders
7 actually voted at the final meeting on what they
8 thought were the most important priorities for us to
9 begin implementation.

10 So from this we created an electronic
11 hub that Lindsay mentioned, phillyautismproject.org,
12 that will include connections to all things Philly and
13 autism. It's also housed on the ASERT website, so
14 that visitors can easily connect to many state
15 resources available.

16 Lindsay had mentioned a clickable map
17 and the Philadelphia Autism Project site currently has
18 a map of Philadelphia where constituents can click on
19 their region in Philadelphia to identify what support
20 groups exist and then directly link to those support
21 groups.

22 We developed a partnership with the Free
23 Library of Philadelphia to help them make their
24 libraries autism-friendly environments, so libraries
25 can serve as physical hubs providing computer access,

1 meeting space for activities, employment supports,
2 vacation opportunities, and sensory story time.

3 We've been proactively targeting
4 underserved and underrepresented groups in two ways.
5 The first is we provided seed money to organizations
6 to have projects that address unmet needs and connect
7 us to underserved communities.

8 Through this project we've already
9 connected to several organizations that were not a
10 part of the large project initially, groups like
11 Afrikaan, that's connected to West African immigrants,
12 an Asian coalition. So that's pretty exciting stuff
13 going on.

14 And we've also provided some support to
15 Karen Krivit, who is with Elwyn, on her innovative and
16 much needed video series that addresses cultural
17 barriers and roadblocks in African American and Latino
18 families.

19 This is just the beginning as we prepare
20 to enter Year 3 of this project where ongoing work
21 groups will delve into specific issues in domains such
22 as education, employment, independent living, and
23 service delivery.

24 For more information about the Philly
25 Autism Project I'll give you a copy of the final

1 report and you can also access the final report and
2 check out our website at phillyautismproject.org.

3 Thank you.

4 REPRESENTATIVE DiGIROLAMO: Thank you
5 very much. Please give my regards to my good friend
6 Councilman O'Brien.

7 MS. KAPLAN: I will. He said he, of
8 course, would have been here but he's in session right
9 now.

10 REPRESENTATIVE DiGIROLAMO: From his
11 work up in Harrisburg and his work on City Council,
12 absolutely a hero to the autism community. And please
13 tell him we all said hello.

14 MS. KAPLAN: I will definitely tell him
15 that.

16 REPRESENTATIVE DiGIROLAMO: I would like
17 to note the presence of Representative Leslie Acosta
18 from Philadelphia. Leslie, welcome.

19 REPRESENTATIVE ACOSTA: Thank you.

20 REPRESENTATIVE DiGIROLAMO: Next, we
21 have a family panel, Jack, Maria, and John Junod. And
22 if they're here and would come forward. And their
23 topic for today is going to be what happens when a
24 person graduates with no services.

25 And before you begin, I would like to

1 recognize Representative and Senator-Elect John
2 Sabatina, who is with us today. We are presently in
3 your district, your House Legislative District, and
4 also your Senate District. Right, John?

5 REPRESENTATIVE SABATINA: Yes, sir.

6 REPRESENTATIVE DiGIROLAMO: He just got
7 elected this past week and is going over to the
8 Senate.

9 REPRESENTATIVE SABATINA: Thank you.

10 REPRESENTATIVE DiGIROLAMO: There's an
11 old saying in Harrisburg when someone leaves the house
12 and goes over to the Senate, that it goes something
13 like this, that the intellectual and common sense
14 level of both body goes up.

15 In John's case I'm going to say that's
16 true for the Senate, not quite so sure for the House.

17 REPRESENTATIVE SABATINA: Thank you.

18 REPRESENTATIVE DiGIROLAMO: You're
19 welcome. Okay. Whenever you're ready.

20 MR. JUNOD: Good morning. Thank you
21 very much for giving me the opportunity to speak with
22 you here today. Please bear with me for I am not the
23 most gifted of speakers.

24 My name is Jack Junod. I'm here today
25 with my wife Maria, our daughter Britney and our son

1 John. I also thought I saw my father here, Jack.

2 We have lived here in the Northeast our
3 entire lives. Maria is a registered nurse. Britney
4 is a special education teacher, and I work at the
5 First Judicial District of Pennsylvania for Judge Ida
6 Chen.

7 Our son John is 20 and he's on his whole
8 autistic spectrum. From birth John was a typical,
9 healthy, happy child, always smiling with his curly
10 blonde hair and crystal blue eyes.

11 At about two years of age we noticed a
12 lack of eye contact. He would start running around in
13 circles, flapping his arms and talking in a sing-song
14 type of language. We just went with it, thinking,
15 hey, he was just happy. He didn't have a care in the
16 world.

17 Two years later we signed him up for
18 pre-care -- pre-K right here at SPIN. He was at SPIN.
19 It was at SPIN that our lives changed forever.

20 There was a teacher here named Diana
21 Constance. She noticed John would not interact with
22 other children. He preferred singular play. He had
23 difficulty focusing and his eye contact with others
24 was poor.

25 He was also becoming increasingly

1 sensitive to certain sounds and smells. She thought
2 he should see a developmental pediatrician. Her
3 suspicions were that he had autism. We were taken
4 back but, surprising, we remained calm. I guess that
5 is just our family makeup.

6 I knew at that time our State
7 Representative Dennis O'Brien was heavily involved in
8 the autism movement. He helped us expedite an
9 appointment at St. Christopher's with Dr. Beth
10 Parrish. This only took a matter of weeks, not
11 months. Thank you, Denny.

12 After a lengthy battery of tests, John
13 was indeed diagnosed with autism, more specifically
14 PDD (NOS), formerly known as Pervasive Development
15 Disorder (Not Otherwise Specified). I'm still trying
16 to figure out what that means.

17 With SPIN he started to receive speech
18 and occupational therapy to help him prepare for his
19 next phase of his life. The next stop, Philadelphia
20 Academy Charter School and formerly known as PACS,
21 where John was fortunately accepted.

22 This was our miracle. This is a great
23 school and has placed great emphasis on children with
24 special needs. John was nervous transitioning into a
25 new environment, but the staff at PACS just adored him

1 and soon enough John loved going to school.

2 But John had a hard time focusing in a
3 structured environment and it was quite difficult for
4 him to stay on task. We'd have session after session
5 of IEP meetings to help all of us game plan for John.

6 The special education coordinator, Kathy
7 Adams, suggested we apply for services through the
8 state so we could get additional help through
9 independent agencies to help better serve John's
10 needs.

11 After jumping through a series of hoops
12 and filling out tons of paperwork, which made doing
13 our taxes look like a walk in the park, John was
14 thankfully granted medical assistance through
15 Department of Public Welfare.

16 Next was finding a behavioral health
17 organization who would best fit John's needs. We went
18 through agency after agency until we finally
19 discovered the Green Tree School. What a godsend.

20 This organization provided terrific
21 outpatient services for children with autism. John
22 was now in third grade and he was receiving
23 occupational speech services through PACS.

24 He was also receiving full-time TSS,
25 therapeutic staff support services, from an

1 outstanding therapist named Erin Morris and
2 psychological counseling from the all-encouraging Dr.
3 Eric Mitchell, both from Green Tree.

4 Everybody was working together as a team
5 to help John become increasingly more social with his
6 fellow students, helping him to focus on his class
7 work and stay on task. John was also receiving social
8 skills training from both the school and the folks at
9 Green Tree.

10 As a family we were so fortunate to have
11 tremendous support staff working with John and helping
12 him deal with his autism. By eighth grade John no
13 longer needed the services of Green Tree. He had
14 performed very well in scoring academically with
15 greater attention and became a little more social with
16 the full support of the school. He enjoyed going to
17 school, never missing a day, staying after school
18 receiving tutoring, helping him with his social
19 skills.

20 When a new adventure to the Philadelphia
21 Academy Charter High School began, John had some
22 difficulties transitioning. Change can be difficult
23 for people in the spectrum. This was a brand new
24 school, new teachers, students. And a whole new
25 environment can be overwhelming.

1 John struggled in both math and English
2 classes but excelled in subject areas dealing with art
3 and science. Those teachers were amazed with his
4 abilities and his interests.

5 In his junior year John was one of the
6 few students chosen to compete with the citywide
7 George Washington Carver Science Fair at Temple
8 University.

9 Senior year, graduation day. Where did
10 the time go? In a total of 13 years John only missed
11 nine days of school, whereas I probably missed that
12 many in one year.

13 John loved school and they loved having
14 him as a student. At the graduation ceremony John
15 received an outstanding student awards in both art and
16 science. He was ecstatic and we were so proud and
17 happy for him.

18 I don't know about John but on that day,
19 at that moment, I was no happier for anything more in
20 my life. We were so thankful to have Philadelphia
21 Academy Charter School in our life. The teachers and
22 staff were some of the most compassionate,
23 hard-working people we have ever known.

24 With the security blanket of
25 Philadelphia Academy no longer there, it was on to the

1 local community college. We decided as a team to have
2 John take small steps entering college.

3 We first met with the people at the
4 Center for Disabilities at the school, then the rude
5 awakening. John was now 18 and he had to advocate for
6 himself.

7 We were left out of the loop. We could
8 no longer advocate for our son. How can that be?
9 We've been doing that his entire life.

10 The people there were very nice and they
11 sat down and talked with us, mostly with John. We
12 felt like a picture on the wall, like we weren't even
13 there. And based on a one-hour interview, John's only
14 accommodations would be he was permitted to have
15 additional time to take his exams and he could bring a
16 recording device with him to class and tape the
17 professor's lectures.

18 Well, needless to say, we didn't have a
19 good feeling after that meeting. John took an
20 entrance test and I guess he didn't do well. So John
21 had to take some introductory classes in both English
22 and math.

23 It amazed me. We have a son with autism
24 and we, as his parents, are completely left out of the
25 loop. We never received his grades from his entrance

1 test, but I guess everything is online these days.
2 And our son with autism is the only one with access
3 and he has to try to struggle to figure out the
4 system. We had no clue.

5 John took two entry-level classes, pass
6 or fail, and he didn't fair well. He took them over
7 again with the same results. Here we have an
8 innocent, young man with autism, who loves school and
9 excelled in school, now struggling tremendously.
10 Eventually, he left school.

11 Consequently, now he has lost his self-
12 confidence and his self-esteem. He feels like a
13 failure and expressed that to us. The biggest hurt
14 for me, the most devastating thing I ever heard out of
15 his mouth was that he felt like he let his parents
16 down. He feels like he's a drain on his parents.

17 That should not be. John, you should
18 never, ever feel that way about yourself. You mean
19 the world to us and we are so proud of the person
20 you've become. You have overcome so much adversity.

21 So what do we do? We have a young man
22 who had all the supports to make him successful from
23 preschool through high school and with a snap of the
24 fingers it was gone. Even though John might feel like
25 this is something that just happened to him, I assure

1 you there are so many, many Johns out there who need a
2 small bridge to help them be successful after high
3 school.

4 These are bright, capable, energetic,
5 motivated young men and women who fall off the cliff
6 after high school. I urge you not to abandon them. I
7 urge you to find the public dollars and the public
8 will to build more connective systems to help these
9 young men and women to have the supports they need to
10 be successful beyond high school.

11 The alternative, that they are home
12 playing video games, losing their skills and
13 confidence, is unthinkable and unwise for the
14 Commonwealth of Pennsylvania, who has invested so much
15 in their success until age 18. Young men and women
16 like John deserve more from us.

17 Thank you for giving me an opportunity
18 to speak with you today.

19 REPRESENTATIVE DiGIROLAMO: Good job,
20 Jack. Very powerful testimony.

21 MR. JUNOD: Thank you.

22 REPRESENTATIVE DiGIROLAMO: Next up, we
23 have Kathy Brown McHale, who is the SPIN president and
24 CEO. Kathy, again, welcome. You're going to have a
25 hard time following that testimony.

1 MS. McHALE: That was powerful. And
2 it's hard to start out when you're crying, but this is
3 what we're here for. That's exactly what we are here
4 for.

5 Good morning and thank you to Co-Chairs
6 DiGirolamo and Cruz and members of the Human Services
7 Committee for focusing on the important issue of
8 autism.

9 I am Kathy Brown McHale, the President
10 and CEO of SPIN, an organization that provides
11 lifespan services and supports for people with autism
12 and people with intellectual disability.

13 It is my pleasure to welcome you, the
14 Committee, and all other guests to SPIN. My testimony
15 today is from the perspective of someone who has
16 worked in the field for 43 years and who 24 years ago
17 had a child with many of the same support needs as the
18 people I have devoted my career to.

19 We know the people: They are our sons
20 and daughters, our grandchildren, our neighbors, and
21 our friends. As we come together this morning
22 projections from the Autism Census are that there are
23 about 18,000 teens and young adults and their families
24 in Pennsylvania anticipating our ideas and hoping for
25 an action plan. By 2020 projections are there will be

1 36,000 adults living with autism in Pennsylvania.

2 We know the challenges confronting these
3 young people and their families: As we just heard,
4 leaving school with its individualized educational
5 plans and the children's behavioral health
6 environment, with the assurance of individualized
7 therapeutic approaches and emerging into a world
8 without the promise for services necessary to navigate
9 adult life's challenges and opportunities.

10 The research shows that as children
11 become adults, their needs for services do not
12 diminish and may even increase.

13 We know the potential and the
14 possibilities: Passionate, creative, young people
15 with endless possibilities and potential for involved,
16 relevant lives if they receive individualized,
17 flexible, comprehensive supports provided by qualified
18 professionals throughout their lifetime.

19 In particular, and by definition, these
20 young people cannot and do not fit into convenient
21 units of service with predetermined time units and
22 duration.

23 In fact, the story we just heard, the
24 key to young John's future in science and art, that
25 all has to be discovered with him. And we have to

1 know how to sit down with him and hear what he wants
2 for his life. The secret to his life is through his
3 passion. It's not in predetermined service units.

4 We know the parents' dreams: To see
5 services they have fought hard for throughout their
6 child's life continue beyond the age of 21 or 18,
7 hoping that their child will continue to grow from all
8 that was hard won and developed throughout their
9 childhood. Parents know that without the right
10 services and support, their child's future is lost.

11 We know what doesn't work: An
12 insufficient budget for adult autism services that
13 only serves a fraction of adults with autism in
14 Pennsylvania; a growing population of transition age
15 and young adults with autism with no promise of
16 services or even a plan; OVR programs leading to
17 employment for only 8 percent of adults with autism; a
18 limited resource of qualified professionals at all
19 levels; service definitions and models that are not
20 flexible or able to consistently meet people's
21 changing needs; rates that don't support innovative,
22 high-quality workplace settings and make good personal
23 and professional choices and decisions.

24 It's rates that don't support
25 innovative, high-quality services, rates that don't

1 support direct service staff earning at least a living
2 wage, stakeholders failing to truly collaborate on a
3 strategic plan to move us forward.

4 We know at least some of the promising
5 answers: We need to benefit from what is working and
6 add new ideas.

7 Eight years ago SPIN was funded to do a
8 pilot project with seed money from the then-emerging
9 Bureau of Autism. We developed a new approach to
10 delivering behavioral services for three-to-five-year-
11 olds in SPIN's Early Intervention Autistic Support
12 Preschool program.

13 It was created based on years of
14 experience of what wasn't working in SPIN's Autistic
15 Support preschool classes and after listening intently
16 to parents and caregivers about what their children
17 really needed.

18 After one year the outcomes from this
19 new service surpassed what was being accomplished
20 through more traditional approaches. We leveraged
21 that success and continued to work with families,
22 government, CBH, and professionals to create new
23 approaches.

24 And ultimately in 2012 SPIN and partner
25 NET was named a Philadelphia Autism Center for

1 Excellence. Services under that moniker are paid for
2 via our contract with Community Behavioral Health,
3 CBH, and private insurers via Act 62. These services
4 have continued to grow, however, are only available
5 for children up to age 21.

6 Six years ago SPIN identified a major
7 gap in service for post-high school career preparation
8 with supportive real-life interviewing, job sampling,
9 and work and social situation in rehearsing for a job.

10 We developed a career development series
11 for transitioning students and young adults with
12 autism. The program teaches effective strategies for
13 people to identify workplace social culture and
14 teaches skill development and practical learning so
15 people learn how to behave in workplace settings and
16 make good personal and professional choices and
17 decisions.

18 The program provides classroom learning,
19 simulated learning, and real world internships and
20 focuses on support and learning for each student.

21 We have partnered with Mastery, Mast and
22 other charter schools and have used the learning
23 approach with many of the people in SPIN's Residential
24 Services.

25 This program has very good outcomes.

1 Many of the students went on to become employed in
2 their internship or with other employers. Others went
3 on to community college, receiving continued support.

4 The program received a small grant from
5 the state a couple of years ago, but this is an
6 example of an innovative service that people need to
7 support their life goals that does not fit into the
8 service definitions and consequently is not available
9 to young adults that we are here to talk about today.

10 Also, several years ago a provider in
11 Harrisburg, Keystone Human Services, worked with the
12 Bureau of Autism, individuals with autism, families,
13 professionals, and others in government to create a
14 new model of service for adults with autism, which we
15 have heard about today, ACAP, the Adult Community
16 Autism Program.

17 Whether a person needs many or few
18 supports, the services and supports are totally
19 individually tailored to each person's strengths and
20 goals.

21 ACAP is a comprehensive service that
22 integrates health care, behavioral support and
23 counseling, social skills, employment and community
24 skills. Services are flexible and modified as a
25 person's needs change over time.

1 This service holds much promise but
2 currently supports only about 150 people -- as Nina
3 reported today it's 146 people -- to achieve
4 meaningful outcomes, based on their aspirations.

5 These examples demonstrate that when we
6 come together as a community, we do have the
7 resources, the experience, and skills necessary to
8 create innovative, individualized, and flexible
9 services and supports that young adults need to
10 flourish in their adulthood.

11 What we need is the urgent priority to
12 adequately fund these services for all people who need
13 them and to use a funding model that works for people.
14 A model similar to the ACAP is believed to hold a
15 great deal of promise for meeting people's needs over
16 their lifetime.

17 This model uses scarce resources
18 effectively by focusing on quality outcomes at an
19 efficient but viable per member per month rate for
20 people rather than on the delivery of specific
21 quantities of services billed by the unit.

22 However, the current proposed
23 Pennsylvania budget provides only a 1.8 percent
24 increase of \$341,000 for autism services overall,
25 which will barely maintain the current level of

1 service.

2 What is our action plan? Our
3 collaborative action plan is urgently needed. I ask
4 that we not just walk away from this morning's stories
5 feeling that we have done all we can do.

6 We must come together and establish an
7 action plan that results in our ability to answer the
8 question posed by parents, caregivers, and young
9 people with autism as they approach their 18th- or
10 21st-year birthdays.

11 "What happens next?" Let's provide good
12 answers so instead of dreading that birthday, they
13 have the hope they need to celebrate instead.

14 Thank you.

15 REPRESENTATIVE DiGIROLAMO: Thank you,
16 Kathleen. Next, we have Julia Barol, Association of
17 People Supporting EmploymentFirst, from George
18 Washington University.

19 Julia, welcome.

20 MS. BAROL: Thank you.

21 REPRESENTATIVE DiGIROLAMO: You're
22 welcome. And you can begin whenever you're ready.

23 MS. BAROL: Thank you. And I want to
24 thank you all for the opportunity to testify today.
25 My name is Julia Barol. I'm a consultant with

1 Transition Consults, LLC.

2 In my role I chair the Philadelphia
3 Transition Coordinating Council and the Philadelphia
4 Transition Work Group, a part of the Employment 1st
5 Philadelphia Initiative of Philadelphia Intellectual
6 Disability Services.

7 I serve on the Pennsylvania State
8 Leadership Team on Transition and I am president of PA
9 APSE, the Association of People Supporting
10 EmploymentFirst.

11 Since its inception 25 years ago APSE is
12 the only national organization with an exclusive focus
13 on integrated employment and career advancement
14 opportunities for individuals with disabilities. PA
15 APSE is Pennsylvania's chapter of this national
16 organization.

17 Lastly, I'm also an adjunct instructor
18 at the George Washington University's Graduate School
19 of Education and Human Development.

20 I've been asked to testify today
21 regarding issues related to supporting people with
22 autism and community-based employment with cost
23 effective and outcome driven supports.

24 I'd like to start with the scope of the
25 issue. As of the 2011 census 10,728 individuals were

1 identified with Autism Spectrum Disorder in
2 Southeastern Pennsylvania alone. A robust service
3 array is already in place for individuals with autism
4 within schools and the children's behavioral health
5 treatment system.

6 The tragedy, however, is that many of
7 these individuals will leave school and enter an adult
8 world unsupported or with much more limited supports.
9 Without appropriate services available to youth with
10 ASD, they will end up at home, sitting on a couch,
11 mindlessly clicking through the channels of the TV.

12 However, a different outcome could
13 exist. EmploymentFirst, a national movement, promotes
14 employment as the first and preferred option for all
15 individuals with disabilities, regardless of severity
16 of disability.

17 With good transition services in place
18 within schools, these young adults could graduate into
19 EmploymentFirst, working side by side with people
20 without disabilities, earning wages based on the value
21 they provide.

22 Some of them may find jobs on their own,
23 but most will need employment services and supports to
24 obtain and successfully maintain employment.

25 Since the 1980s, when many demonstration

1 projects demonstrated the efficacy of supported
2 employment programs, the field has evolved greatly.
3 Currently, person-centered supported employment and
4 customized employment are options for individuals with
5 significant disabilities, matching an individual's
6 interests, skills, and strengths with the needs of
7 businesses in the community.

8 Often jobs for individuals with
9 disabilities are developed from existing jobs and from
10 additional employer needs. A job coach or employment
11 specialist provides support generally at the work site
12 that includes hands-on training on how to do the
13 specific tasks required of the job, as well as
14 training in the soft employment skills, such as
15 appropriate workplace behaviors, communicating with
16 co-workers and supervisors and appropriate dress,
17 areas that often are difficult for individuals with
18 autism and undermine their success in the workplace.

19 The amount and length of job coach
20 support depends on the individual's skills and needs.
21 These skills are best learned on the job as learned in
22 an isolated situation, such as the classroom often
23 does not lend to generalization to other environments,
24 such as the workplace.

25 The barriers to achieving successful

1 employment outcomes are two-fold. Having access to
2 public funds sufficient to provide long-term support
3 for individuals in employment and the ability to build
4 a confident, qualified workforce to provide the
5 services needed.

6 I'd like to elaborate on these two key
7 issues. Support services, both job coaching and
8 follow-along support, are a key ingredient for
9 successful, full integration into a community
10 workplace.

11 According to the 32nd Institute on
12 Rehabilitation Issues, "The lack of extended services,
13 also called long-term support, has been identified as
14 one of the major barriers to successful employment of
15 persons with ASD.

16 "Funding cuts to state developmental
17 disabilities agencies, as well as the reduction in
18 Medicaid waivers, has restricted the ability of
19 Vocational Rehabilitation agencies to utilize
20 supported employment (for people with ASD)."

21 And this has certainly been an issue in
22 Pennsylvania. Currently, there are approximately 500
23 individuals with ASD who receive Medicaid waiver
24 funding in Pennsylvania, but many, many more could
25 benefit from these services if funding were available.

1 I urge you to expand funds to meet the
2 needs of these Pennsylvanians so that they can achieve
3 successful employment within the community.

4 A second barrier to achieving employment
5 outcomes at a high standard is a lack of highly
6 trained and qualified workforce. Currently, there are
7 no training requirements for people working in the
8 field of supported employment.

9 There is no minimum level of competency
10 expected to work as a job coach and there is little
11 opportunity to increase knowledge and competency of
12 best practices while working as a job coach due to the
13 nature of activity-based, fee-for-service
14 reimbursement for supported employment services
15 specifically for people with ASD.

16 For the field to grow and the discipline
17 to achieve improved outcomes for individuals with
18 autism working in the community, a strong focus on
19 increased professionalism of the workforce will be
20 required.

21 In order to achieve this, a rate and
22 reimbursement structure must be established that
23 supports the employment, retention, and ongoing
24 professional development of the workforce. Sufficient
25 funds are needed to offset the costs of training, to

1 offer mentoring opportunities to staff and to
2 establish an entry-level professional accreditation
3 through either ACRE, the Association of Community
4 Rehabilitation Educators, or through APSE'S CESP,
5 Certified Employment Support Professional.

6 Requiring certification will also
7 enhance the employment specialist's credibility with
8 the business community when they approach businesses
9 looking to develop relationships.

10 Accreditation assures individuals and
11 their families that they are working with a qualified,
12 trained professional who has committed themselves to
13 the best practices in the field.

14 Research and data indicate that a
15 recognized professional certification program not only
16 holds promise of promoting a more uniformly qualified,
17 stable, and competent workforce, but that it could
18 lead to increased employment outcomes for individuals
19 accessing supported employment services.

20 I urge you to work in the legislature to
21 assure that professional credentialing is supported
22 and that an adequate rate and reimbursement structure
23 is established to support the recruitment, retention,
24 and professionalization of this workforce.

25 For your reference I've attached several

1 articles on best practices from leaders in the field
2 regarding creating systems change for the support of
3 individuals with ASD. I urge you to act now to assure
4 improved community-based employment for individuals
5 with ASD.

6 Thank you very much for the opportunity
7 to speak to you today.

8 REPRESENTATIVE DiGIROLAMO: Julia, thank
9 you very much. I'd like to note the presence of
10 Representative Mike Driscoll from Philadelphia.

11 Next up we have a family, Kathy and Jim
12 Costello. Come on up to the table. And they have a
13 topic of how having the right services throughout a
14 person's lifespan can lead to good outcomes.

15 JJ COSTELLO: Good morning.

16 REPRESENTATIVE DiGIROLAMO: Good
17 morning.

18 JJ COSTELLO: Father, Son, Holy Spirit,
19 Amen. Uncle Bob died. The funeral home last day and
20 then Uncle Bob say, say prayers, Uncle Bob died.
21 Heaven, my friend, Uncle Bob.

22 REPRESENTATIVE DiGIROLAMO: Okay. For
23 Uncle Bob we'll all say a prayer.

24 MS. COSTELLO: Good morning. Good
25 morning to all of the Committee members and SPIN

1 staff. Thank you for inviting us to testify this
2 morning.

3 I will do my best not to get emotional
4 but, unfortunately, any family with a person with
5 disability, our lives are emotional and stressful at
6 times.

7 But my name is Kathy and my husband Jay
8 and I are the proud parents of JJ Costello. JJ is a
9 young man who has a diagnosis of an intellectual
10 disability and Autism Spectrum Disorder.

11 The latter diagnosis, however, was given
12 when JJ was around 18, but was something we knew in
13 our hearts to be very true early on. But back then it
14 just wasn't diagnosed as much.

15 And MR, or what we call these days as
16 ID, kind of just stuck with us. But if you have had
17 the chance, like you just did, to be a friend of JJ,
18 you will know that ASD is very much a part of his
19 being.

20 We wanted to come today, though, to
21 impress upon you how JJ's life has been positively
22 changed due to the services that he has received since
23 the age of three and a half.

24 It was not by any means an easy road.
25 But with a lot of hard work and educating ourselves

1 about the systems, JJ has grown into an amazing young
2 man.

3 As I said, at the age of three and a
4 half it was recommended to us that JJ be evaluated by
5 SPIN after being kicked out of his first daycare.
6 That day we got a call. He successfully bit every
7 child in the classroom. Why they waited for him to do
8 that is still beyond me and a whole other story but
9 that was our beginning.

10 He was evaluated and received the
11 diagnosis of MR, now intellectual disability. He
12 started receiving speech, occupational and physical
13 therapy and attending daycare here at SPIN for
14 socialization.

15 At age five we moved into the
16 Philadelphia School District and, to our dismay, JJ
17 tried two schools and just did not seem to fit in. He
18 was still basically nonverbal with strong autistic
19 tendencies but yet we still could not get that
20 diagnosis.

21 We were then advised that I should get
22 JJ registered with the City of Philadelphia as a child
23 with a disability. We were told that we would get a
24 supports coordinator to help us get more services and
25 someone to help us with finding the right placement in

1 the school district.

2 At the time we also learned of this
3 little organization called Right To Education. I
4 still have that copybook in my filing cabinet to this
5 day. It did become like a Bible to us.

6 With this support, now we found a
7 program within the school district, John Hancock
8 School, which at the time was labeled low cognitive.
9 It took a bit for us to get him in there, but we were
10 finally successful.

11 And we saw for the first time JJ
12 starting to learn and grow but, more importantly, had
13 a smile on his face instead of that look of
14 frustration and helplessness.

15 We did continue to lobby throughout the
16 years for more speech, OT, PT, and sensory integration
17 therapy up until his middle school years. Again, when
18 we were trying to find a middle school/high school to
19 fit JJ's unique needs, we needed to get support again
20 from our base service unit to help us with this.

21 We did finally choose to pull him from
22 the Philadelphia District and went on and he made
23 great progress at Our Lady of Confidence, which was
24 housed at Cardinal Dougherty High School.

25 Just when we started to breathe a

1 little, right, suddenly our happy-go-lucky son was
2 going through some emotional and behavioral changes
3 that caught us all by surprise. He became very angry,
4 aggressive towards us, but mostly Dad, and sometimes
5 just uncontrollable.

6 We now needed more help desperately. It
7 was heartbreaking for us. At this point with our
8 world upside down, we began lobbying for JJ to get the
9 consolidated waiver, truthfully, because we thought
10 what if, what if we would not be able to keep him at
11 home.

12 After countless hours of talking and
13 meeting with many people, JJ did get waiverized and
14 through therapies and meds we slowly began to see JJ
15 come back to us. Great, right? But now --

16 JJ COSTELLO: Teacher.

17 MS. COSTELLO: With teachers. There was
18 another transition as JJ was getting ready to exit
19 high school and needed to be ready for that adult
20 life. We had no idea what that was going to look
21 like.

22 Fortunately, through our base service
23 unit, or now known as Supports Coordination
24 Organization, which is Partnership for Community
25 Support, we heard about a program called the

1 Transition Planning Project administered through
2 Networks for Training and Development.

3 That program at the time was choosing
4 individuals to mentor to get them ready for life as an
5 adult. We formed a support team and started to ask
6 what it was that JJ could do but, more importantly,
7 what would he want to do with his life.

8 We again were lucky enough to get as a
9 part of that team a woman from SPIN. Her name was Pat
10 Ray and she would provide us the support part of that
11 as a part of this project.

12 I am proud to say that since that time
13 back in 2007 JJ has been working and/or volunteering
14 somewhere with SPIN employment or Home and Community
15 Habilitation Service support to this very day.

16 He is now ready to take on a new chapter
17 of his life. After much lobbying and advocating and
18 reaching out to people, we are happy to say that JJ is
19 moving into his own residential home. Our dream is
20 finally coming true.

21 He will be moving into a home supported,
22 yes, by SPIN and he will be living with two other
23 young men, Anthony and Michael, who he has grown up
24 with since the age of 6. They will be living in their
25 own neighborhood where they are active community

1 members already and will continue to be.

2 This whole successful journey would not
3 have been possible, obviously, without the services
4 and the waiver. All people with disabilities deserve
5 these rights. There is nothing worse than hearing
6 that your loved one could benefit from a service but
7 then be told, oh, you can't get that because there's
8 no funding or that you're not waiverized.

9 JJ is a true example of what can be done
10 with great services and people listening and working
11 together to provide a person with a fulfilling life
12 and then parents can have some sense of relief that
13 their loved ones will be taken care of when we are no
14 longer here to do so ourselves.

15 Planning and enacting services now will
16 avoid crisis management later when the inevitable does
17 happen. This should not, should not be a constant
18 battle. Please help us make this a reality for all.

19 Thank you.

20 REPRESENTATIVE DIGIROLAMO: Thank you,
21 Kathy, and thank you JJ.

22 JJ COSTELLO: You're welcome.

23 REPRESENTATIVE DIGIROLAMO: Our last
24 testifier this morning is Annemarie Clarke, a
25 corporate officer of Behavioral & Developmental

1 Services. Annemarie, welcome.

2 MS. CLARKE: Thank you.

3 REPRESENTATIVE DiGIROLAMO: Whenever
4 you're ready, you can begin.

5 MS. CLARKE: Good morning, co-chairs
6 DiGirolamo and Cruz and Members of the Human Services
7 Committee.

8 I am Annemarie Clark, a corporate
9 officer at SPIN. I oversee the services provided
10 through SPIN's Autism Center For Excellence as well as
11 services to adults receiving supported employment and
12 home and community habilitation, many of whom have
13 autism along with other developmental challenges.

14 Thank you for being with us today and
15 shining the spotlight on this critical issue. Thank
16 you also to our partners from the Bureau of Autism
17 Services, the Eastern Region ASERT Collaborative, the
18 Philadelphia Autism Project, and Pennsylvania APSE for
19 joining with us to highlight both the important work
20 that has already been done and the work that lies
21 ahead.

22 A special thank you to the Junod and
23 Costello families and, most particularly, to John and
24 to JJ for sharing your lives and your stories. You
25 offer us two gifts: the privilege of having

1 participated in part in your growth and development
2 and a face and a personal story to drive our urgent
3 call to action for the 18,000 and growing
4 transition-aged youth across the Commonwealth and all
5 of those who are in need of expanded services.

6 I'd like to summarize what we have
7 learned today and focus my remarks on what work lies
8 ahead. We have seen the people today. They are your
9 constituents and Pennsylvania's sons and daughters.

10 With the current incidence of autism at
11 one in 68, they are also our friends, neighbors,
12 co-workers, and Pennsylvania's future workforce. They
13 are bright, diverse, motivated and eager with
14 passionate and persistent families standing with them,
15 as you've seen clear examples of that today.

16 They possess many of the gifts and
17 talents needed in a 21st century economy and can
18 achieve independence and success within college and
19 within the community workplace with very modest
20 ongoing support needs. I urge you to work with all of
21 us to find creative solutions, supports, and services
22 to harness their gifts and talents.

23 We have also heard the challenges. As
24 the family stories today have eloquently demonstrated,
25 even in the successes there have been too many

1 challenges. There are multiple, labyrinthine systems
2 to navigate and coordinate that many of us who work
3 professionally in the field find daunting.

4 There are too many transitions from one
5 system to another with either imperfect or absent
6 bridges from systems throughout the lifespan. There
7 are too few services. There is too little funding.
8 There are too many rules and regulations and often too
9 poorly of a trained and qualified workforce to meet
10 the unique, diverse, exciting support needs of the
11 population of adults living with autism.

12 I urge you to work with all of us to
13 find creative solutions to reduce or eliminate
14 unnecessary challenges, to reduce the administrative
15 burden on parents and providers, redirecting savings
16 into innovative outcomes-focused pilot projects that
17 build on prior successes.

18 These young men and women are also
19 depending on us to establish effective rate and
20 regulation structures that allow providers to recruit,
21 retain, and develop a highly skilled and qualified
22 workforce that will meet the needs of those living
23 with autism across their lifetime.

24 They are also depending on us to
25 establish and support an entry-level credential for

1 work in the field of supported employment that will
2 allow Pennsylvania to become a national model for
3 workforce development within the field of autism
4 services, stating emphatically that work is a
5 professional, sustainable, desirable career path so
6 the turnover, due to a lack of living wage, does not
7 drain our profession of its knowledge and its
8 expertise.

9 We have heard the potential and the
10 possibilities. These stories have told us that when
11 the stars align and advocacy works and persistence
12 pays off, the possibilities are limitless.

13 But when a small bridge or a foothold is
14 missing, the cliff is deep and lonely. It shouldn't
15 be that hard or the outcomes that variable, yet our
16 stories have also told us that when the best and
17 brightest from all stakeholder groups collaborate,
18 self-advocates, families, government, academia,
19 advocates, the provider community, professional
20 societies and others, examples of which were noted
21 within the ASERT Collaborative, the Philadelphia
22 Autism Project, the APSE work groups, we see glimpses
23 of a future where innovative ideas come to fruition
24 and creative solutions are incubated and hatched.

25 Again, however, those opportunities are

1 fragile and hard fought. I urge you to nurture them
2 with expanded, flexible, funding and rate and
3 regulation structures and ongoing partnerships that
4 will grow and not stifle creative solutions, providing
5 measurable deliverable outcomes.

6 We have heard the dreams. Young adults
7 with autism can work, want to work and must work in
8 order for Pennsylvania's economy to thrive and grow.
9 Currently, through SPIN's employment services, over
10 125 adults with disabilities, 50 of whom also have
11 autism, are working.

12 On average these employees earn more
13 than \$1.50 an hour more than the minimum wage and they
14 work an average of 50 hours per month and have an
15 average tenure in their job of greater than four
16 years.

17 In the past year alone these individuals
18 have earned more than a half million dollars
19 contributing vital tax revenue into state and local
20 coffers while greatly expanding their relevance and
21 social capital within the community.

22 They're supported by a talented and a
23 vibrant group of 21 employment specialists at SPIN,
24 most of whom have been trained in best practice
25 strategy, such as customized employment, and many of

1 whom have achieved or are pursuing the professional
2 credentials spoken about earlier by Julia Barol that
3 are so vital to workforce development in our field.

4 Working together, the employees and
5 their employment specialists are a glimpse of what is
6 possible and achievable. With expanded funding for
7 transition services and schools, more of these young
8 adults would leave school working, having completed
9 successful work-based learning internships and having
10 what we all had as young adults, a first job that
11 helped us clarify and launch our futures.

12 With expanded capacity in OVR and
13 waiver-funded programs and improved, seamless linkages
14 between schools and adult services, imagine what we
15 could accomplish? I urge you to work with us to build
16 and fund those programs and bridges. It's a win-win
17 for Pennsylvania.

18 In closing I echo the comments of Kathy
19 Brown McHale and others: Now is the time to partner
20 on an action plan.

21 I urge you to work with us to make the
22 dreams of Pennsylvanians living with autism realities,
23 to make what is now too difficult for too few young
24 adults and their families less difficult for many
25 more; to establish a viable, actionable, funded plan

1 for more services and options for adults living with
2 autism so that each may achieve and enjoy a life of
3 possibilities.

4 Thank you.

5 REPRESENTATIVE DiGIROLAMO: Thank you,
6 Annemarie. That was our last testifier, so we've got
7 about a half hour for some questions. And I would
8 like to start off and I might ask, Nina, we're going
9 to put you on the spot right away.

10 MS. WALL: Okay.

11 REPRESENTATIVE DiGIROLAMO: We really
12 heard some terrific testimony today, especially from
13 the two family groups. And I have a five-year-old
14 grandson who me and my wife Donna have legal custody
15 of and he actually just this week has started some
16 testing for a possibility of having an intellectual or
17 developmental disability.

18 So I am very possibly going to be
19 experiencing some of the things that we've talked
20 about here. And from Kathy Costello and JJ, at the
21 end of her testimony, "This whole journey would not
22 have been possible obviously without the service and
23 waiver. All people with disabilities deserve these
24 rights."

25 And I absolutely agree with that. There

1 is nothing worse than hearing that your loved one
2 could benefit from a service but then be told, Oh,
3 they can't get it because there is no funding or that
4 they have not received a waiver.

5 So, I mean, we heard some good testimony
6 today. I mean, what would you want this committee to
7 hear? I mean, I know revenue and funding is really
8 important, but is that the solution and if you only
9 had more money, we could take care of some of these
10 problems that we heard about today?

11 MS. WALL: Well, it's undeniable that
12 resources are needed. I mean, I think we'd be naive
13 to say that resources aren't needed. I do think,
14 though -- certainly one of the things we've endeavored
15 to do in our work is to look at how we can use the
16 research and the knowledge that we're amassing in the
17 field and also how to support people effectively and
18 embed that into the services that we're providing so
19 that we can see better outcomes for people.

20 I think that's critically important.
21 New dollars are going to be needed, but we have to
22 look at how we're using existing dollars. I think
23 that's critically important.

24 And I'm a strong believer in looking at
25 what's happening in the field to look at which

1 approaches, which strategies are helping individuals
2 and families.

3 The other thing, and I referenced this
4 in my testimony, and I feel very strongly about this,
5 is the need to create partnerships within government
6 across program offices, across departments, but also,
7 too, with colleagues and individuals and groups and
8 partners in the private sector.

9 And I heard a lot today the reference to
10 needing a comprehensive plan. I couldn't agree more,
11 but I think that plan has to also include the
12 establishment of partnerships. I don't believe the
13 government can fix it all.

14 I think government is an essential
15 partner, but in order to deal with the magnitude of
16 what we're seeing happening right now with this
17 increase in number of individuals with autism, these
18 partnerships are going to be critical. And I think
19 with ASERT we've taken a stab internally at leveraging
20 the resources in the Commonwealth around autism.

21 We knew when we launched this work and
22 we had -- the task force was referenced and we had
23 1200 pages of report with great thinking and great
24 ideas. And at the time I think it was myself in a
25 cubicle outside then-Secretary Estelle Richman's

1 office.

2 And where do you start? What do you do
3 when the enormity of the challenge is so daunting?
4 And I realized early on, and maybe very humbly, that
5 this was going to need to be a partnership. And I
6 knew there was great expertise in the area of autism
7 around the Commonwealth.

8 There was great energy in the advocacy
9 community from families. There was great history in
10 the service system already. And we're going to need
11 to pull everybody together. So it's a partnership,
12 and it's complicated. And there isn't a single bullet
13 or answer to what is an incredibly complex challenge.

14 I'll say, though, that Pennsylvania, I
15 think, is uniquely poised because we are a state that
16 I would have to say is ten years ahead of the rest of
17 the country in recognizing that children with autism
18 become adults with autism.

19 And even though we're at the very
20 beginning of this work, and we really are, we have an
21 opportunity, I think, to set a tone for this
22 discussion, which is not just a Pennsylvania
23 challenge. This is a national service system
24 healthcare crisis. So there's great opportunity in
25 this as well, if we can do that important work.

1 The other thing that I want to mention,
2 too, is -- and I've really come to see this in my work
3 overseeing the two programs that the bureau
4 administers, and I referenced this in my testimony,
5 this is such a diverse community.

6 I mean, we have folks who are very, very
7 profoundly affected by their autism and individuals
8 who -- I don't like to say high functioning because I
9 think that diminishes the challenge of individuals who
10 may be verbal, who may have great cognitive ability
11 but who lack social understanding to navigate the
12 world safely, those folks are winding up in
13 interaction with law enforcement in numbers that
14 should really alarm all of us.

15 But I think it's going to be very
16 important to continue to listen to the narratives of
17 family members and individuals affected who are able
18 to share their experiences. That has to inform what
19 we do here.

20 And I certainly in my work and as a
21 parent of someone with autism who launched an
22 advocacy, I continue to go out and listen to the
23 stories. It's very easy in government and in some of
24 the roles we're in to become very distant from the
25 challenge.

1 And so hearings like this, where we can
2 hear the stories and the real-time experiences of
3 people, has to be an integral part of whatever we do
4 here. So I just wanted to emphasize that point as
5 well.

6 REPRESENTATIVE DiGIROLAMO: Thank you,
7 Nina, really. It's good for us to hear that. It
8 really is. Representative Murt for questioning.

9 REPRESENTATIVE MURT: Thank you, Mr.
10 Chairman. Nina, two questions. The first is you
11 mentioned in your testimony about the needs to
12 address -- the need to address the unique needs of
13 individuals with Autism Spectrum Disorders who reside
14 in rural communities.

15 And we don't have a whole lot of rural
16 communities here in southeastern Pennsylvania, but
17 most of Pennsylvania is very rural, even remote.

18 And I guess my question is, what can we
19 do to help those communities upstate in the western
20 part of the Commonwealth that have a child or loved
21 one with an Autism Spectrum Disorder that needs
22 programs and services?

23 MS. WALL: I think it's a tremendous
24 question and there actually was a subcommittee of the
25 Autism Task Force that looked at the needs of

1 individuals with autism and their families living in
2 rural areas.

3 Autism is an inherently isolating
4 experience just out of the gate because of the
5 challenges that individuals experience and how that
6 impacts the family. Many of our families are already
7 isolated. And I think that's important just to set
8 the stage with that observation.

9 When you add the complexity of
10 geographic isolation, that adds another layer on top
11 of what is already extremely challenging. So one
12 of -- and I'm glad Dr. Shea is here today from ASERT.
13 This was one strategy by engaging our partners. In
14 the establishment of the ASERT Collaborative we
15 thought we could begin to tackle some of the
16 challenges in the more rural parts of the state.

17 ASERT is a statewide network but it's
18 also regionally configured. So Dr. Shea is here from
19 eastern ASERT. We have ASERT in the central region
20 and the western region. One of the tasks of ASERT is
21 to ensure that resources and information are getting
22 out to the more rural, isolated parts of the
23 Commonwealth.

24 It's a way of extending our reach into
25 the rural areas and also getting information back from

1 folks living in these regions in terms of what their
2 experiences are.

3 And so ASERT provides -- we also have a
4 resource hub that ASERT provides, but our folks in
5 western region ASERT actually go out into the
6 communities and they talk to the families and they
7 talk to the providers.

8 And the idea is if we're developing a
9 training, for example, in the Bureau of Autism
10 Services, that there's a way that that will access
11 folks in the more isolated parts of the state.

12 But I want to mention, too, something
13 that I've learned and it was really very helpful to
14 me. When I had first -- we do a lot of outreach
15 around the Commonwealth and I was doing a
16 presentation. It was actually in the Philadelphia
17 area.

18 And I spoke with a parent. This was a
19 presentation in Center City, and it was a parent who
20 was sharing information about ASERT and the idea of
21 supporting folks in more isolated areas.

22 And she said to me, you know, I live in
23 the city but I feel alone as well. She said it's
24 interesting how you think about rural areas and
25 isolation. She said, I don't know if it's worse to

1 actually be geographically isolated or to be in a city
2 surrounded by people when my son is melting down and
3 having all eyes on me in that moment and feeling as
4 alone as anybody could.

5 So I think it's important when we think
6 about all of these things, there's so many nuances.
7 So how do we support individuals who are without
8 supports, without social supports, without concrete
9 supports, whether they're in a rural area or they're
10 in an urban area or places in between?

11 Our efforts through ASERT will continue
12 to grow our network and our access to folks across the
13 Commonwealth. So it's the beginning.

14 REPRESENTATIVE MURT: One more question,
15 Mr. Chairman. When the Junods were testifying, I was
16 curious, is there any kind of mandate in Pennsylvania
17 about what accommodations a college student must
18 receive relative to remedial English and math and
19 untimed tests and so forth?

20 MS. WALL: That's probably outside my
21 lexicon, but I would say that -- one thing I can
22 say -- and, I don't know, maybe someone else can speak
23 to this.

24 REPRESENTATIVE MURT: It seems like it
25 varies institution to institution.

1 MS. WALL: Yeah, it is. I want to make
2 that point. And as part of our ASERT work we have
3 been working extensively with the colleges and the
4 universities in helping to develop the supports that
5 individuals with autism need and require in those
6 settings for those who are able to go on to higher
7 education.

8 And that was actually a specific ASERT
9 initiative, to work with the colleges and the
10 universities and, you know, to ensure that the right
11 supports are there, because we have individuals on the
12 spectrum who have tremendous cognitive abilities.

13 The academic part of their college
14 experience is not where they're going to struggle.
15 Where they're going to struggle -- and the same theme
16 we see in employment settings as well -- is when there
17 are social requirements.

18 And think about how much of our day,
19 every day, has a social focus, right? And if you
20 don't understand how to decode and navigate the social
21 world, regardless of what your IQ score is, you're
22 going to struggle.

23 And that's what we see happening to so
24 many of our young people with autism at that place on
25 the spectrum in college settings and in work

1 environments. The rate of unemployment and
2 underemployment in the autism community is staggering.

3 And it's often not because individuals
4 can't do the job. It's not that they can't learn the
5 task. It's that they struggle in learning how to
6 navigate all of the social demands of a work
7 environment.

8 And so we have to continue, I think, to
9 work with the colleges and the universities and
10 education, Department of Education, to ensure that
11 those supports are there.

12 REPRESENTATIVE MURT: Mr. Chairman, the
13 woman in the back wanted to make a comment, is it
14 okay, on this issue?

15 REPRESENTATIVE DiGIROLAMO: Absolutely.

16 REPRESENTATIVE MURT: Yes, ma'am.

17 MS. TOWNSEND: Good morning. Thank you
18 for taking my hand. There are a number of people here
19 who are members of the Autism Society of America's
20 Pennsylvania Chapter and we have a policy work group.

21 If I may, we have a brief statement on
22 positive suggestions that might move this effort
23 forward toward the information that was presented
24 today with Dr. Felicia Hurewitz as our representative.

25 REPRESENTATIVE DiGIROLAMO: Do you want

1 to make a statement, a brief statement?

2 MS. TOWNSEND: Yes.

3 REPRESENTATIVE DiGIROLAMO: Come on up
4 to the table.

5 MS. TOWNSEND: Hi. My name is Sabra
6 Townsend. I'm a parent of a 17-year-old on the
7 autism spectrum who attends public schools in
8 Philadelphia.

9 As I mentioned in the back briefly, we
10 are representatives of the Autism Society of America's
11 Pennsylvania Chapter and we have a policy work group.

12 Councilman Dennis O'Brien is familiar
13 with us, as you may be. He's made some comments about
14 this work group. One of the pieces that we discussed
15 was an issue of parity in terms of the budget.

16 When we talk about services that are
17 provided, as Nina Wall mentioned, there are often
18 times when people who are on the spectrum receive
19 services through the intellectual disability system
20 and if those services aren't necessarily appropriate
21 for people in the autism spectrum, there needs to be a
22 parity of budget funding for folks on the autism
23 spectrum.

24 The other, I think, practical suggestion
25 as we talked about is the Advisory Committee to the

1 Office of Developmental Programs, that there be a
2 parity of representation of people who are speaking to
3 the issues of folks on the autism spectrum, in
4 addition to the folks who are speaking to issues of
5 people with intellectual disabilities.

6 I introduce Dr. Felicia Hurewitz.

7 DR. HUREWITZ: Hello. I'm a member of
8 the policy work group, and I'm also somebody who
9 created a college support program, actually the Drexel
10 Autism Support Program.

11 I'm no longer there, but I created that.
12 And I can actually answer your question in terms of
13 provisions. The American Disability Act does provide
14 for certain types of accommodations for people with
15 autism, just to answer the question that was asked
16 earlier, such as extra time on tests.

17 But it does not require specially
18 designed instruction, meaning there's no requirement
19 that you give things like remedial math for people
20 with disabilities. So there are requirements that you
21 get access to classes, but there aren't requirements
22 that you change classes.

23 Just to move on to what I wanted to talk
24 about today, in addition to previously working at
25 Drexel, I now run a consulting company called EdMent

1 Consulting, where I help families, including in the
2 transition process.

3 And I wanted to talk particularly today
4 about applied behavior analysis. This is a scientific
5 field you might have heard of that's a research-based
6 body of knowledge that helps learners to acquire new
7 skills, such as speaking, dressing, navigating in the
8 community, and even high-level skills like completing
9 assignments for college classes, self-advocating
10 appropriately in the workplace, or in a college class.

11 ABA can change problem behaviors to
12 become -- to change to more functional replacement
13 behaviors and help to generalize new skills in
14 community settings.

15 When I ran the Drexel Autism Support
16 Program, we ran that under an ABA model. The
17 scientific literature suggests that it is the most
18 effective intervention to help people with autism to
19 acquire new socially significant skills and to reduce
20 problem behaviors. It is the gold standard.

21 When it is delivered in an
22 evidence-based way, it is overseen by something called
23 a board-certified behavior analyst. And these are
24 nationally-certified individuals who have met practice
25 standards and passed a comprehensive examination to

1 demonstrate extensive applied knowledge of ABA.

2 Part of the promise of Act 62, our
3 autism insurance bill, was to ensure access to ABA to
4 people with autism in Pennsylvania. However, access
5 to ABA -- in fact, I should say ABA is explicitly
6 stated in the statute as something that people with
7 autism should have access to.

8 However, it has fallen short. Act 62
9 eligible families have found it difficult to get this
10 service authorized as medically necessary and some
11 have had to engage in lawsuits against the insurance
12 companies to get this coverage.

13 Second, Act 62 is available only to a
14 segment of the population of people with autism.
15 People in certain exempt insurance categories, people
16 who lack insurance other than Medicaid, and adults
17 don't have access to -- don't have Act 62, so they
18 don't have access to ABA.

19 This is very problematic because this is
20 a technology we have that can actually solve some of
21 the problems that people are expressing today, for
22 example, someone going to college but not being able
23 to get together the insurance there. An applied
24 behavior analysis intervention could work.

25 Furthermore, as a state we created a new

1 license, the behavior specialist license, that does
2 not require the kind of knowledge, experience, and
3 certification as board-certified behavior analysts.
4 And by doing that we are generating a large class of
5 licensed clinicians who are not knowledgeable enough
6 to deliver ABA.

7 As a state we are not currently
8 developing an infrastructure where there's a critical
9 capacity to deliver ABA to the people with autism who
10 need it. There are practically no practitioners to be
11 found in the Philadelphia area who will deliver ABA to
12 adults and who can get that funded through insurance.
13 I've looked for my clients and I have not been able to
14 find any.

15 We need to be able to help our adults
16 who are academically capable and those who aren't. We
17 need to be able to help those people who have some
18 problem behaviors that, if they were resolved, they'd
19 be able to work. And so we really need a way to have
20 these PBAs who will deliver services and, in
21 particular, to adults.

22 REPRESENTATIVE DiGIROLAMO: Thank you
23 very much. We appreciate you being here. We have
24 time for a couple more questions by Representative
25 Acosta.

1 REPRESENTATIVE ACOSTA: Yes, I have a
2 quick question on the ABA. And you said that -- so
3 what you're saying is that if we implement ABA or we
4 get folks that are certified in ABA training, that
5 will help with social skills, as Nina was addressing
6 earlier.

7 And also you're saying that we don't
8 have enough certified folks in the ABA spectrum; is
9 that correct?

10 DR. HUREWITZ: We don't have enough
11 people who are board-certified behavior analysts.
12 There are very few. In fact, when there was a
13 development of the licensure for behavior specialists,
14 I appeared before the medical board and requested that
15 we make that license tied to the board certification
16 for behavior analysts, just like the American
17 Psychological Association mandates who becomes a
18 psychologist.

19 And the answer was, well, we don't have
20 capacity. Right now we don't have enough board-
21 certified behavior analysts to make that the license,
22 so instead we chose a lower standard.

23 But now we're maintaining that lower
24 standard. I'm saying we need a mechanism to have more
25 board-certified behavior analysts.

1 REPRESENTATIVE ACOSTA: So what you're
2 saying is if we get more board-certified folks in ABA,
3 that can help then with the socialization skills that
4 Nina was addressing; is that correct?

5 DR. HUREWITZ: There's a lot of research
6 to suggest that the ABA technologies where you're
7 teaching skills that will then be -- that will then
8 make contact with natural reinforcers. If you say
9 hello appropriately, people say hello back and smile,
10 that that works.

11 REPRESENTATIVE DiGIROLAMO: Okay. Thank
12 you. Can I ask Nina to come up? I think she has an
13 answer for you.

14 MS. WALL: Thank you. I do want to
15 speak -- I'm glad Act 62 was raised because it is
16 relevant to the discussion today. The thinking -- and
17 this is the Autism Insurance Mandate that was
18 championed by Councilman Dennis O'Brien when he was in
19 the legislature.

20 I think the thinking at the time Act 62
21 was passed, many families experienced if you had a
22 child who was diagnosed with autism, you called your
23 commercial insurer and you found out that there was an
24 autism exclusion in your policy.

25 What happened though, as many families,

1 they got involved with their support groups and they
2 found out that they could get services paid through
3 Medicaid, which many families did. And they were able
4 to receive their services.

5 When the work started around Act 62, the
6 thinking was -- and, again, the shift needed to go
7 back to the commercial side to begin taking some
8 responsibility for paying for services to children
9 with autism.

10 At the time I think there was actually
11 an effort to expand Act 62 to include adults. We were
12 not successful with that. We're just now beginning to
13 reinvigorate the work around seeing Act 62
14 implemented.

15 Part of what I think Dr. Hurewitz is
16 referring to also is there's a requirement or part of
17 the statute that speaks to the licensing of behavior
18 specialists. Since Act 62 was designed really to move
19 the services to the commercial side when we were
20 negotiating the act, the language, the commercial
21 insurers were very clear that they were not going to
22 pay for services provided by unlicensed professionals.

23 That was very hard, because in the
24 autism community, as you've heard, board-certified
25 behavior analysts have tremendous expertise in working

1 to help individuals learn to manage challenging
2 behavior.

3 So it is an issue. And I think the
4 larger issue is, and something that was raised several
5 times today in testimony, is the need to build
6 professional capacity, to have a sufficient number of
7 trained people who know how to work with this
8 population.

9 That continues to be a real challenge
10 for us. There aren't enough individuals who know how
11 to do this work and the idea that someone has very
12 serious behavioral issues. We see this across our
13 systems and we typically crisis manage those
14 situations very poorly most of the time.

15 The idea of being able to intervene
16 early when someone is struggling behaviorally, to
17 understand when someone is struggling behaviorally
18 what that means and to work with that team and that
19 individual to provide them with the skills that they
20 need in order to more effectively make their wants and
21 their needs and their frustrations known. So lots of
22 work to do there.

23 Anyway, I thought that might be helpful.

24 REPRESENTATIVE ACOSTA: It was very
25 helpful. Thank you.

1 REPRESENTATIVE DiGIROLAMO:

2 Representative Staats, did you have questions?

3 REPRESENTATIVE STAATS: Thank you, Mr.
4 Chairman and thank you to all those who testified
5 today. I learned so much, as does this Committee,
6 through these hearings.

7 Nina, to your point about the increase
8 in autism cases, this was stated a couple times today.
9 Julia Barol stated that as of the 2011 census 10,728
10 individuals were identified with autism in
11 southeastern Pennsylvania alone.

12 And, Nina, you stated that between 2009
13 and 2014 there was a 181 percent increase in autism
14 and a 334 percent increase in adults with autism.
15 Those numbers are staggering.

16 Do you have any insight on what's
17 driving that?

18 MS. WALL: Oh, boy, I knew it was
19 coming. Actually, that's the question that's
20 typically asked at the beginning. And I might ask
21 Dr. Shea to help me out on this one.

22 The answer to that is it's complicated.
23 We are most certainly diagnosing individuals more
24 effectively than we have in previous decades. I think
25 we're doing a much better job.

1 I think the other piece, too, is we are
2 including individuals under that umbrella who might
3 not have been identified or diagnosed with autism
4 before. So that is absolutely a factor, too.

5 And then I usually end by saying and
6 there are lots of really, really smart people who are
7 trying to understand what other factors might be at
8 play. So there is research going on right now looking
9 at the genetics of autism, whether or not there is a
10 genetic component, whether or not there's an
11 intersection between genetics and some environmental
12 factors. We just don't know.

13 And that is really hard. That's an
14 answer people don't like to hear, that we don't yet
15 understand what's happening. It is not, again, just a
16 Pennsylvania challenge, though. This is something we
17 are seeing nationally and internationally.

18 We're lucky to have some of the smartest
19 researchers here in Pennsylvania who are looking at
20 this, and we do touch base with them. But it's a
21 great question, but in the meantime we have to prepare
22 because regardless of what is the causal factor, the
23 etiology of autism, we have a responsibility to ensure
24 that those individuals who are diagnosed or who have
25 been at home without an appropriate diagnosis, those

1 kids who are coming into our system, that we have the
2 right kind of supports to ensure that they can
3 experience a quality of life. So a lot of head of us.

4 Thank you.

5 REPRESENTATIVE DiGIROLAMO: Any of the
6 other members have any questions?

7 REPRESENTATIVE ACOSTA: I have one more
8 question.

9 REPRESENTATIVE DiGIROLAMO: Go ahead,
10 Representative Acosta.

11 REPRESENTATIVE ACOSTA: And this is for
12 Julia, a quick question about the reimbursement rate.
13 You mentioned in your testimony that -- and I'll quote
14 exactly where you state it on your second page of your
15 testimony where it says that "The fee-for-service
16 reimbursement for supported employment services is
17 actually lacking," or you have it but it's not
18 sufficient.

19 What is the current reimbursement rate
20 for that?

21 MS. BAROL: Autism services
22 reimbursement rate is much lower than the
23 reimbursement rate through, for example, ODP's
24 intellectual disabilities services, so much so that
25 very few providers are willing to work at that lower

1 rate. I can get you the exact numbers.

2 REPRESENTATIVE ACOSTA: So they're not
3 willing. So you don't know exactly what that current
4 rate is now?

5 MS. BAROL: \$45 an hour for autism
6 versus \$71 an hour for intellectual disability.

7 REPRESENTATIVE ACOSTA: And how long has
8 that rate been -- that particular reimbursement has
9 been at that rate? So it's been like that forever?

10 MS. BAROL: Yes. Intellectual
11 disability services has adjusted their rates depending
12 on location around the state and cost of living but
13 autism has not.

14 REPRESENTATIVE ACOSTA: So that has not.
15 The needle has not moved in terms of that; is that
16 correct?

17 MS. BAROL: Correct.

18 REPRESENTATIVE ACOSTA: How can we move
19 that needle?

20 MS. WALL: That's also a hard question.
21 I want to say that one of the things with being a very
22 young program is that we came in with very limited
23 understanding of what it would cost to serve adults
24 with autism in a model designed for adults with
25 autism.

1 All we had was experience from existing
2 waivers where sometimes folks with autism had been
3 served. We are looking at our rate structure all the
4 time and trying to ensure that when there's a request
5 to make a change with rates, that it's informed by
6 data and by knowledge. So it's something that we're
7 looking at.

8 And I had mentioned in my testimony that
9 we're in the process of undertaking strategic planning
10 right now. Part of that is, okay, what has the
11 experience been in actually providing services?

12 I don't think we ever landed on because
13 it's done in the system a certain way, that that's
14 necessarily what we will emulate. I recognize,
15 though, we want to be attracting qualified providers
16 who know how to work with this population.

17 So looking at rate structure is
18 obviously something you should do. Strategic
19 planning, that's critically important.

20 REPRESENTATIVE ACOSTA: Thank you.

21 REPRESENTATIVE DIGIROLAMO: I think that
22 ends our questioning. And, Kathleen, thank you and
23 everybody here at SPIN for the hospitality and hosting
24 the hearing today. And thank you for the great work
25 that you do each and every day.

1 The testimony we heard today was very
2 powerful, very compelling. And I think you have a
3 commitment from all of us on the committee to continue
4 to work with you to -- we want to make the services
5 for people that have autism and all types of
6 disabilities the best it can be in Pennsylvania. You
7 have a commitment from us to continue to work with
8 you.

9 So, again, thank you everybody for
10 attending. God bless you and let's all work together.

11 (The hearing concluded at 11:57 a.m.)
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CERTIFICATION

I, JOANNE ROSE, a Registered Professional Reporter and Notary Public in and for the Commonwealth of Pennsylvania, hereby certify that the foregoing is a true and accurate transcript of the deposition of said witness who was first duly sworn by me on the date and place herein before set forth.

I FURTHER CERTIFY that I am neither attorney nor counsel for, not related to nor employed by any of the parties to the action in which this deposition was taken; and further that I am not a relative or employee of any attorney or counsel employed in this action, nor am I financially interested in this case.



JOANNE ROSE
Registered Professional Reporter
Registered Merit Reporter
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