

COUNCIL OF THE CITY OF PHILADELPHIA
COMMITTEE ON THE DISABLED AND
SPECIAL NEEDS

Room 400, City Hall
Philadelphia, Pennsylvania
Monday, February 2, 2015
10:30 a.m.

PRESENT:

COUNCILMAN DENNIS O'BRIEN, CHAIR
COUNCILWOMAN CINDY BASS
COUNCILWOMAN JANNIE BLACKWELL
COUNCILMAN BOBBY HENON
COUNCILMAN DAVID OH

RESOLUTION 150026 - Resolution authorizing
Council's Committee on the Disabled and
Special Needs to hold public hearings to
examine the Philadelphia Autism Project's
final report and strategic plan.

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1
2 COUNCILMAN O'BRIEN: Good
3 morning. This hearing is now called to
4 order. This is the public hearing of the
5 City Council Committee on the Disabled
6 and Special Needs. The purpose of this
7 public hearing is to hear testimony
8 regarding the Philadelphia Autism Project
9 authorized by Resolution 150026.

10 I recognize the presence of a
11 quorum of Committee members, starting to
12 my right Councilman David Oh,
13 Councilwoman Jannie Blackwell, and
14 Councilwoman Cindy Bass.

15 Are there any members that wish
16 to make opening marks?

17 (No response.)

18 COUNCILMAN O'BRIEN: Well, then
19 I will.

20 Good morning, Committee members
21 and thank you, everyone, for being here
22 today. This hearing was originally
23 slated for last week, but was postponed
24 to all that inclement weather. Thanks
25 for your flexibility and your willingness

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2 to change your busy schedules. It really
3 displays the commitment of so many on
4 this very important issue.

5 Today I'm pleased to present
6 the final report of the Philadelphia
7 Autism Project. This Philadelphia Autism
8 Project created a citywide task force to
9 examine services and supports for
10 individuals and families who are living
11 with autism in Philadelphia. The effort
12 represents the first of its kind. It's
13 never been done on a municipal level and,
14 more importantly, we've done it in a city
15 that's already been recognized as one of
16 the best cities in the nation to live in
17 if you are diagnosed with autism.

18 We undertook this effort
19 because despite the wonderful
20 recognition, we realize that we can and
21 must do better to address the gaps in our
22 service systems. Furthermore, the
23 challenges are still evolving and growing
24 with increased research about autism.
25 Recently, the Center for Disease Control

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2 stated that 1 in 68 Americans lives with
3 autism. This prevalence is staggering
4 and presents a challenge to policymakers.

5 When we sketched out the
6 Philadelphia Autism Project, we found it
7 very important to clearly identify a core
8 set of three guiding principles. One, to
9 address individuals across the entire
10 spectrum and lifespan; two, to develop
11 innovative approaches to meet the needs
12 of individuals and their families; and,
13 three, to address the underserved and
14 underrepresented populations in the City.

15 In our planning, we also
16 established five clear goals for this
17 project. One, generate a strategic plan
18 that provides a set of recommendations
19 for bringing about positive change; two,
20 develop a clear set of both short- and
21 long-term initiatives for ensuring real
22 change; three, create a strategy for
23 utilizing existing innovative approaches
24 for supporting individuals and families
25 that can be sustained; and, four,

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2 promoting opportunities that will lead to
3 increased communication on all relevant
4 systems to foster a comprehensive
5 approach that will result in better
6 coordination of services among these
7 systems; five, generate novel approaches
8 that can maximize the quality of life for
9 individuals and their families.

10 The experts testifying today
11 are going to highlight their personal
12 stories, the latest research trends in
13 the field, highlighting Philadelphia and
14 Pennsylvania specific data, and
15 celebrating the hard work of a dedicated
16 group of well over 100 stakeholders, our
17 stakeholders.

18 Our stakeholders represented a
19 diverse group of individuals, including
20 self-advocates, family members,
21 advocates, educators, providers,
22 administrators, City agency personnel,
23 policymakers, and researchers. We're
24 grateful for their tireless efforts as
25 they drove this process and were the

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2 heart and soul of this project. This
3 extraordinary progress and new direction
4 could not have been achieved without
5 their vision and commitment. The
6 Philadelphia Autism Project stakeholders
7 have created a roadmap that will guide us
8 in our efforts to improve the quality of
9 life for Philadelphians living with
10 autism.

11 I would like to thank Dr. Evans
12 for his partnership on this project. I
13 would also like to recognize the
14 Philadelphia School District for coming
15 to the table, Kim sitting over here, in a
16 very meaningful way. Thirteen
17 representatives, including top
18 administrators, special education staff,
19 principals, and teachers represented the
20 School District.

21 We also had meaningful
22 commitment from our Department of Human
23 Services, the judiciary, and other
24 members of law enforcement. We were also
25 grateful to the Philadelphia District

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2 Attorney, Seth Williams, for his
3 generosity in allowing us to use his
4 training center for three full days of
5 stakeholder meetings.

6 Finally, I would like to
7 recognize the important work undertaken
8 by the Pennsylvania Autism Task Force,
9 which I co-chaired alongside my
10 colleagues Estelle Richman, Nina Wall,
11 David Mandell, and Nancy Minshew. That
12 effort, completed ten years ago, laid the
13 framework for the establishment of the
14 Bureau of Autism Services and all the
15 national models the Bureau has created to
16 assist Pennsylvanians with ASD. That
17 effort was the template for the
18 Philadelphia Autism Project.

19 To provide a snapshot of the
20 Philadelphia Autism Project, we will now
21 hear from a number of individuals who
22 will offer insights into their respective
23 areas of expertise.

24 The Clerk will now read the
25 title of the resolution.

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2 THE CLERK: Resolution No.
3 150026, authorizing Council's Committee
4 on the Disabled and Special Needs to hold
5 public hearings to examine the
6 Philadelphia Autism Project's final
7 report and strategic plan.

8 COUNCILMAN O'BRIEN: Thank you.
9 I would like to now bring up
10 the first panel, and that will be titled
11 Personal Perspective: Maneuvering the
12 Current System, and we'd like to bring up
13 Jackie Gallagher, Esquire, who is a
14 parent; Michele Abraham-Montgomery, who
15 is a parent, a mother; and Khyllil
16 Robinson, an individual living with
17 autism. Would you please come up.

18 (Witnesses approached witness
19 table.)

20 COUNCILMAN O'BRIEN: Before you
21 begin your testimony, I'd like to
22 recognize my friend and colleague Bobby
23 Henon, Councilman Bobby Henon, who has
24 joined us on the panel.

25 First I would like to thank

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2 you, Jackie -- Michele can't be here --
3 and Khyllil for your testimony and for
4 your hard work over the course of this
5 project. I'm sure your preparing for
6 this testimony was emotional given all
7 that you've experienced in your lifetime,
8 and I know how difficult that is to bring
9 your personal experiences to a forum like
10 this in a very public way. So I want to
11 recognize that sense of advocacy on both
12 of your parts, and you really will serve
13 as the face of this Autism Project.

14 So, Jackie, do you want to
15 start.

16 MS. GALLAGHER: Thank you,
17 Councilman.

18 Good morning, Councilmembers.
19 I am Jackie Gallagher. I am a partner at
20 a major firm here in the City, Obermayer
21 Rebmann Maxwell and Hippel. Most
22 importantly, I am a mother of three
23 beautiful children, the youngest of whom,
24 Jack, has autism.

25 I have been a lifelong resident

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2 of Philadelphia, and until six years ago,
3 I lived in the blue-collar neighborhood
4 of Bridesburg where I was born and raised
5 and where I have many friends and family
6 members.

7 The journey that I have been
8 through over the last six years to obtain
9 appropriate services for my Jack has been
10 nothing short of an ordeal, but it is an
11 ordeal that brought us to a very positive
12 outcome. I am here today to share my
13 journey, my trials and tribulations to
14 illustrate for you how difficult it is
15 for ordinary Philadelphians to obtain
16 appropriate services, but to educate and
17 highlight for you if we all work
18 together, we can produce wonderful
19 outcomes and produce citizens who are
20 individual and capable of performing and
21 living independently in society, like
22 Khyllil, who I'm proud to work with today.

23 Our journey started in June of
24 '08, and I'd be remiss not to tell you
25 where we had come from. I found out I

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2 was expecting Jack, my third, the day my
3 cousin was admitted to the hospital to
4 battle leukemia. Maureen Muzikar was and
5 is my inspiration. She had spent her
6 life working with special education, had
7 pursued her Master's, and ironically was
8 an aide to a young man with autism.

9 Unfortunately, she lost her battle in May
10 of '08. Three weeks later, Jack was
11 diagnosed. The magnitude of that
12 diagnosis did not resonate. I'm a type
13 A, been called bull-in-a-China-shop
14 personality. So I went right into what
15 do I do and how do I get help for this
16 child. And the first intervention as to
17 enter our life three weeks later was
18 herself Beth Condie and a leukemia
19 survivor. To some, coincidence. To
20 those of us who have faith, clearly not.
21 We knew Maureen was with us. Maureen is
22 Jack's godmother. We knew that she would
23 be with us guiding the way for Jack.

24 But that was just the
25 beginning. I initially was told from the

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2 birth to three system that intensity for
3 young kids is not appropriate. So I
4 brought the research to show them it is
5 appropriate and here's why. So they
6 agreed, and we received intense services,
7 20 to 30 hours a week of services.
8 However, they weren't appropriate.

9 At the age of two, an expert
10 from Children's Hospital of Philadelphia,
11 Margaret Souders, looked me directly in
12 the eye when I explained how he was
13 aggressive and wild, and I said, When
14 does he grow out of it, Margaret?

15 And she said, He doesn't,
16 Jackie. Worse-case scenario, kids with
17 autism with this level of aggression,
18 they wind up institutionalized.

19 I'm sure many of us in this
20 Chamber have never heard that about a
21 two-year-old.

22 And I said, What do I do?

23 Find an experienced behaviorist
24 and work with them to develop a
25 comprehensive treatment plan.

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2 I said, What the hell is that
3 and where do I find one?

4 The first group that she
5 recommended would not service
6 Philadelphia. At that moment, for other
7 reasons, we had made an abrupt decision
8 to leave Bridesburg and move to the Pine
9 Valley section of the Far Northeast, and
10 I had said to this agency, Well, I'm
11 going to be private pay and I want you to
12 come in and work with my intervention
13 team. They're wonderful people. They
14 just don't have the expertise in autism.

15 And they said, No, we won't
16 service Philadelphia.

17 I won't say their name
18 publicly, but privately if anybody wants
19 to know, I'd be happy to share with you
20 so you can figure out why they won't
21 service Philadelphia.

22 I trolled the Internet for
23 hours sitting at my desk, and I stumbled
24 upon Clarity Consulting Services. And
25 the woman who changed our life is sitting

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2 in the Chambers behind me, and that's
3 Kathleen Stengel. And she is a
4 Board-certified behavioral analyst and a
5 true clinician who has a passion for
6 helping kids. And she came into the
7 picture and she said, Here's what you
8 need to do, boom, boom, boom, boom, boom.
9 And it became clearer between Jack's
10 second and third birthday that really
11 this agency understood how to treat
12 autism, and I directed them to develop a
13 comprehensive treatment program. And
14 they said, No one will ever pay for that.

15 I said, That's not your worry.
16 That's my worry.

17 And while I'm not a clinician,
18 I'm just a parent, I am a trial attorney,
19 and I knew what to do to get a team in
20 place. So I had the soup to nuts plan
21 developed, what does my child need from
22 8:00 in the morning until 7:00 at night,
23 because like most individuals with
24 autism, Jack's behaviors were very
25 different at school than they were at

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2 home. At school, he ultimately had an
3 ABA, applied behavioral analyst, trained
4 therapist with him as a one-to-one. At
5 home, it was just the Gallagher family.
6 And believe me, Jon and Kate Plus 8 had
7 nothing on us, because our house was
8 chaos.

9 So I had fought with the birth
10 to three system to contract with Clarity,
11 and they finally agreed. And it took
12 three months to negotiate the contract,
13 and in November of 2009, Clarity took
14 over full programming for Jack.
15 Unbeknownst to me, we were about to
16 encounter our first transition to the
17 three to five system, and it did not go
18 well.

19 I was told at the transition
20 meeting that his services that I had just
21 fought for and spent thousands of dollars
22 to get into place would remain until we
23 worked out an agreement with the three to
24 five agency. I was told four days later
25 on the phone, I'm sorry, Mrs. Gallagher,

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2 we were wrong, there's no continuity
3 between the two systems, so that you have
4 to start all over when he turns three in
5 two weeks, otherwise you'll lose all
6 services.

7 My point here today is not to
8 chastise any agency. My point is to
9 illustrate for you the systemic problems
10 that exist, because what I've learned is
11 there are many wonderful people in these
12 agencies and organizations, but there are
13 many systemic problems that need to be
14 changed.

15 I retained counsel. We invoked
16 our rights under the federal statute, the
17 Individual with Disabilities in Education
18 Act. I wound up in the emergency room
19 with shingles in my eye. The doctor
20 said, Are you under stress?

21 I said, Pick one. Pick one off
22 the wheel.

23 Long story short, we did obtain
24 an appropriate educational program
25 through intense months of negotiations.

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2 I breathed a sigh of relief in January of
3 '10 and I said, All right. And then
4 Kathleen said to me, Jackie, now you need
5 a home program. So fortunately, thanks
6 to the good work of the Councilman, who
7 really is a true public advocate for
8 those of us that are challenged with
9 special needs, the Autism Insurance Act
10 had just taken effect, which requires
11 private insurers to pay for autism
12 treatment. Like most new initiatives,
13 very few people knew how to implement it.
14 Again, being a partner at a major firm, I
15 e-mailed the CEO of our private health
16 insurance carrier and said, I'm a
17 partner, can you kindly introduce me to
18 somebody in your organization who knows
19 how this operates. I got services within
20 a week.

21 We started Jack's home program,
22 and at that time, he was -- when we got
23 his program in place at the age of three,
24 in spite of having intense intervention,
25 he was still only functioning on an

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2 18-month level. The real tremendous
3 strides did not take place until we had
4 an appropriate program in place, and the
5 appropriate program for Jack was an
6 ABA-trained team of therapists with him
7 from 8:00 in the morning until 7:00 at
8 night working under the clinical
9 supervision of a Board-certified
10 behavioral analyst.

11 When Jack's challenges hit
12 their crisis, he was physically attacking
13 us and my other two children and my
14 husband. And none of you, unless you've
15 lived it, can understand the pain of
16 having to restrain your own child while
17 your other children are crying.
18 Fortunately, I had experts to lead me
19 through it, and I recall vividly the day
20 when I restrained Jack for 45 minutes
21 with him kicking, screaming, biting,
22 scratching us while the house was crying,
23 but the therapist looking me in the eye
24 and saying, Mom, don't give up. It will
25 get worse before it gets better. If you

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2 trust us, you'll get through this. And
3 I'm here today to tell you we have.

4 Today, my Jack is eight years
5 old. He's mainstreamed in a typical
6 second grade classroom. As of December
7 1st, 2014, he no longer has a one-to-one
8 aide. Today, his programming consists of
9 ABA intervention in the after-school and
10 in the home community to deal with social
11 skills, because as individuals age, they
12 face different challenges. But the one
13 thing I can tell you is, my Jack will be
14 independent. He's fully verbal. He's
15 academically on par. He is socially and
16 emotionally about two years behind, but
17 he's the most engaging little boy you'll
18 ever want to meet. And I'm here today to
19 implore you to give every child in
20 Philadelphia the choice that my Jack had.

21 You don't need to spend more
22 money. You need to spend it more wisely.
23 I can tell you all of the inefficiencies
24 that exist in the current system. I am
25 confident that we can produce a better

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2 outcome if you partner up with the
3 wonderful universities that we have in
4 this area to develop a pilot program that
5 is based on science and best practices.
6 So with continuity of care, you can make
7 a difference for these children. And I
8 have learned through my colleagues on the
9 Task Force that you cannot ignore those
10 who are living on the spectrum and didn't
11 have the benefit of best practices,
12 didn't have the benefit of leaders like
13 Denny and Nina way back when to forge the
14 way for services. So oftentimes we're
15 pitted young against old, and I'm here to
16 tell you, there's no need for that. You
17 can take the current dollars that are
18 spent today by Behavioral Health in the
19 School District of Philadelphia, partner
20 up with a Jim Connell at Drexel or a
21 David Mandell at Penn and develop a
22 state-of-the-art program that is better
23 than any one in the country. And as a
24 Philadelphian and as a parent, I implore
25 you to make that difference in the life

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2 of every child in Philadelphia.

3 Thank you.

4 (Applause.)

5 COUNCILMAN O'BRIEN: Thank you,
6 Jackie. We're going to hear from Khyllil
7 and then we'll open it up for questions.

8 MR. ROBINSON: Hello. My name
9 is Khyllil Robinson. I was too involved
10 with Project Autism with the guidance of
11 Community College of Philadelphia Center
12 on Disability. Even though I've been
13 enduring so much in my high school --
14 during my years in high school and
15 college, I feel as though that I've
16 achieved independence and understanding
17 myself with the help of my mother and my
18 friends to make me understand how to
19 become more organized in the business and
20 education aspect.

21 With the help of everything
22 that I have done in school, I don't feel
23 as though that I have fully improved, but
24 I think it's much better than before. So
25 because of that, I can actually say that

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2 I understand what it means to communicate
3 with others and to use what I have
4 learned at school or at home or even with
5 the use of technology.

6 I am still currently having
7 issues in the communication area
8 sometimes because I may not know when to
9 include myself in certain conversations.
10 And even when I first joined Project
11 Autism, it was actually hard for me to
12 utter a word, because talking wasn't
13 really -- because talking isn't really my
14 thing in general.

15 I think that there should be
16 more programs involving speech therapy or
17 learning how to understand the body
18 language, because from what I've
19 witnessed personally and with the few
20 others who were also in the area of
21 autism, I believe that most are involved
22 with this particular issue. And the
23 support that I had mostly in my middle
24 school and my high school years was with
25 a therapeutic support specialist and with

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2 therapy for about ten years. I lost
3 count. And they taught me how to become
4 more organized within home and school,
5 and with the help of both of them, I was
6 able to get around with school and
7 project and become more aware of myself
8 when I would get ready for classes or
9 whenever I would just do any particular
10 activity on a normal basis and also
11 involving myself in social activities.

12 Then there was also my
13 involvement with the Settlement Music
14 School, Musicopia, and Girard Academic
15 Music Program, which were music programs
16 that also helped me with developing
17 emotions in areas where my mother
18 couldn't help me.

19 But with all the programs that
20 I've joined in the past and also being
21 involved with Project Autism, I would
22 like to thank my mother for supporting me
23 and also being there with me. And even
24 though she's not here right now, I would
25 really like to thank her for having me --

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2 for believing in me and having me and
3 growing up to where I'm at right now.

4 So other than that, I think
5 that's all I have to say. Thank you.

6 COUNCILMAN O'BRIEN: Thank you,
7 Khyllil.

8 (Applause.)

9 COUNCILMAN O'BRIEN: I'd also
10 like to recognize and thank Maureen's
11 parents. Would you please stand up.
12 Thank you for being here.

13 (Applause.)

14 COUNCILMAN O'BRIEN: Jackie, I
15 remember when -- and I appreciate you
16 sharing your life experience with us, as
17 I said before. I remember you coming to
18 me and telling me that it was a real
19 struggle, as you identified here today,
20 but that you wanted to make a difference
21 for other families so that they could
22 have a clearer path to services and
23 supports to achieve the maximum
24 developmental advancement that was
25 humanly possible, and we want to thank

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2 you for participating in the Philadelphia
3 Autism Project.

4 One of the great things about
5 what we're celebrating today is the
6 Philadelphia Autism Project, all the
7 stakeholders' ideas and recommendations
8 are now embodied in maybe 119
9 recommendations, and that was
10 extraordinarily hard to do. But that
11 doesn't mean anything unless we implement
12 those strategies, and that's what we're
13 here to celebrate today.

14 And, Jackie, how do you feel
15 from that first conversation we had in
16 our office and experience in the
17 Philadelphia Autism Project? Do you
18 think we're approaching the mission of
19 creating a system that will not only work
20 here in Philadelphia, but for all
21 jurisdictions across the Commonwealth and
22 beyond?

23 MS. GALLAGHER: I'm incredibly
24 optimistic, Denny, that we have so many
25 talented people working together to bring

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2 best practices to the fore. I'm
3 cognizant of the fact that it requires a
4 lot more work. It requires people to
5 think outside the box and it requires
6 people to challenge the status quo. And
7 if we do all those things which you
8 encouraged us to do, probably much to the
9 chagrin of your colleagues on Council --
10 you told us to forget about the
11 checkbook and to dream without worry for
12 the cost. But we live in a practical
13 world where resources are scarce and we
14 need to spend those resources in a wise
15 way. And my son is proof that if you do
16 that, that you can make a difference.
17 And, yes, I'm very, very optimistic.

18 I think we have a lot more work
19 to do, and that's the importance of what
20 we're doing here today, to talk about
21 those initiatives. But this will be the
22 best city in the world for an individual
23 living with autism with the commitment
24 and heart of everybody in this room.

25 COUNCILMAN O'BRIEN: Thank you,

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2 Jackie.

3 Khyllil, you serve as an
4 inspiration for all individuals who are
5 living with autism. You demonstrate
6 clearly how you can contribute to society
7 in very significant ways. You talk about
8 speech therapy, but I congratulate you
9 for being wonderfully articulate here
10 today. And I'm looking at our new
11 friend, Lee Woodall from the San
12 Francisco 49ers in the back. And he won
13 a Super Bowl, and there's a lot of people
14 that looked at Lee and say, When I grow
15 up, hopefully I'll be able to play on the
16 Philadelphia Eagles and beat the 49ers in
17 the NFC championship.

18 But, Khyllil, there are so many
19 people who look at you and relate to your
20 accomplishments and hope that for
21 themselves and family members, look at
22 you and hope that for their siblings or
23 for their children.

24 Do you want to just share with
25 us -- you were wonderfully contributory

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2 to so many aspects of the Philadelphia
3 Autism Project. Do you want to share
4 what your experience was on that project?

5 MR. ROBINSON: Well, my
6 experience was at first I didn't know
7 what to share during the Autism Project,
8 because like this was like -- it was like
9 new. But then after that, I just
10 realized that just pointing out my
11 personal experiences, from inviting my
12 mother on the second time we did the
13 stakeholders meeting, and then after
14 that, I was like, wow. I mean, I never
15 really thought of that. I mean, even
16 though in the first meeting I was kind of
17 shocked. I was kind of shocked with the
18 story that I shared, because for someone
19 who can't walk or talk or do any of that
20 and then grow up to be this, that's kind
21 of -- that is kind of hard to break down.
22 I mean, even to me myself, I didn't think
23 like a lot of people would be surprised
24 by that, because like getting a reaction.
25 I don't know. I think out the extreme

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2 with some things I'm about to say, and
3 that's why I don't really like share as
4 much.

5 But when I did the Autism
6 Project, it was really astounding to know
7 that everyone was like -- everyone like
8 seemed pretty happy about it. And also I
9 could also like share within the parents
10 as well.

11 Other than that, it was still
12 kind of nervous for me. So I was just
13 nervous the whole time through, and I
14 still enjoyed it.

15 COUNCILMAN O'BRIEN: Thank you,
16 Khyllil.

17 Are there any questions?

18 COUNCILWOMAN BASS: Yes. I
19 just want to make a couple of statements.
20 Thank you, Mr. Chairman.

21 Khyllil, Mr. Robinson, I just
22 wanted to say that, you know, I am so
23 impressed, and I really want to thank you
24 for being here, but also in her absence,
25 I really wanted to thank your mother and

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2 your father for the hard work and for the
3 commitment to you and to your future,
4 because I've seen both sides of the
5 spectrum. I've seen, you know, where
6 there are some parents who really don't
7 want to admit that something might be
8 needed here, some additional assistance
9 might be required. And so as a parent
10 myself, I know that's very difficult to
11 acknowledge and to admit. And so for
12 your parents to have done obviously such
13 a wonderful job on you and putting you
14 first and not, you know, what people may
15 think or what their own concerns or
16 worries were, you know, I just think it's
17 wonderful. And so please let your
18 parents know how much we as parents
19 appreciate the work that they have done
20 on your behalf.

21 And, Ms. Gallagher, I just
22 wanted to say to you I really appreciate
23 your testimony. I have to say I was
24 really somewhat horrified at the idea
25 that a provider of services for children

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2 had made a determination that they didn't
3 want to come into Philadelphia, and I'm
4 very curious as to who that is and I
5 would like to know who it is, and we'll
6 ask you off the record. You can feel
7 free to say it now, but if not --

8 MS. GALLAGHER: I'd prefer not
9 to stay it on the record, but I'm happy
10 to share.

11 COUNCILWOMAN BASS: That's
12 fine. I'm very curious.

13 And also the idea that you were
14 advised that there basically was no
15 assistance that could be helpful to your
16 son, that you were advised that -- kind
17 of like his condition could only worsen
18 and there's nothing that can be done,
19 there's not much that can help him. And
20 so those kinds of things really have no
21 place, particularly in a city like ours,
22 which is a city of eds and meds, and we
23 promote that, we speak about it proudly.

24 And so I do hope that we'll be
25 able to have future conversations so that

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2 we can address providers who really
3 aren't providing the services that are
4 needed particularly in this region.
5 Because, again, we have such a strong
6 reputation, that if someone is not living
7 up to what we believe they should be
8 living up to in terms of providing
9 accurate information, we ought to know
10 about it.

11 So thank you very much.

12 MS. GALLAGHER: Sure.

13 COUNCILMAN O'BRIEN: Thank you,
14 Councilwoman.

15 Councilman Henon.

16 COUNCILMAN HENON: Thank you,
17 Chairman. First I want to publicly say
18 congratulations to you for the Autism
19 Project and the celebration, as you
20 indicated here today, with this report.
21 And I think it's extremely important as I
22 sit here, a father of two kids, and
23 sometimes we don't realize how lucky we
24 are as parents in some cases, but I've
25 come to the realization -- and I'm going

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2 to ask the panel -- that the general
3 public, including myself, really does not
4 know enough about autism. And you see
5 some advertising on TV of raising
6 awareness and we have these walks, but it
7 just doesn't -- I don't realize how
8 ingrained it is or how much it affects a
9 family as a whole.

10 I mean, just from your
11 testimony, Jackie, that -- and, Khyllil, I
12 just want to say thank you for being
13 here. The courage that you showed today
14 is commendable. So I want to thank you
15 and your parents for the commitment to
16 making you shine here today. You are an
17 example, and we're proud of you. I'm
18 proud of you for being here.

19 We just don't know how much it
20 affects a family. We talk about when
21 seniors and elders are sick and
22 caregivers, but the amount of time
23 that -- and if you don't have the
24 resources, it must be more difficult.

25 And that goes to my question to

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2 you, Jackie. One, thank you for being
3 here. I've known you for a long time. A
4 few questions. One, you were so
5 dedicated, as any parent would be to
6 their child. You were in an unfortunate
7 situation where you're an advocate by
8 trade and a partner in a firm making some
9 calls.

10 How important and how critical
11 is getting the proper care that's
12 consistent throughout all the providers
13 at an early age?

14 MS. GALLAGHER: Critical. And
15 I liken it to this is an epidemic. I'm
16 not an expert on stats, but I know the
17 recent confirmed stats from the CDC are 1
18 in 68 children. If 1 in 68 children in
19 this community were diagnosed with
20 cancer, we would all wake up and listen.
21 And what all of the systems have done to
22 families, including the medical systems,
23 when a child -- my child was lucky, was
24 diagnosed at 18 months, but even then, I
25 was handed a packet of papers with no

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2 clear direction on what a treatment plan
3 should look like.

4 If my child were diagnosed with
5 cancer and I were told to go figure out
6 if he needs chemo or radiation, I
7 couldn't do it, and that's what we expect
8 families to do, not just in Philadelphia
9 but everywhere, figure out what the
10 appropriate treatment plan should be.

11 I don't know anything about the
12 interventions. I need a clinical
13 quarterback who can direct that. And if
14 you don't have that kind of competent,
15 evidence-based intervention on a
16 consistent basis, you're not going to get
17 the results and you're wasting money, and
18 proof of that is if you go back and pull
19 Jack's records from 18 months to three
20 years, you'll see how much money was
21 spent. It wasn't spent appropriately.

22 So it's absolutely critical,
23 and we have to invest in the workforce so
24 that we have skilled clinicians. And
25 I'll defer to the experts as to whether

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2 that should be a doctor, a psychiatrist,
3 a psychologist, a Board-certified
4 behavioral analyst, but I'm telling you,
5 these families need quarterbacks. I was
6 able to pull it together because of my
7 training, and even that, it had me on my
8 knees. There were times I didn't know
9 where to turn. But I know not to take no
10 as an answer, and what I've learned
11 through the process, what about the
12 families who don't even know the question
13 to ask. They don't know where to begin,
14 and they're thrust through the
15 bureaucratic system, again, by the
16 medical community with no clear guidance.

17 And I wholeheartedly believe,
18 Councilman, that you have the talent,
19 many of whom are sitting in this room,
20 and you are already spending the money.
21 I'll defer, but my understanding is
22 there's a significant amount of money
23 being spent by Community Behavioral
24 Health to provide therapeutic support
25 staff workers to individuals diagnosed

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2 with autism in the School District of
3 Philadelphia. Those individual staffers
4 aren't trained. They don't know best
5 practices with autism. The difference
6 for Jack was, he had a trained provider
7 from morning till night. And, yes, it
8 was a big expenditure, but now look at
9 how that expenditure has dwindled and in
10 a relatively short period of time. We're
11 talking from four until eight. He
12 started kindergarten with a full-time
13 aide. He is now in second grade and has
14 no aide in the classroom. I can
15 appreciate that not every individual will
16 make that kind of stride, but most can
17 make significant strides, and the key is
18 the continuity of care across all
19 environments. Because Jack is a very
20 different child in school than he is at
21 home, and there needs to be constant
22 communication. The same way that if a
23 child has cancer, there's a doctor
24 quarterbacking the treatment plan, and
25 there may be a nurse facilitating it, but

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2 if Johnny has a fever in the morning or
3 some kind of reaction in the morning, the
4 night team knows about it and vice versa,
5 and that's why we had such success.

6 There was a constant dialogue between his
7 morning team and his evening team, and it
8 was fluid and it changed based on the
9 needs of the day.

10 One real-world example. Jack
11 didn't recognize facial expressions, very
12 common with individuals with autism.
13 They don't recognize body language. So
14 our team took photographs of each of the
15 family members making different
16 expressions - mommy's happy, mommy's sad,
17 mommy's angry - and worked with the iPad
18 in teaching Jack. It's now intuitive to
19 him. And the medical doctors will tell
20 me it's like rewiring the brain. The
21 brain is so neuroplasticity. At the
22 earlier you intervene, the more you can
23 make a difference and you put the train
24 tracks going in a different direction.

25 Khyllil and his mom are my real

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2 heroes, because his mom is not here
3 today, but what I know of his journey,
4 his mom was a single mom and she was told
5 that there was no help for Khyllil. She
6 didn't have the benefit of an education
7 or resources, and she never gave up, and
8 look at how far Khyllil has come.

9 (Applause.)

10 COUNCILMAN HENON: Thank you
11 both for coming in. We appreciate your
12 experience and sharing it with us, and I
13 believe that the Councilman, the
14 Chairman, is committed, as well as not
15 just this Committee but the City of
16 Philadelphia to try to move forward the
17 Autism Project. So thank you very much.

18 MS. GALLAGHER: Thank you.

19 COUNCILMAN O'BRIEN: Thank you,
20 Councilman.

21 I would just like to feed off a
22 comment that my friend Bobby Henon just
23 made, and we all reflect as parents how
24 lucky we are. I have three young men,
25 and I don't know that they're typically

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2 developing on any given day, but I'd like
3 to turn that comment upside down, because
4 I believe that my life -- I know that my
5 life has changed because of my
6 involvement with individuals with
7 disabilities. It made me a much better
8 person. It certainly made me a better
9 legislator and it made me a better dad
10 for my guys, and I learned so much from
11 my experience and interacting with our
12 guys with disabilities. And when you
13 look at the public-private partnerships
14 that need to be developed, as Jackie and
15 Khyllil, that you've identified, we're
16 rich with those resources and the
17 academic health centers and the
18 partnerships that we've forged here, and
19 the best researchers in the world are
20 coming to Philadelphia, and you're going
21 to hear from a lot of those individuals
22 here today. And our institutions of
23 higher learning are embracing our
24 individuals. They're getting their
25 undergraduate degrees, graduate degrees,

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2 Ph.D.'s. They're self-advocates, and we
3 learned from them, because when people
4 talk about a cure, these individuals are
5 very happy and they should be proud of
6 the accomplishments that they've made in
7 their lifetime, but we want our
8 individuals to be able to work, to be
9 able to audit classes that reflect their
10 specific interests, and we need
11 employers. We need employers to give our
12 guys opportunities, so that all of us who
13 know individuals living with autism can
14 experience the joy that parents and
15 individuals like us, we can see the
16 potential and we can realize that
17 potential. We are going to apply that
18 research, create portals of information,
19 all of which you're going to hear about
20 today.

21 So, again, I would just like to
22 emphasize that from a parent perspective,
23 from an individual advocacy standpoint,
24 it's very difficult to take your personal
25 life and put it out there. And I think

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2 if we all take a moment and just think
3 about how difficult that would be for us
4 to take our most personal parts of our
5 life and just put them out there on
6 display for everybody, that's a huge
7 challenge. So it's very courageous as
8 well as informative for you to come and
9 share your life experience with us today.
10 Thank you very much for your testimony.

11 (Applause.)

12 COUNCILMAN O'BRIEN: And now we
13 would like to bring up our second panel,
14 Lindsay Shea, Dr. Lindsay Shea, who is
15 the Director of the ASERT Collaborative
16 at Drexel University, and Karen Krivit,
17 LSW, to speak about training and
18 resources. She's a training and resource
19 specialist at Elwyn.

20 (Witnesses approached witness
21 table.)

22 MS. KRIVIT: Who is first?

23 COUNCILMAN O'BRIEN: Whoever
24 would want to. Karen, do you want to go
25 first?

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2 MS. KRIVIT: Hello.

3 COUNCILMAN O'BRIEN: Please
4 state your name for the record and then
5 you can begin your testimony.

6 MS. KRIVIT: I'm Karen Krivit.
7 Good morning, Councilman O'Brien and
8 members of the Council. Thank you for
9 giving me the opportunity to share my
10 thoughts with you today. I'm the
11 Training and Resource Specialist at
12 Elwyn's Philadelphia Early Intervention
13 program. This is the sole provider of
14 special education therapies and supports
15 to over 7,000 children ages three to five
16 in the City of Philadelphia.
17 Approximately 800 of those children have
18 been diagnosed with autism.

19 Autism in our country and in
20 this city is a public health matter. It
21 affects every aspect of our community.

22 I received my Bachelor's degree
23 in Psychology from NYU in 1985 and my
24 Master's in Clinical Social Work from
25 Simmons in 1987. I'm a licensed social

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2 worker and have worked with families with
3 children with special needs my entire
4 career. I specifically began working in
5 the field of autism in 1996. At that
6 time, 3 in 1,000 children were diagnosed
7 with autism. Today it's, as you heard, 1
8 in 68. At that time, there were at least
9 ten social workers in my field. At this
10 time, I'm the only one.

11 I work in homes and in
12 communities, which allows me to feel the
13 pulse of our city. In addition, I work
14 with the agencies and systems that
15 support these families.

16 I am told I'm known in
17 Philadelphia as the go-to person for
18 autism. I also create many programs and
19 resources that are intended to address
20 the needs of underserved families, with
21 the goal of increasing the chances that a
22 child will get an early diagnosis and
23 then get good services.

24 In my role as an autism
25 consultant, I meet with families who have

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2 a child who is newly diagnosed. I meet
3 with the directors of day care centers
4 who have children with autism who are not
5 getting the help they need and they don't
6 know where to turn for resources, and I
7 meet with community and professional
8 groups who are uncomfortable and unsure
9 about autism. It's on these visits where
10 I find out what's not working. I hear of
11 heartbreaking struggles that families
12 endure just to get a diagnosis. I hear
13 so many myths, that parents think their
14 child's autism means they can't learn,
15 that parents who are -- they might be
16 ashamed because they fear they caused
17 their child's autism or that their
18 child's autism will just go away because
19 the school will take care of it.

20 I often hear that doctors tell
21 parents that their child is too young to
22 be diagnosed or that their child is a
23 late talker because they come from a
24 bilingual household. I often hear that
25 there's a year-long waiting list to get a

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2 diagnosis, so why bother.

3 Kids are underserved when they
4 don't get diagnosed early and they don't
5 get services. So in order to reach many
6 families, I've created a number of
7 resources and programs to address their
8 needs. In 2005, I launched the Elwyn
9 Autism Resource Guide, better known as
10 the "A List." It's the who's who and
11 where to go in Philadelphia for autism.
12 It's a tool that makes anything about
13 autism accessible. It's available for
14 free and it's online and I update it each
15 year. I also created and run free
16 monthly workshops that are open to
17 everyone. They cover everyday topics
18 such as how to manage difficult behaviors
19 and how to toilet train a child with
20 autism.

21 In addition, I have met with
22 hundreds of families, and I've concluded
23 that videos are the best way to break
24 down the wall of misunderstanding that
25 surrounds autism. And last year I

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2 created the first Asian autism video.

3 It's translated into seven different

4 languages, and my buddy, Councilman David

5 Oh, was generous enough to help dedicate

6 this video at the opening.

7 Underserved is not necessarily

8 an ethnic group. It is not a

9 neighborhood. It is not a class.

10 Underserved is a family or community

11 that, for a variety of reasons, cultural,

12 environmental, intellectual or emotional,

13 is not accessing help. Compared to

14 children who receive early and effective

15 services, underserved children and their

16 families require disproportionately more

17 services as they age. I've been the

18 co-chair of the work group on underserved

19 communities in the Philadelphia Autism

20 Project. We've recommended that an

21 autism hub be established to help

22 identify, inform, support, and guide

23 those in need. Well-trained community

24 ambassadors would staff this hub, and

25 ultimately there really would be no child

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2 left behind. This would be Jackie's
3 clinical quarterback.

4 Right now Philadelphia is a
5 city with the potential to be a model for
6 others. The measures that the Autism
7 Project proposes will enable you, the
8 members of City Council, to take
9 systemwide approaches that will really
10 make a difference. Your efforts can
11 reduce future duplication of services,
12 create opportunities for inclusion and
13 enrichment, and reduce the stigmas and
14 isolation that creates this subculture of
15 families.

16 To sum up, autism affects the
17 things that make a family function well;
18 for example, that you can go to work and
19 provide for your family knowing that your
20 child is safely cared for by others in
21 day care because he can speak up and say,
22 I'm hungry, or that your child can use
23 the community playground, comfortably go
24 with you to shop in stores and ride the
25 bus that allows you to walk around in

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2 your neighborhood and make friends. When
3 autism comes to a family, many ordinary
4 things become impossible.

5 Imagine your child doesn't
6 talk. He doesn't notice when you call
7 his name. He bangs his head. He puts
8 coins and paper in his mouth, and he
9 doesn't notice when he's injured. He's
10 not able to go to church. He's not able
11 to go to family functions, and he doesn't
12 enjoy going to birthday parties. With
13 the prevalence of 1 in 34 families, this
14 is your neighbor too.

15 I'm hopeful that my years here
16 and my experiences and my longstanding
17 relationships in the community can help
18 guide your efforts to provide useful and
19 effective programs for this vulnerable
20 population.

21 Thank you, Councilman O'Brien
22 and members of the Council.

23 COUNCILMAN O'BRIEN: Thank you,
24 Karen.

25 Dr. Shea.

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2 (Applause.)

3 DR. SHEA: Good morning,
4 Councilman O'Brien and members of the
5 Disabled and Special Needs Committee.
6 This morning, as will the presentations
7 that follow me, we'll be using
8 multi-media. We have some slides with
9 some data I hope you'll find interesting
10 and exciting.

11 My name is Lindsay Shea and I'm
12 the Principal Investigator of the Autism
13 Services, Education --

14 COUNCILMAN O'BRIEN: Dr. Shea,
15 could you please pull the microphone
16 closer.

17 DR. SHEA: Better?

18 My name is Lindsay Shea. I'm
19 the Principal Investigator of the Autism
20 Services, Education, Resources and
21 Training, or the ASERT, Collaborative
22 Eastern Region. We're funded by the
23 Bureau of Autism Services within the
24 Pennsylvania Department of Human
25 Services. The ASERT Collaborative

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2 Eastern Region houses the A.J. Drexel

3 Autism Institute at Drexel University.

4 In addition to my leadership of the ASERT

5 Collaborative, I have a Master's degree

6 in Social Policy from the University of

7 Pennsylvania and a Doctoral degree in

8 Health Policy from Drexel University.

9 For over a decade, I've led and managed

10 data-oriented, policy-based,

11 autism-focused research projects and

12 programs locally, within Pennsylvania,

13 and with a national scope.

14 The mission of the ASERT is to

15 improve the lives of Pennsylvanians

16 living with autism. In doing that, we

17 provide a head start on the

18 infrastructure that will help support the

19 Philadelphia Autism Project. The ASERT

20 engages in a wide portfolio of projects,

21 from training and educating employers

22 about autism to working with attorneys

23 and judges. We use data and the

24 self-reported needs of the autism

25 community to drive our priorities. We

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2 focus on generating information and
3 resources to support individuals with
4 autism and their families.

5 The ASERT has a manned resource
6 center. Any Pennsylvanian or
7 Philadelphian can call or e-mail to get
8 help navigating systems, whether they're
9 an individual with autism, a family
10 member, a service provider, or any other
11 member of the community.

12 I authored the Pennsylvania
13 Autism Census originally released in 2009
14 and the recent update to that report,
15 which was published in November 2014.
16 Pennsylvania Autism Census uses data from
17 multiple diverse systems to count the
18 number of individuals with autism
19 receiving services in Pennsylvania,
20 describe where they live, and profile
21 their characteristics, including the
22 kinds of services they are receiving over
23 time. We gather and analyze data from
24 the Medicaid system, education, child
25 welfare, vocational rehabilitation, and

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2 both the child and adult criminal justice
3 system.

4 Today, along with members of my
5 team, I'll be presenting data to you on
6 Philadelphians living with autism who are
7 receiving services across these multiple
8 systems. This data serves an important
9 purpose, because it helps to quantify
10 need and gives an indication of how many
11 additional people are facing the
12 struggles and barriers we've heard about
13 this morning. This data is critical to
14 identifying opportunities to improve
15 systems.

16 From the Pennsylvania Autism
17 Census, we found the number of
18 Philadelphians with autism receiving
19 services more than doubled from 2005 to
20 2011. This isn't surprising, especially
21 in light, as we heard, of the increasing
22 prevalence figures released by the CDC in
23 2014, citing a prevalence of 1 in 68
24 children eight-year-olds meeting criteria
25 for an autism diagnosis. The CDC study

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2 and the Pennsylvania Autism Census use
3 different methods, but they echo the same
4 trend.

5 When we apply the CDC
6 prevalence rate of 1 in 68 children to
7 the Philadelphia population, it suggests
8 there could be an additional -- a total
9 of about 23,000 Philadelphians living
10 with autism, many of whom are likely
11 adults who are not receiving services,
12 are not yet diagnosed or maybe carrying a
13 different diagnosis.

14 One of the most important
15 aspects of the autism population in
16 Philadelphia is that it's getting older.
17 In credit to the tremendous efforts to
18 raise awareness of the importance of
19 diagnosing autism early in a child's
20 life, many people think of young children
21 when they hear the word "autism."
22 However, in the vast majority of cases,
23 children with autism -- autism will last
24 a lifetime, and services and supports are
25 needed throughout life's transitions,

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2 especially during the critical shift into
3 adulthood at age 21, which is identified
4 by the blue line in this figure.

5 As you can see as my colleague
6 Pam clicks through the slide, we are
7 literally in the midst of an aging autism
8 population, with more and more
9 individuals aging out of child service
10 systems, and this trend will continue.

11 The data from the Pennsylvania
12 Autism Census allows us to get a thorough
13 picture of the clinical characteristics
14 of individuals with autism. This graph
15 shows the percent of Philadelphia's
16 autism population with an additional
17 psychiatric diagnosis or diagnoses and
18 how these proportions change with age.

19 When children with autism are
20 very young, ADHD and behavioral or
21 conduct disorder diagnoses are common --
22 are the most common additional diagnoses,
23 and as these children reach school age,
24 more and more of them accrue these
25 diagnoses. As children read to

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2 adolescents, a diagnosis of intellectual
3 disability increases dramatically, while
4 ADHD and behavioral or conduct disorders
5 remain constant.

6 As adolescents transition into
7 adulthood, comorbid ADHD and conduct
8 disorder diagnoses decrease, but mood
9 disorders, depression, and anxiety
10 increase, and about half will have a
11 comorbid intellectual disability
12 diagnosis.

13 In adulthood, these trends
14 continue with other disorders such as
15 bipolar disorder and schizophrenia also
16 increasing, but intellectual disability
17 remaining the predominant comorbid
18 diagnosis.

19 My final slides illustrate the
20 growing population of individuals with
21 autism in Philadelphia. This slide gives
22 a visual depiction of the number of
23 individuals with autism receiving
24 services in Philadelphia today and the
25 gap between the number of adults to the

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2 number of funded slots in autism programs
3 for adults. Each person on this slide
4 represents 50 people with autism
5 receiving services in Philadelphia. And
6 as mentioned, these numbers, especially
7 the number of adults with autism, will
8 continue to grow. As you'll see in later
9 presentations, these individuals of all
10 ages live in every corner of
11 Philadelphia.

12 This slide shows the number of
13 adults with autism we predict live in
14 Philadelphia this year. In particular,
15 as we look at the booming growth in the
16 population of adults with autism, it's
17 important to remember that research is
18 lagging far behind funding to study
19 children with autism. This presents a
20 critical gap in the knowledge base, and
21 even once that knowledge base is
22 bolstered, it will take time to shift
23 that information into programs, policies,
24 and practice. Funding for programs for
25 adults with autism is disproportionate

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2 when compared to other programs.

3 Finally, this slide shows how
4 we predict the number of adults with
5 autism will continue to grow in the next
6 five years. As we consider how to
7 understand and meet the needs of this
8 growing group, efforts like the
9 Philadelphia Autism Project and the ASERT
10 Collaborative are essential to filling
11 these gaps to help individuals with
12 autism of all ages, their families, and
13 the people who provide services to them
14 to thrive and succeed. Focused
15 collaboration and work will continue to
16 be much needed on this under-researched,
17 underfunded, and underserved group.

18 On behalf of all three branches
19 of the ASERT Collaborative across
20 Pennsylvania, we extend our gratitude to
21 Philadelphia for being an innovative
22 place for us to dig more deeply into this
23 work and specifically to Councilman
24 O'Brien for being a voice for these
25 individuals far before we understood the

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2 true breadth and depth of their needs.

3 Thank you.

4 (Applause.)

5 COUNCILMAN O'BRIEN: Karen, I
6 just want to thank you for connecting the
7 traditionally underserved families to
8 services and for your efforts to support
9 professionals as well with your training
10 models and also for sharing your "A List"
11 with our office, because we send that out
12 as a resource and we use it as a resource
13 for people that contact us for services.
14 And we'll be glad to share that with the
15 other Councilpeople.

16 But is there anything else you
17 want to emphasize as you define the
18 underserved population and
19 recommendations that you consider
20 important through the Autism Project
21 report?

22 MS. KRIVIT: I think just
23 overall like you had mentioned, our city
24 is filled with such wealth of
25 universities, and I think my only concern

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2 is that we make efforts not to remain
3 siloed and to find a forum like the
4 Autism Project to make sure we're always
5 more collaborative. I think that
6 sometimes when there's limited funding,
7 it can create a feeling where people
8 don't always share resources in that same
9 way. And I know that, for example, if a
10 family might call one agency and they
11 have a long waiting list, they might not
12 refer to another agency. And so that's
13 something to sort of keep in mind, is to
14 foster collaboration. I do that a lot in
15 my work, and I think on behalf of
16 underserved families, more collaboration
17 about resources and services would keep
18 things more accessible. That's my
19 biggest challenge, I'd say.

20 COUNCILMAN O'BRIEN: Thank you.

21 Dr. Shea, I would just like to
22 thank you for being here today and for
23 all of your contributions in putting this
24 report together and recognize your boss,
25 Craig Newschaffer, David Mandell and

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2 others, and I'd like to recognize Nina
3 Wall from the Bureau of Autism Services,
4 because it's those models that are
5 created on the state level that have
6 helped us build this synergy and
7 concentration of researchers and that led
8 to the census.

9 But I'd also like to emphasize
10 that the way that you and your partners
11 process data is significantly different
12 than anything we've ever seen before.
13 You basically take data, you strip it of
14 its bias, you establish outcomes and
15 create new programs, and then you support
16 those programs through a continuing
17 analysis as we move forward to achieve
18 those outcomes. And this is wonderfully
19 reciprocal. The Bureau of Autism
20 Services and the wonderful conversation
21 that was started several years ago has
22 attracted those researchers from all over
23 the world to Philadelphia, because they
24 see that nucleus that's here and they
25 want to be part of it, and when they get

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2 here, they enrich our conversations
3 beyond anything that we can ever imagine.

4 But I would like to just put it
5 out there. By the year -- and you can't
6 say this enough. By the year 2020, we're
7 going to have 25,000 adults crash the
8 system. They'll have no services
9 whatsoever, because the bus literally
10 stops when you're 21. It doesn't come to
11 your house anymore, and your family
12 member is relegated to the couch. And
13 we've all heard about the wonderful
14 successes and developmental achievement
15 that has been made, but once that bus
16 stops, regression is the biggest
17 challenge facing them.

18 But, Lindsay, if you want to
19 please tell us why there has to be a
20 focus on adults, and if you can expand on
21 the comorbid diagnosis and how important
22 that is in the census information that
23 you've compiled.

24 DR. SHEA: So adults are
25 important for lots of reasons. You

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2 primarily spend the majority of your life
3 as an adult, and that transition
4 especially into adulthood can be an
5 important primer for how your experience
6 will persist through that transition to
7 adulthood and throughout your adult life.
8 So it's important to focus on services
9 and supports during that time in an
10 individual with autism's life.

11 I think it's also that adults
12 are -- when you compare it to the amount
13 of research, the funding for research,
14 and the amount of attention on children
15 with autism, which is all important and
16 very worthy of every bit that it gets,
17 there's not as much of a dialogue
18 happening around adolescents and their
19 transition into adulthood and adults
20 living with autism, and we have a lot to
21 learn, especially when it comes to the
22 comorbid diagnoses. This data is among
23 the first efforts to really profile what
24 does autism look like in your 60's, in
25 your 70's, and even in your 80's, and how

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2 do we begin to consider clinical
3 approaches, policies, and programs that
4 can be there for those individuals,
5 because they're going to need support as
6 well in the vast majority of cases.

7 So I think we have an exciting
8 start on understanding the comorbid
9 diagnoses and what that profile will look
10 like as you saw from the slides and data.
11 I think we have more work to do to dig
12 in, as you said, Denny, to strip it down
13 to what's meaningful. We do this because
14 we want to build up programs and
15 supports, not necessarily for a research
16 article. That's really a secondary focus
17 for me and for my really smart and
18 enthusiastic team, who I also think are
19 playing an important role in making this
20 data what it is.

21 So I think you'll be seeing a
22 lot more from us. I think the
23 Philadelphia Autism Project gives us a
24 chance to really dive in and begin to
25 understand that, profile it, and get

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2 together the partners who need to think
3 about it.

4 COUNCILMAN O'BRIEN: Thank you.

5 I also would like to add that
6 through the Bureau of Autism Services --
7 and your wonderful work is funded through
8 the Bureau of Autism Services -- we're
9 ten years ahead of everybody else in the
10 country, and that's kind of encouraging,
11 but it's also very frustrating, because
12 when you embark on creating something
13 new, you want to go out and you want to
14 look at what's happening in other places
15 that we can bring home. And as I said,
16 it's wonderfully encouraging for us that
17 we can't go out and learn anything
18 because everything is happening here, but
19 we did the Autism Task Force ten years
20 ago and we had 12 committees. We
21 implemented all those recommendations,
22 and that serves as a platform. We took
23 inventory, and we're jumping off that
24 platform now.

25 But I'm very excited that

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2 you're going to run or help guide us
3 through the implementation process and
4 that, again, I would just like to say
5 that the epidemiology and the way it's
6 used here has not been done anywhere on
7 the planet, and as we identify the
8 wonderful work that our researchers do,
9 it takes someone special like you to pull
10 that research out so that you can create
11 models that put the boots on the ground.
12 It's wonderful to do the research, but
13 it's also very important, Karen, as you
14 do at Elwyn and so many of our people on
15 the "A List" to translate the wonderful
16 work that these researchers are doing and
17 drive it out to everyday responses so
18 that it empowers our family members and
19 individuals to be as successful as they
20 possibly can.

21 Are there questions?

22 (No response.)

23 COUNCILMAN O'BRIEN: Thank you
24 very much.

25 (Applause.)

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2 COUNCILMAN O'BRIEN: And now I
3 would like to invite Valarie Oulds,
4 Esquire, who is the Program Manager for
5 DBHIDS -- it sounds like a radio
6 station -- and Mary Mathew, MPH, a Policy
7 Specialist at the ASERT Collaborative at
8 Drexel University. If you would come
9 forward.

10 (Witnesses approached witness
11 table.)

12 COUNCILMAN O'BRIEN: Valarie,
13 if you want to identify yourself again
14 for the record and then you can present
15 your testimony.

16 MS. DUNBAR: Sure. Good
17 morning. I'm Valarie Oulds Dunbar. I'm
18 a Program Manager with the Department of
19 Behavioral Health and Intellectual
20 disAbility Services.

21 I would like to start off by
22 thanking all of you for the opportunity
23 to speak here today on Resolution No.
24 150026. And on behalf of the Department
25 of Behavioral Health and Intellectual

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2 disAbility Services, I would like to
3 thank Councilman O'Brien for all of his
4 efforts as an advocate for individuals
5 with disabilities and those with special
6 needs in Philadelphia.

7 In addition to my role with the
8 Department of Behavioral Health, I am
9 also the parent of a 22-year-old son with
10 autism. One of my roles at our
11 Department involves strategic planning
12 and policy development which serves
13 individuals with autism and their
14 families. Our Department represented
15 Councilman O'Brien's office for the
16 purpose of selecting, using a formal City
17 request for proposal process and
18 contracting with, the facilitator for the
19 Autism Project stakeholder process. So
20 in my role with the Department, I have
21 had the honor to work very closely with
22 Councilman O'Brien's office and, more
23 specifically, with Ms. Katy Kaplan in
24 carrying out our Department's
25 responsibilities in connection with the

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2 launch of the Philadelphia Autism
3 Project.

4 I have been asked to share
5 today some of the key activities and
6 outcomes of the very first Autism Project
7 stakeholder meeting, which was held on
8 May 12th, 2014. At this meeting,
9 Councilman O'Brien expressed his desire
10 to create an inclusive process that
11 relied upon self-advocates, family
12 members, policymakers, researchers,
13 service providers, educators, government
14 agencies, and other key stakeholders to
15 design a more effective, efficient, and
16 comprehensive system of care for
17 individuals with autism and their
18 families.

19 Our first stakeholder meeting
20 was filled with energy and excitement and
21 resulted in a facilitated and rigorous
22 discussion with all stakeholders present
23 regarding strengths, challenges, and
24 concerns facing the community of
25 individuals living with autism and their

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2 families. Participants were divided into
3 small groups, each with a
4 cross-representation of stakeholders, and
5 were asked to consider all domains of
6 life, from infants to the elderly. This
7 process involved identifying which
8 services are currently available, the
9 strengths, areas in need of improvement,
10 as well as any gaps. This nearly
11 five-hour process resulted in over 150
12 pages of group notes. And there was a
13 clear recognition that although
14 Philadelphia has an array of resources,
15 there is a need for better coordination,
16 particularly during transitions between
17 service systems, identification of gaps
18 where no supports currently exist, and
19 increased community awareness about
20 autism and available resources.

21 As a result of these
22 discussions, there were ten themes for
23 improvement that emerged, and I will
24 direct you to the PowerPoint slide that
25 is showing -- which identifies each of

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2 those ten themes.

3 The first, Clinical Concerns
4 Across the Lifespan. One of the key
5 concerns was how to navigate the array of
6 services and supports that may be needed.
7 This also involves the identification of
8 best practices in autism, early
9 intervention, and ongoing treatment as an
10 individual with autism ages into
11 adulthood. Here, solutions would be
12 developed to support individuals and
13 families as they navigate the system
14 transitioning from one system of care of
15 service to the next.

16 Second, Family Support. This
17 involved identifying solutions to support
18 families educationally, emotionally,
19 socially, and financially to meet the
20 needs of their family member with autism
21 and to address the impact it has on all
22 the family members. This arena can
23 include family-friendly information about
24 autism and available resources, respite
25 services, support groups, and financial

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2 support.

3 Third, Post-Secondary

4 Educational and Employment Opportunities.

5 There is a specific need to design

6 post-secondary education, employment

7 preparation, and job opportunities for

8 young adults and adults with autism once

9 they leave high school that rewards,

10 challenges, and takes full advantage of

11 the individual's potential and strengths

12 while fostering self-determination.

13 Fourth, Underserved

14 Communities. It is necessary to identify

15 barriers and create solutions to support

16 the needs of individuals and their

17 families in communities that are

18 underserved. Due to differences in

19 culture, language barriers, poverty,

20 unsafe neighborhoods, et cetera,

21 solutions will include community

22 awareness, access to diagnosis, early

23 intervention, as well as a full array of

24 needed services that are both culturally

25 and linguistically appropriate.

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2 Fifth, Capacity Building and
3 Workforce Development. There is a need
4 to develop solutions to promote more
5 autism-specific competencies for all
6 professionals who work with this
7 population; for example, educators,
8 healthcare workers, behavioral health, et
9 cetera. Solutions must support the
10 training and professional development
11 needs of these individuals and work to
12 ensure the number of professionals
13 required satisfies both the current and
14 the future needs of individuals with
15 autism and their families.

16 Sixth, Enhancing Community
17 Inclusion for Individuals and Families
18 with Autism. Too often individuals with
19 autism are isolated or limited in being
20 able to enjoy their communities. This
21 can be augmented by identifying specific
22 areas of concern - day care, respite,
23 transportation, recreation, social,
24 entertainment, family living, and the
25 list goes on, and working to provide

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2 solutions to create a more inclusive
3 community and living environment for
4 individuals living with autism and their
5 families.

6 Seventh, Supports for Adults.

7 Oftentimes parents refer to the time
8 their young person turns 21 as, quote,
9 "falling off the cliff," end quote, and
10 it is during this time that special
11 education and other supports for children
12 and adolescents disappear. Creating
13 solutions to address the complex needs of
14 adults with autism from the ages of 21
15 onward and throughout adulthood is of
16 paramount importance. The types of
17 supports needed will include, but are not
18 limited to, developing independent living
19 skills, access to post-secondary
20 educational and vocational training
21 opportunities, and a continuum of
22 appropriate and adequate housing
23 alternatives.

24 Eighth, Child Welfare and
25 Criminal Justice Systems. Oftentimes

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2 children and adults end up in our
3 criminal justice and juvenile justice
4 systems because of actions taken that are
5 really a function of the autism or
6 because they are easy targets to be
7 induced into criminal behavior by others.
8 A solution is needed to divert these
9 individuals from landing in these systems
10 in the first place.

11 Another issue is how to
12 appropriately meet the needs of
13 individuals who end up in these systems,
14 starting with the legal process to
15 sentencing, rehabilitation, and reentry
16 into the community. Similarly, children
17 who are in foster care or other
18 out-of-home DHS placements need a
19 specialized approach to ensure that their
20 needs are being met.

21 Ninth, Education, with a
22 particular emphasis in this case on
23 kindergarten through grades 12 up to age
24 21. Children with autism spend
25 significant portions of their life in

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2 school. It is a critical period of
3 development to learn and acquire the
4 knowledge, experience, and skills to be
5 successful in life. Areas of focus would
6 include developing strategies that
7 increase the use of best practices in
8 classrooms, creating more mainstream
9 opportunities for students with autism,
10 improving the individual educational
11 plan, or IEP, process for families,
12 retaining high-quality teachers, and
13 increasing awareness among all school
14 staff.

15 And, lastly, tenth, the
16 Blending of Funding Streams. There is a
17 need to identify strategies for blending
18 the funding from various systems -
19 education, public sector, private
20 insurance, for example - to create a more
21 integrated and coordinated service system
22 to offer to individuals with autism and
23 their families.

24 Again, I appreciate the
25 opportunity to speak here at this

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2 hearing, and I am willing to answer any
3 questions the Committee may have.

4 Thank you.

5 (Applause.)

6 COUNCILMAN O'BRIEN: Mary,
7 would you please identify yourself and
8 begin your testimony.

9 MS. MATHEW: Hello. My name is
10 Mary Mathew and I'm the Policy Project
11 Coordinator for the Eastern Region of
12 ASERT housed at the A.J. Drexel Autism
13 Institute. I'd like to take a minute to
14 thank Chairman O'Brien and members of the
15 Special and Disabled Needs Committee for
16 allowing me the opportunity to speak
17 today.

18 I will be continuing the
19 presentation on the processes behind the
20 Philadelphia Autism Project. Ms. Oulds
21 previously outlined the ten themes that
22 were developed during the first meeting
23 of the Philadelphia Autism Project.
24 Based on these themes, stakeholders were
25 organized into groups during the second

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2 Philadelphia Autism Project meeting. For
3 instance, stakeholders could be part of
4 the Clinical Concerns Across the Lifespan
5 group or the Child Welfare and Justice
6 System group based on their interests and
7 experience. The groups were then asked
8 to create initiatives to address the
9 challenges associated with each theme.
10 Based on these discussions, the groups
11 created a total of 119 initiatives, with
12 timeframes for implementation.

13 These 119 initiatives addressed
14 many different and challenging needs.
15 However, there were common themes among
16 these initiatives. Based on their focus
17 and common themes, the initiatives were
18 organized into four categories, the first
19 being Resources, Outreach, Awareness,
20 Training, and Education; the second,
21 Infrastructure; the Third, Capacity; and
22 the fourth, Policy.

23 Initiatives which were placed
24 into the first category of Resources,
25 Outreach, Awareness, Training, and

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Education addressed the need for resources that provide general information about autism, best practice methods, and means of connecting individuals with autism and their families to additional resources in Philadelphia.

The Infrastructure category contained initiatives that were focused on the need for coordination across systems in Philadelphia to improve efficiency and access. Several initiatives in this category recommended additional service creation and workforce support.

The Policy category consisted of initiatives that outlined possible policy options such as local ordinances that could create system change that would benefit individuals with autism.

The category of Capacity refers to the need to build capacity in terms of a future workforce and also to enhance the existing capacity of the current

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workforce through trainings on best practices and other relevant topics. It also includes building capacity within the community to create welcoming environments and opportunities for individuals with autism and their families.

The Capacity category initiatives were focused on community institutions and how they could be supported to meet the needs of individuals with autism and their families.

Overall, these categories were created to systematically and thoroughly review the initiatives that were created during the second Philadelphia Autism Project stakeholder meeting.

From its start, the Philadelphia Autism Project has valued stakeholder involvement and perspective to help address the current challenges that the City faces as it works to support individuals with autism.

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2 Therefore, the third Philadelphia Autism
3 Project meeting was focused on
4 identifying stakeholder opinions about
5 which initiatives were the most important
6 to implement. A survey was designed to
7 assess the stakeholder views on the
8 initiatives.

9 This slide shows an image of
10 the survey, which was distributed to
11 stakeholders at the third stakeholder
12 meeting. Stakeholders who were unable to
13 attend the third meeting had the
14 opportunity to take the survey online.
15 They were also provided with the option
16 to participate in conference calls with
17 Chairman O'Brien's staff to update them
18 on the meeting they missed and the
19 survey.

20 For survey organization, the
21 initiatives were organized into three
22 different categories, the first being
23 short-term initiatives that build on
24 existing resources. The second category
25 was short-term initiatives with new

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2 resource development, and the third was
3 long-term initiatives with new resource
4 development. For these categories, short
5 term indicates a timeframe of less than a
6 year, whereas long term is for
7 initiatives that will take more than a
8 year. These categories were created
9 because they designate the general
10 timeframe and resource allocation, which
11 are important for planning and
12 implementation of initiatives. For the
13 survey, stakeholders were asked to select
14 their top three initiatives for each
15 category.

16 The survey was completed by 80
17 stakeholders. It contained questions
18 about stakeholder demographics and
19 initiatives. First we will take a minute
20 and discuss the stakeholder demographics.

21 In the beginning of the survey,
22 stakeholders were asked to identify their
23 stakeholder type. This slide shows the
24 group of stakeholders who participated.
25 Both government staff and researchers

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2 each made up 16 percent. Fifteen percent
3 of stakeholders were family members,
4 while another 15 percent were providers.

5 At the end of the survey, stakeholders
6 were asked to indicate if they wanted to
7 participate in the implementation phase
8 of the Philadelphia Autism Project. If
9 they responded yes, they were asked to
10 specify what theme they were interested
11 in working on. For their reflected
12 theme, they were asked if they would like
13 to take on a leadership role, participate
14 as a member of a community or work group
15 or share resources and/or disseminate
16 information.

17 The answers to these questions
18 provided important information about if
19 and how stakeholders wanted to be
20 involved for the implementation phase of
21 the Philadelphia Autism Project.

22 Through the survey, the top
23 initiatives in each category were
24 identified. The top initiatives dealt
25 with several different topics, including,

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2 but not limited to, resource development,
3 research, and training. The categories
4 allow for more systematic planning and
5 execution of these initiatives. For
6 instance, the top voted initiative for
7 the category of long-term initiatives
8 with new resource development was the
9 creation of a centralized resource hub.
10 Moving forward, a Philadelphia-specific
11 research hub will be created and housed
12 on the ASERT website at paautism.org.

13 One of the top voted
14 initiatives for the category of
15 short-term initiatives with new resource
16 development was the need for training.
17 In order to address this need, the
18 resource hub will have links to different
19 trainings and their respective materials.
20 This implementation plan is a prime
21 example of the Philadelphia Autism
22 Project's use of the initiative and
23 stakeholder feedback. Panel 3 will
24 elaborate on the implementation of these
25 initiatives.

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2 Overall, these survey results
3 have provided a strategic focus for the
4 ongoing implementation phase of the
5 Philadelphia Autism Project. The process
6 for generating the initiatives engaged
7 stakeholders and created a promising
8 endeavor toward community engagement to
9 support individuals with autism, their
10 families, and providers. The involvement
11 of the community has helped make this
12 project extremely innovative and unique.
13 The discussion to create the initiatives
14 during the stakeholder meeting and the
15 voting process allowed stakeholders to
16 express their views on what is needed in
17 Philadelphia. As initiatives are
18 implemented, these stakeholders will
19 continue to play an important role in the
20 Philadelphia Autism Project.

21 I would like to thank
22 Councilman and Chairman O'Brien for his
23 developing this project and for his
24 leadership and focus through its planning
25 and implementation. I would also like to

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2 thank the Chairman and the Committee for
3 allowing me the opportunity to speak
4 today.

5 (Applause.)

6 COUNCILMAN O'BRIEN: I would
7 just like to state how difficult it is
8 for me to control my ADHD and not just
9 expand on the ten recommendations and the
10 process. I think for those who are
11 viewing this hearing today, it looks like
12 a very simple, straightforward
13 conversation that we had. It was
14 anything but that. And Valarie and Mary,
15 I'd like to thank you for your
16 contributions to putting this to paper.
17 And I think it's important to recognize
18 that this process is significant beyond
19 Philadelphia. What people are already
20 inquiring about is how we put a process
21 like this together in Philadelphia so
22 they can replicate it in other counties
23 in Pennsylvania and in other states
24 beyond our borders. We know that,
25 because with the other programs that we

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2 have in the Commonwealth through the
3 Bureau of Autism Services, other states
4 are constantly inquiring as to how we
5 built conversations that led to those
6 programmatic advancements.

7 Valarie, putting together this
8 RFP was an extraordinary endeavor, and it
9 should be recognized that not only
10 Behavioral Health and Dr. Evans were
11 participatory, but DHS, CBH, and our
12 partners at the School District were also
13 present, and that cross-agency discussion
14 that's going to lead to the second phase
15 of this, the implementation process, is
16 critical, as Jackie pointed out.

17 For parents and individuals to
18 navigate these systems, it's next to
19 impossible. Just this process identifies
20 all the complexities and the silos that
21 exist that have to be broken down in
22 order to achieve the ultimate goal and,
23 that is, to advance best practices and to
24 advise individuals and family members how
25 they can access that information and how

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2 we can move this process forward and
3 create efficiencies that create better
4 programs.

5 As I just look at it, with the
6 four categories and the short-term -- the
7 two short-term initiative groupings and
8 the long-term, there are so many
9 opportunities, both short term and long
10 term. We call it the low-hanging fruit.
11 And on the long-term, there are --
12 there's a recognition that certain steps
13 have to be taken before you can move to
14 this big initiative, and that includes
15 recognizing the reshaping of funding, the
16 blending and braiding. Also we have some
17 of the best people that we've identified
18 in our autism conversations in the
19 Commonwealth where we can take an
20 instrument, all the stuff that's said
21 about ObamaCare, there are great
22 opportunities for us to fund great
23 initiatives in comorbid diagnosis and
24 recognize the impending tsunami for
25 adults that are going to crash the

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2 system, and we have to explore those
3 opportunities.

4 And just for the clarification
5 of my colleagues, I didn't want them to
6 think that money is not an object. It is
7 significantly an object, and we know that
8 because we have \$28 million for autism in
9 a \$3 billion budget for intellectual
10 disability. So when you get a percentage
11 increase, our increase is very slight
12 compared to what other funding mechanisms
13 embrace. But the reality is that if we
14 looked at this through a lens as to what
15 was fiscally possible, we would never get
16 to where we have to go. And I'm hoping
17 and I am very confident that with the
18 knowledge of all the people that are here
19 beyond the brass rail -- and I want to
20 thank all of you. As I look, there's a
21 story, almost every seat in this room,
22 and the wonderful contributions that
23 you've made to make this report possible,
24 that there is going to be a contagious
25 excitement that surrounds the

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2 implementation process. And I just want
3 to thank you from the bottom of my heart
4 for that.

5 And, Valarie, again, we
6 recognize you as a parent, as someone who
7 knows how to shepherd us through the
8 bureaucracies. And I would also like to
9 reflect back on my relationship with
10 Estelle Richman and with Nina and the
11 other people on the state level, because
12 we tend to run around and say that
13 bureaucracy is the enemy. And the
14 sharing of those four agencies that was
15 unconditional in just identifying what we
16 perceive as deficits in the system and
17 not deficits from the people who are
18 charged with running those systems --
19 this isn't a finger-pointing exercise.
20 This is an identification process so that
21 we can find out where the gaps are, where
22 we got to fill those gaps, and what we
23 have to expand on for this really
24 working.

25 So I think not only is this a

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2 learning process for autism, but it's a
3 learning process with the way that we
4 process data. The national trend is
5 going to be because of this conversation
6 and focus on outcomes and how we can do
7 it better. This is an opportunity for
8 Philly to say we got it right for autism,
9 and the models that we are creating here
10 can be expanded to all other types of
11 disabilities and conversations. The way
12 that Lindsay and David Mandell and Craig
13 Newschaffer process information and data
14 have allowed me to expand programs in the
15 criminal justice system, which we will
16 hear from PJ and others in another panel.

17 But, again, I just am trying to
18 control my ADHD. I can go on forever,
19 because this is a very exciting project.
20 But I just want to thank you for all that
21 you've done to make this a reality.

22 Are there any other questions?

23 (No response.)

24 COUNCILMAN O'BRIEN: No? Thank
25 you so much.

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2 (Applause.)

3 COUNCILMAN O'BRIEN: And as we
4 move through the process, I would like to
5 recognize my staff people who are also
6 here, starting with Matt Braden, my Chief
7 of Staff, and Dr. Katy Kaplan, who is
8 intimately known by almost everybody in
9 this room for her great work. Where are
10 you, Katy? Oh, there she is. She's back
11 here. And, Miriam, I know you're
12 watching us on TV, and she's got a
13 newborn at home. So hello, Miriam, and
14 congratulations, and I know you wish you
15 were here. Not really. And Kevin
16 Carroll, who has got multiple
17 personalities, and Margie Caputo and
18 Marita Trimmer, all of whom have
19 contributed significantly to creating
20 this process along with all of you and
21 also the infrastructure, which is
22 planning these breakout sessions and
23 making sure that everybody who has been
24 continuously involved has been
25 extraordinary.

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2 So now that brings us to Panel
3 No. 4, and we're going to talk about the
4 implementation process and we'd like to
5 recognize PJ, otherwise known as Paul
6 Turcotte, who is an MPH, Data Analyst for
7 the ASERT Collaborative at Drexel
8 University, and Kaitlin Miller, MPH,
9 Policy Coordinator, ASERT Collaborative
10 at Drexel University, and late to the
11 table but never late to the conversation
12 is Nina Wall, MSS, LSW, Director of the
13 Pennsylvania Bureau of Autism Services.

14 (Witnesses approached witness
15 table.)

16 COUNCILMAN O'BRIEN: So I would
17 ask all of you in turn to identify
18 yourself and then begin your testimony.
19 And, PJ, you can begin.

20 MR. TURCOTTE: My name is Paul
21 Turcotte. I am the Data Project Manager
22 for the ASERT Eastern --

23 COUNCILMAN O'BRIEN: Can you
24 pull your microphone closer.

25 MR. TURCOTTE: Sure. My name

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2 is Paul Turcotte. I am the Data Project
3 Manager for the ASERT Eastern Region at
4 Drexel University.

5 COUNCILMAN O'BRIEN: Paul, you
6 can start and then they can identify
7 themselves.

8 MR. TURCOTTE: So I want to
9 talk to you a little bit about the
10 justice system data that we have, which
11 is driving some of our justice
12 initiatives.

13 COUNCILMAN O'BRIEN: Do you
14 want to identify Pam?

15 MR. TURCOTTE: Sure. This is
16 Pam. She's our Clinical Coordinator for
17 the ASERT Eastern Region, and she is a
18 fantastic slide helper as well.

19 COUNCILMAN O'BRIEN: And also a
20 rock star that Katy likes to talk about.

21 MR. TURCOTTE: So I wanted to
22 use the slides over here to try to guide
23 you through some of the data that we have
24 for Philadelphia.

25 So the lighter color in the

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2 back is the rate of pre-adjudicated
3 justice charges per 100 individuals with
4 autism in Philadelphia. So as you can
5 see, from 2005 to 2011, it increased from
6 15.2 to 17.6. And whether that increase
7 is significant, we're still examining,
8 but the important part is that as you can
9 see below it, the 6.6 and the 14.2 bars,
10 that's Pennsylvania as a whole. So
11 Philadelphia is seeing more charges
12 compared to the rest of the state on
13 average.

14 So this next slide also looks
15 at basically what's going on as people
16 age. So it's the number of charges going
17 from ages 12 to 20. And you can tell
18 later in the teen years is when we're
19 seeing most of the charges and contact
20 with the justice system happening. So
21 that kind of gives us an idea of where to
22 target, what this might look like in
23 Philadelphia. And the brackets around
24 the 18, 19, and 20-year-old charges is
25 there because we don't think that there's

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2 a decrease happening. We think that
3 something is moving on into the adult
4 system. So we're still trying to figure
5 out what that balance is, but the
6 transition from the juvenile justice to
7 the adult justice system is a very
8 important transition that we're still
9 looking into.

10 So these slides are going to
11 come in in kind of waves here, but we're
12 going to look at charge severity across
13 age as well. So looking at 12 to 20
14 again, you can see that felonies increase
15 as well as they get up to the 15, 16,
16 17-year-old range, but most of the
17 charges that we're seeing are
18 misdemeanors in severity, and in the last
19 category is summary charges. But
20 basically this also gives us more of a
21 clue of what's happening in Philadelphia.
22 We're seeing a lot of felony and
23 misdemeanor charges compared to summary
24 charges, which is not good,
25 unfortunately.

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2 So I kind of wanted to quickly
3 give you an idea of what the parents are
4 seeing, because in our academic setting,
5 we kind of -- we can look at data and bar
6 charts all day, but in the end, it's the
7 parents' experiences which are very
8 valuable to us.

9 So the first quote is from a
10 parent who was describing an event that
11 happened when her son was 17. He had an
12 incident when he was about 17 years old
13 involving the police. He was not charged
14 with anything. It was a misunderstanding
15 and caused him great anxiety. Police
16 departments need to learn more about
17 those who have different degrees of
18 autism, especially Asperger syndrome,
19 because they are most likely to be in
20 situations which can result in a
21 misunderstanding. Head and eye movements
22 can cause an individual to look as if he
23 or she is on drugs or inebriated.

24 So while this has a positive
25 outcome while no charges were assessed,

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2 that initial manifestation of symptoms
3 still led to justice contact, which is
4 unfortunate.

5 And then the second one I
6 thought was pretty funny and clever
7 little experience. My child was
8 called -- my child called the local
9 police department in the past to report
10 his father when he was being disciplined.
11 This was very inappropriate and he
12 learned when things are and are not
13 emergencies. He also wrote a letter of
14 apology to the police officer.

15 So, you know, just like any
16 other kid, they have to learn the
17 boundaries of the law, and we believe
18 that kind of instituting interventions in
19 the justice system as well as helping
20 families can help clear up any
21 misunderstandings that happen and support
22 the systems to support individuals with
23 autism.

24 So I'd just like to wrap up by
25 saying that Philadelphia is well on the

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2 way to being the leader on this front.

3 I've done a lot of research, and there's
4 not a lot of justice supports out there
5 across the nation.

6 And I'd like to thank you for
7 the opportunity to testify today.

8 (Applause.)

9 MS. MILLER: Good morning,
10 Councilman O'Brien and members of the
11 Disabled and Special Needs Committee. My
12 name is Kaitlin Koffer Miller and I'm the
13 Policy Project Manager at the ASERT
14 Collaborative Eastern Region. In the
15 past three years under the direction of
16 Dr. Lindsay Shea, I have developed and
17 executed many policy projects and
18 specialized with the focus on qualitative
19 and quantitative research methods. I
20 have a Master's degree in Public Health
21 from Drexel University and a Bachelor's
22 degree in Metropolitan Studies from New
23 York University.

24 So I'm going to direct your
25 attention to the PowerPoint, and here is

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2 a map of Philadelphia drawn down by the
3 ten Council districts. The darkest color
4 indicates the highest number of
5 individuals with autism who are receiving
6 publicly funded services. As you can
7 see, the City Council districts with the
8 highest number of individuals with autism
9 are in District 6 and District 7.

10 Autism affects people of all
11 races, ethnicities, and socioeconomic
12 statuses and it's present in every corner
13 of Philadelphia across the entire City.
14 The uniqueness and the diversity of the
15 communities in Philadelphia present many
16 unique and diverse challenges that need
17 to be and have been considered in the
18 development of initiatives for the
19 Philadelphia Autism Project.

20 According to the 2011
21 Pennsylvania Autism Needs Assessment,
22 over 77 percent of individuals with
23 autism in Philadelphia report that they
24 do not participate in any community
25 activity and over 88 percent do not

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2 participate in any advocacy group. Of
3 the family members in Philadelphia
4 represented in the PA Autism Needs
5 Assessment, greater than 97 percent are
6 not receiving any support for the
7 siblings of their children with autism.
8 Any additional reports are available at
9 paaautism.org/needsassessment.

10 So having presented the unique
11 needs of Philadelphia and the needs of
12 individuals with autism and their
13 families, I'm now going to discuss three
14 of the Philadelphia Autism Project
15 initiatives that are meant to address
16 these needs for families, individuals,
17 and providers. So those three
18 initiatives are seed money, a website
19 (hub of resources), and engagement with
20 the Free Library of Philadelphia.

21 To help address the unmet needs
22 across Philadelphia, a process to receive
23 applications for seed money in order to
24 assist community-driven efforts will
25 engage community organizations and/or

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2 advocates. Individuals with autism or
3 their family members in the community
4 from every corner of Philadelphia will be
5 able to submit applications and proposals
6 for seed money in order to facilitate a
7 support group, a program for individuals
8 or their families, an event, et cetera,
9 that directly meet the specific needs of
10 their given community. It is our hope to
11 work with the members of City Council to
12 target applicants in each of the ten City
13 Council districts to reach individuals
14 across the City, with a special focus on
15 underserved communities.

16 In the three stakeholder
17 meetings that Mary and Valarie discussed
18 of the Philadelphia Autism Project, the
19 development of an accessible resource hub
20 for individuals with autism and their
21 families was a consistent priority. To
22 accomplish this initiative, we are in the
23 development phases of a Philadelphia
24 Autism Project portal to be housed on the
25 ASERT website, paautism.org.

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2 Paaautism.org is a state-level resource,
3 and the Philly Autism Project portal will
4 allow Philadelphians to drill down
5 specifically to resources that are most
6 relevant to them and to utilize state
7 resources as well, including a manned
8 call line and an online account creation
9 feature. This hub will house clickable
10 Philadelphia maps by autism, including
11 maps by zip code, neighborhood, and will
12 also house resources, the Philly Autism
13 report that Councilman O'Brien has
14 discussed, and a method to request
15 trainings in a variety of topics specific
16 to autism.

17 Another mechanism to reach
18 individuals with autism and their
19 families as well as professionals and
20 other community members, we have engaged
21 the Free Library of Philadelphia given
22 its reach across the City and its long
23 history of engaging Philadelphia
24 communities in a vast array of ways.
25 There are 61 Philadelphia library

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2 branches located all over the City,
3 offering a myriad of resources that are
4 beneficial to individuals with autism and
5 their families, including employment and
6 vocational opportunities, access to
7 computers and the Internet, and a
8 potential space for sensory story time,
9 community meetings, events, trainings,
10 and activities. As the Philly office and
11 project continues to develop, it will be
12 important to use emerging data on the
13 needs of Philadelphia communities to
14 continually engage with the Free Library
15 of Philadelphia to maximally support
16 individuals with autism and their
17 families in their own communities.

18 To conclude, I would like to
19 circle back to the map I presented
20 earlier and highlight the prevalence of
21 the individuals with autism located in
22 each of your districts. Please consider
23 the autism population in your district
24 and the City at-large. The needs are
25 apparent. The Philadelphia Autism

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2 Project is a unique opportunity to reach
3 the diverse communities throughout
4 Philadelphia.

5 Finally, I would like to pay
6 special thanks to the Committee for
7 hearing me today and to Chairman O'Brien.
8 The ability to accomplish these
9 initiatives is thanks largely in part to
10 Chairman O'Brien. Without his fervent
11 support of the autism community and his
12 efforts to organize the stakeholders and
13 systems of Philadelphia, we would not be
14 able to make these strides to continually
15 and maximally support individuals with
16 autism in Philadelphia as well as their
17 caregivers, family members, support
18 professionals, educators, and fellow
19 community members.

20 Thank you.

21 (Applause.)

22 MS. WALL: Good morning. I
23 think it's afternoon now. Good morning.
24 My name is Nina Wall and I'm really
25 delighted to be here today. I serve as

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2 the Director of the Bureau of Autism
3 Services at the Office of Developmental
4 Programs, Department of Human Services.
5 I want to also just give a shout-out to
6 my colleague, Pia Newman, who is sitting
7 back. Pia Newman is the Assistant
8 Director of the Autism Bureau. She's
9 also the architect and manager of Adult
10 Autism Waiver. So I'm delighted to have
11 Pia here today, and I'm also delighted to
12 be joined by my colleagues from ASERT.
13 And as you can see from the presentations
14 today, these folks are doing some
15 incredibly groundbreaking work that is
16 going to advance the system of supports
17 for individuals with autism and those who
18 love them.

19 In addition to overseeing the
20 Bureau of Autism Services, which I want
21 to point out is one of the first
22 state-level offices specifically
23 dedicated to address the challenges
24 around autism, and like Councilman
25 O'Brien said earlier, it's a really cool

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2 thing to be one of the first, but it's
3 also very hard, because as is the case
4 with so much of what we're trying to do,
5 there are no templates that exist right
6 now. So we really are in some instances
7 creating the wheel. We are inventing the
8 wheel.

9 I do want to just -- the Bureau
10 of Autism Services, for folks who don't
11 know, was actually one of the
12 recommendations -- the establishment of
13 an autism hub at the state level was one
14 of the recommendations of the Autism Task
15 Force, which, as Councilman O'Brien
16 mentioned, is now ten years old, and I
17 had the great good fortune of serving as
18 Co-Chair of the Autism Task Force with
19 Councilman O'Brien at the state level ten
20 years ago.

21 I really am heartened by the
22 release of this report today, and I'll
23 just share with all of you, when we
24 brought together 300 individuals to form
25 the Autism Task Force ten years ago,

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2 there were many people who really, as is
3 the case with many initiatives that roll
4 out at that level of government -- and I
5 have to say I had a little bit of
6 skepticism myself having participated as
7 an advocate and as a parent of someone
8 living with autism in many different
9 processes. It's very rare when you
10 actually see vision translate into
11 something tangible and concrete, and
12 what's very exciting to me is to see this
13 process mirrored now with the
14 Philadelphia Autism Project.

15 The Autism Task Force gave
16 birth not only to the Bureau of Autism
17 Services, but some of the first models to
18 support individuals, adults, with autism
19 that have ever been developed, and I
20 think that is very exciting. This was
21 really the vision of the 300 individuals
22 who participated in that process over 18
23 months. And I don't know. You had 100
24 and how many recommendations? We had
25 1,200 pages of report when the Autism

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2 Task Force completed its work.

3 I'm pleased to say that we have
4 implemented the primary recommendations
5 of that report. And so now for all of us
6 here, I think the challenge is to take
7 this great vision, this great energy.
8 We, I think, certainly have heard very
9 poignantly from many of the folks who
10 have -- the experts who have presented
11 testimony today the magnitude of the
12 challenges we're facing in the system to
13 address the needs of folks living with
14 autism. But the challenge now is to take
15 that vision and begin to translate it
16 into action.

17 And I often say it's not so
18 easy to develop the "what." It isn't.
19 It takes great commitment and time and
20 dedication from certainly the folks in
21 this room and others who participated in
22 the process. But the real challenge is
23 in the "how." How do you get it done,
24 how do you get the right people in the
25 room, how do you get folks to think

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2 innovatively outside the box, how do we
3 make sure that the recommendations and
4 the work going forward really reflects
5 the needs that I think we're hearing sort
6 of boots-on-the-ground folks telling us
7 about.

8 From my perspective at the
9 state level -- and I certainly know
10 different levels of the system -- we do
11 far too much crisis management. We are
12 putting out fires perpetually, and quite
13 honestly, I think most of us would like
14 to be more involved in all of that good
15 work that averts crisis and helps
16 individuals acquire the skills that they
17 need in order to become contributing,
18 valued members of their communities.

19 So I think I have great hope
20 with respect to this initiative because
21 you have mapped out a vision that I think
22 proactively lays out a process to begin
23 not looking at the strengths you have in
24 the City, which are abundant, but also
25 looking at the gaps in what's going to be

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2 needed going forward.

3 I do want to say that we are
4 facing a healthcare systems crisis of
5 enormous magnitude. When Councilman
6 O'Brien references the 25,000 individuals
7 who are going to be impacting our system
8 over the next few years, I'll share with
9 you that currently the Bureau of Autism
10 Services is funded to support just shy of
11 600 adults with autism in our two
12 innovative models. Certainly for me, for
13 my staff, for those of us who are
14 invested and care about this population,
15 that number should really raise the hair
16 on the back of your neck. We have
17 developed models, but the reality is
18 funding and resources are needed to grow
19 the supports -- the system of supports
20 that these individuals will require.

21 This is going to be an
22 all-hands-on-deck, folks. I would say --
23 and I often say when I go out in the
24 stump and I talk about the work that's
25 underway in the Bureau of Autism

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2 Services, you really can't wait for the
3 state to figure it all out. We have
4 rolled out some things that I think are
5 extraordinary and are serving as models
6 for other states in the national
7 dialogue. I love the idea of what's been
8 born here in Philadelphia, the idea of
9 communities defining their strengths,
10 their gaps, their hopes in beginning to
11 develop a path for -- certainly we're
12 talking about individuals with autism,
13 but having the state and communities
14 working in tandem is extraordinarily
15 important, that we're doing top down and
16 we're doing bottom up.

17 And then I would also say
18 outside of government -- and, Councilman
19 O'Brien, you referenced the need for
20 innovative partnerships. ASERT is
21 certainly I think an example for us as an
22 extraordinary partnership. These guys
23 have allowed us to extend our reach, as
24 you can see, in some very substantive
25 ways, but we're going to need to continue

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2 to partner with the private sector,
3 particularly when we're looking at the
4 challenges around finding meaningful
5 employment for this very capable
6 population of individuals and addressing
7 the challenges around housing and
8 transportation. These partnerships and
9 collaborations are going to be critically
10 important going forward.

11 So it's been a pleasure to be
12 part of this process, and I am very
13 hopeful and deeply appreciative to
14 Councilman O'Brien for his continued
15 advocacy in this area, to members of the
16 Committee, and to all of the people in
17 this room who have contributed so much of
18 their time and energy to this process.

19 I want to also recognize
20 certainly for those individuals living
21 with autism and the families of
22 individuals living with autism the need
23 to continue to tell the stories and to
24 share the narratives keeps it very real.
25 And in addition to the "what" and the

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2 "how," there's the "so what." We have to
3 make sure that whatever we build,
4 whatever we grow is reflective of the
5 experiences of people who are affected by
6 this challenge every single day.

7 So with that, thank you so much
8 for the opportunity to offer some remarks
9 today. I do have written testimony that
10 I'll submit for the record, but with
11 that, I'd also be pleased to answer any
12 questions.

13 Thank you.

14 (Applause.)

15 COUNCILMAN O'BRIEN: I'd just
16 like to thank all of you for your
17 testimony here today and just reflect
18 back on a conversation that I had. There
19 was a guy named Mike Piecuch, who was my
20 Chief of Staff when I was Speaker of the
21 House, and he kept dragging me down to a
22 place called Franklin and Marshall, and
23 he introduced me to a gentleman by the
24 name of John Fry. And we started having
25 conversations about individuals with

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2 autism and kids with ADHD and dyslexia.

3 And then he called me one day and he

4 said, Mr. Speaker, I want to put my

5 shoulder -- let me amend that. I want to

6 put the shoulder of Franklin and Marshall

7 behind your initiatives. Then he moved

8 down here to Drexel University. And I

9 called him and I said, You have a bigger

10 shoulder.

11 He says, I'm going to put it

12 behind this conversation. And, boy, has

13 he ever, as you can see from the

14 wonderful testimony, involvement of all

15 those at Drexel University. He's raised

16 over \$20 million and he's incorporated

17 wonderful researchers and epidemiologists

18 and creators of wonderful designs in the

19 system.

20 And, PJ, thank you for

21 recognizing the importance of our guys'

22 involvement and contact with the criminal

23 justice system. I'd just like to say

24 flat out, our guys are not dangerous.

25 They just have odd behaviors at times and

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2 they have tremendous anxiety. These
3 individuals sometimes have 10,000 things
4 coming at them at any given moment, and
5 if we have five or six a day, we're out
6 of control. So just imagine what it's
7 like to live with autism and overcome
8 those complexities. And there's not a
9 day that goes by that I don't get a call
10 or Nina or some of the other partners
11 from somewhere in the Commonwealth of
12 Pennsylvania where one of our guys has
13 inappropriately been detained or engaged
14 with the criminal justice system in one
15 way or another. And sometimes it's
16 because of my contacts with DAs and as
17 Chairman of the Judiciary with judges
18 that we can intervene and just say, Can
19 you take another look at this. And PJ is
20 looking at those kinds of diversion
21 programs and identification of these
22 individuals so we can fast-track them and
23 bring the resources to the criminal
24 justice system that are necessary for
25 appropriate processing of these

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2 individuals and their situations.

3 I remember just profoundly
4 Kevin Dougherty, who is a wonderfully
5 gifted person. I met him first when he
6 was in the Juvenile Unit in the
7 Philadelphia District Attorney's Office.
8 It was through that understanding that he
9 became a judge and he became President
10 Judge of Family Court, and now he's
11 President Judge of the entire court
12 system in the City of Philadelphia. But
13 there wasn't a time that I called that he
14 wouldn't come over and sit down and bring
15 all of his wonderful resources, whether
16 it was Probation and Parole or other
17 judges or opportunities to engage
18 informationally and programmatically with
19 the courts. And his thirst for new
20 information as to how to bring resolution
21 to this complex conversation was just
22 absolutely extraordinary. And just to
23 give you an insight, he recognized one
24 time that there was an individual living
25 with autism in front of him in the court,

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2 and he thought that individual was being
3 disrespectful because he was not making
4 eye contact. And that's so informative,
5 because these individuals when they look
6 away, that's when they're able to
7 concentrate and put their thoughts
8 together and process it.

9 So we have to understand the
10 behaviors. We have to understand that
11 it's important that we make not only
12 individuals ready for the community but,
13 more importantly, we have to make the
14 community ready for our individuals
15 living with autism. And we have to have
16 a broad vision that we want to make
17 Philadelphia the first autism-friendly
18 city on the planet so that our guys can
19 go to museums, they can go to schools,
20 they can go to Dunkin Donuts or Wawa or
21 any place they want and there are people
22 there that are going to understand them,
23 they're going to respect who they are,
24 they're going to recognize them for the
25 wonderful talents they have, whether

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2 they're an aspiring paleontologist or
3 whether they work at Keystone Aviation in
4 Northeast Philadelphia, where one of our
5 individuals -- there's an aerial
6 photography place at Northeast
7 Philadelphia Airport, and this individual
8 looks in the margins and finds all the
9 issues that are challenging in high
10 resolution photography. But the most
11 significant thing is, he improves the
12 workforce every day. He makes everybody
13 in that organization better, because he
14 doesn't bring any prejudice. He doesn't
15 bring any judgment. He just makes
16 everybody feel better, because he's
17 unspoiled by all the things that
18 complicate our lives. And I dare say
19 sometimes the individuals with autism are
20 much better off than we are, because we
21 can't help it but be judgmental and
22 discriminatory in things that have
23 affected us through our life, but they
24 are wonderfully refreshing and so
25 wonderfully capable.

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2 And, PJ, I just have one
3 question for you and, that is, again, if
4 you can just expand as to why the justice
5 system is highlighted in the Philadelphia
6 Autism Project but, more importantly,
7 we're talking about individuals who have
8 been -- has had contact with the criminal
9 justice system because they've been
10 accused of certain misdemeanors. But how
11 about the victims? Can you speak to that
12 as well?

13 MR. TURCOTTE: Well, I think
14 you touched on it nicely, that we are
15 preparing the community for individuals
16 with autism, and just to reiterate what
17 you said, individuals are not more
18 dangerous. We think that just because of
19 circumstance, they might come into
20 contact with the criminal justice system,
21 and having those preparations in place
22 before they get there and having the
23 awareness in there before they arrive in
24 that system is crucially important. And
25 what we've seen is that when we've had

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2 discussions with people in the justice
3 system, they've been more than receptive
4 to receive training or advice on how to
5 deal with these individuals.

6 And the status of victims,
7 we've heard anecdotally about individuals
8 being easily -- people can take advantage
9 of them pretty easily, as well as being
10 susceptible to manipulation in bad ways.
11 So it's an under-researched area and
12 something that we're definitely looking
13 into. A big part of the Philadelphia
14 Autism Project is looking into not only
15 offenders but victims, everything from
16 their -- even eloping, because police
17 will see somebody with autism. If they
18 run away -- we just had an instance at
19 CHOP last week. So all those different
20 interactions that people in the justice
21 system can have we're looking into.

22 COUNCILMAN O'BRIEN: Thank you.

23 I just remember some challenges
24 that have been brought to the attention
25 of our office, and law enforcement looks

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2 and sometimes they may not prosecute a
3 case where an individual is autistic
4 because they don't, quote -- they're not
5 good witnesses, but the DA's association
6 in Pennsylvania has gotten
7 extraordinarily better in embracing that,
8 and so have our judges, and, PJ, you're
9 driving the conversation in an
10 extraordinary way.

11 And, Kaitlin, I know a lot of
12 our members are looking at that
13 demographic, and the highest
14 concentration is in the 6th Councilmanic
15 District. That's Bobby Henon's District,
16 so I know he'll be challenged and also
17 very supportive of that. But can you
18 tell us why there's a higher number of
19 individuals receiving services in some
20 districts than other districts, and also
21 why do you think it is that there is such
22 a low percentage of individuals that are
23 participatory in advocacy and in the
24 other conversations that we're trying to
25 drive through the Autism Project?

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2 MS. MILLER: Sure. So the
3 map -- and Pam did pop back over to it so
4 you can look up there for reference.
5 This is only broad numbers, so it doesn't
6 take into account differences in like
7 population numbers. It's not a
8 proportion. It's probably largely due to
9 lack of resources or diagnostic awareness
10 potentially that is lower represented
11 in -- like if you were to look at
12 District 4, it's one of the lower
13 prevalence rates of autism. However, we
14 know from our research that autism is,
15 like I said in my testimony, it's present
16 regardless of race, socioeconomic status,
17 and ethnicity. And I do believe that if
18 we were to also take into account
19 privately insured folks, because this is
20 only the publicly served individuals,
21 that that number would be higher across
22 the board. It might reflect a different
23 proportion, a different prevalence
24 density.

25 And then to your other point

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2 about participation, so that also
3 probably would kind of fall in the same
4 reason about lack of access or
5 availability. So when I said I believe
6 it was 90 -- or it was 97 percent are not
7 receiving sibling services, in between 77
8 and 88 percent are not in community
9 groups or advocacy groups, it could be
10 lack of access. Maybe transportation is
11 an issue, getting to those groups, or
12 perhaps those groups just don't
13 adequately meet their needs. And so we
14 hope that by having seed money, that
15 folks can apply for the seed money and
16 then maybe create a group that is more in
17 line with their interests or at a better
18 time or location for their own needs of
19 themselves and their community members.

20 COUNCILMAN O'BRIEN: Thank you
21 so much.

22 Nina Wall, I understand that
23 you have a wonderful complement of at
24 least 28 people running the whole Bureau
25 of Autism Services for our population,

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2 and someone used the term one time that
3 the Bureau of Autism Services moves
4 mountains with shovels and --

5 MS. WALL: I would agree.

6 COUNCILMAN O'BRIEN: That's an
7 appropriate thing to recognize. But,
8 again, I would like to focus on the
9 census information, and we have again --
10 and I can't emphasize it enough. We have
11 25,000 adults that are going to crash the
12 system by the year 2020. And once you
13 identify that number, we as policymakers
14 have a responsibility to act. And we
15 created Act 62, which has not been
16 implemented, but you have two wonderful
17 service models in the ACAP model and the
18 adult service model, one being managed
19 care and one being MA. They have the
20 same goals with different funding
21 streams. It's a wonderful republican
22 mechanism where you can have competition.
23 But the reality is that we have -- I
24 don't know what the numbers are. Maybe
25 we have a little less or a little over

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2 500 slots that are funded right now,
3 25,000 on the way. And I guess this is
4 more of a way of a statement. Part of
5 the Philadelphia Autism Project's charge
6 is not only to bring stakeholders in this
7 diverse conversation of researchers,
8 educators, diagnosticians, people that
9 assess, and stakeholders who are families
10 and individuals living with autism, but
11 there has to be a new energized sense of
12 advocacy so that we identify the basic
13 needs of this population going forward.
14 We're all going to -- we're all aware
15 that the Commonwealth is struggling with
16 a huge deficit, but the information
17 contained in the Philadelphia Autism
18 Project outlines or identifies a critical
19 need of this population going forward,
20 and they can't wait. They've waited
21 20-some years to get to this point. And
22 the wonderful programs that the Bureau of
23 Autism Services has created are unique.
24 No one else in the country is doing them.
25 And, again, could you outline as a parent

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2 and as the Director of the Bureau of
3 Autism Services the need for that
4 advocacy? I know when Estelle was there,
5 she did such a wonderful job advocating
6 inside for the needs of the autism
7 community and others who were vulnerable,
8 but she did such a good job that she kind
9 of made everybody sit back in their big
10 comfortable chairs and the thought was
11 that someone is going to take care of it.
12 There's no one going to take care of this
13 unless we do it ourselves. Do you want
14 to comment on that?

15 MS. WALL: Certainly. I do
16 want to point out that there are -- we
17 hear Bureau of Autism Services. That
18 sounds really large and impressive. It
19 is impressive because of the moving
20 mountains with shovels, but --

21 COUNCILMAN O'BRIEN: And can
22 you comment, you administer all the
23 programs for the Bureau of Autism
24 Services. In the intellectual disability
25 community, those services are handled by

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2 our local municipalities.

3 MS. WALL: Right. But there
4 are 38 on my team. Our headquarters are
5 in Harrisburg. We have staff in
6 Philadelphia and Pittsburgh, and that is
7 correct. The Autism Task Force that gave
8 us the charge to create a waiver for
9 adults living with autism was very
10 explicit when they recommended that that
11 waiver would be administered directly by
12 whatever autism entity was established at
13 the state level. Unlike in the ID system
14 where the counties serve as the
15 administrative entities, the Bureau of
16 Autism Services directly administers our
17 Adult Autism Waiver. So that obviously
18 poses tremendous challenges when you
19 think of growing the waiver itself. You
20 have to also grow the support, the staff
21 support, to make sure that we can
22 continue to administer the waiver
23 directly.

24 I want to point out, on the
25 advocacy theme my roots are in grassroots

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2 advocacy. I have seen what can happen
3 when you bring a group of professionals
4 and parents and self-advocates together
5 in one place. The energy that is
6 created, the good thinking that is
7 created really has fueled what's happened
8 in the area of disability advocacy. It
9 is central.

10 I guess I would share,
11 Councilman O'Brien, your perspective too
12 that perhaps there was -- I don't want to
13 say complacency because that sounds very
14 judgmental, but it was a very cool thing
15 that the Bureau of Autism Services was
16 established, and I think people felt that
17 through the efforts of the Task Force and
18 the establishment of an autism entity at
19 the state level, that there would in fact
20 be representation of the interests of the
21 autism community, which we have certainly
22 endeavored to do, to fill that need.
23 However, I would say if you look at the
24 census information that's been provided
25 today, there really is no room for

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2 anyone, I think, to assume that it's all
3 going to be taken care of. I think there
4 is an extraordinary amount of work that
5 needs to be done.

6 I do really appreciate most
7 profoundly when I've gone out and spoken
8 to parent groups and I've said, Hey,
9 folks, you really have to keep the heat
10 on, you must -- and I hear families say,
11 We're tired. And if you listen to the
12 stories that families will share about
13 the challenge of navigating these very
14 complex, entrenched, bifurcated systems
15 and then add the very real and most
16 salient need to support your son or your
17 daughter in their growth and their
18 struggles, you can understand why
19 families are tired. And I hear that, and
20 that's usually when I say, That's why you
21 travel in a pack, because at any point,
22 any one of us -- and there are several
23 folks on my team who also are parents of
24 individuals living with autism. Our cell
25 phones are always on and at any point we

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2 can get called out of a meeting because
3 something is happening with that person
4 that got us -- drove our efforts in this
5 arena to begin with.

6 So we need to work very closely
7 and collaboratively in groups, and I
8 think that is needed. That is needed at
9 the state level. That is needed at the
10 City level.

11 I started my advocacy in a
12 support group in my school district, and
13 I met other parents who I could share my
14 stories with, who validated my
15 experience, and that's where my work
16 started, was in the support community.

17 I think we do need some
18 refueling of advocacy. I think it's
19 critically important. And I think we're
20 doing a lot of work with ASERT right now
21 in helping to connect families to the
22 support groups in their communities. I
23 think that's where folks can be most
24 effective, is in their own backyard. And
25 there's an awful lot you can do, and I

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2 think a lot of my advocacy predates
3 what's gone on with the Internet and the
4 way we can now communicate. And so I
5 would say I would agree wholeheartedly
6 with the fact that advocacy is strongly
7 needed at this time.

8 COUNCILMAN O'BRIEN: Again,
9 I'll go back to the 25,000, and this is
10 my sense of advocacy. We have
11 over-waivers, consolidated waivers, and
12 we have ACAP and the adult waiver. And
13 when I look at the year 2020, and I'd
14 like to work backwards off of that -- and
15 I'm not asking you to commit to this.
16 I'm just saying this as a statement of
17 the gravity of the challenge that's
18 facing us.

19 If you take the year 2020 and
20 as proven policymakers you work off that
21 number and you work backwards and say how
22 do we build and design a system that's
23 going to accommodate the needs of those
24 25,000 adults by the year 2020, that
25 necessitates that we're going to have to

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2 increase staff to do all the things that
3 are necessary to incorporate these
4 individuals in those programs. And you
5 can't wave a magic wand and say if we put
6 this money on the table, all these people
7 are going to be taken care of.

8 But perhaps, Nina, you can
9 comment on what is called the Interest
10 List and why it's called an Interest List
11 as opposed to a waiting list, and perhaps
12 what the process is and as it's different
13 to other systems as they incorporate
14 adults into their systems and --

15 MS. WALL: What I can say is
16 that we are currently funded between our
17 two adult programs by the end of this
18 fiscal year to support and assist just
19 shy of 600 adults with autism. We also
20 maintain what we call an Interest List.
21 These are individuals who have heard
22 about our programs, who have expressed an
23 interest in receiving services. There's
24 a great deal of information about how to
25 access or get someone's name on the

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2 Interest List if you go to pautism.org
3 into some of our resources. And Pia is
4 actually -- she's here today, and if
5 folks have specific questions about that
6 process, we can certainly get back to
7 you.

8 I want to -- I just want to
9 point something out too, that I've been
10 really appreciating in my travels around
11 the state and particularly as I speak to
12 adults living with autism not -- I think
13 we've touched on this today. Autism is a
14 heterogeneous challenge. There are folks
15 who are profoundly affected by their
16 autism and then individuals who with some
17 support are going to lead -- can lead
18 very independent lives. Not everybody
19 with autism is going to want or need
20 necessarily a waiver. There are certain
21 very specific requirements that folks
22 must meet around eligibility to receive
23 waiver services across our system.

24 One of the things that has
25 become really striking to me -- and I had

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2 gone to a meeting of adults with autism,
3 self-advocacy group, and I sat next to a
4 gentleman with autism who said, I'm
5 really not interested in the waiver or
6 the ACAP program, because in order to
7 meet eligibility, I have to be Medicaid
8 eligible, and I really want to make money
9 and I don't want to remain impoverished.
10 But he said, I also need help.

11 And I think when we think about
12 what is going to be needed, we have to
13 think very broadly about the need to
14 develop models that reflect the continuum
15 of need across the spectrum, and that's
16 going to require some very innovative
17 thinking.

18 Some of the regulations that we
19 adhere to at the state level are federal
20 regulations. So it's outside of our
21 purview to -- obviously we have to meet
22 those requirements. But I would really
23 encourage this group as you go forward to
24 really think outside the box, and because
25 it doesn't exist in the system right now

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2 doesn't mean that it can't exist. And I
3 think we have to really look at
4 developing a flexible continuum of care
5 and, again to echo, the need to address
6 the needs of folks as they age.

7 We do not yet have much
8 research that we can access around the
9 intersection of autism and aging, and it
10 is wonderful to hear about all the
11 extraordinary work that's been done to
12 build a system to support children with
13 autism, realizing there's more to do, but
14 the dialogue around adults with autism is
15 still very, very young. And I will say
16 we administer these two programs. We are
17 really challenged because we've developed
18 models in an environment where we don't
19 have sufficiently -- we don't have a
20 sufficient number of trained
21 professionals to provide the kind of
22 supports that adults need. A lot of the
23 folks who work in our systems have gotten
24 their experience in the children's
25 system. There's a huge need to begin to

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2 develop standards around training and
3 staff, professional development in the
4 area of providing supports to adults with
5 autism. It is different. It is markedly
6 different when you are working with an
7 adult.

8 So think broadly. Think
9 boldly. If folks do need information
10 about our programs, we're here. We can
11 get you on the right path. But there's a
12 lot of work to do here, and I think
13 you've got a hub where that energy can be
14 unleashed, so it's a good thing.

15 COUNCILMAN O'BRIEN: Thank you
16 very much.

17 Any questions?

18 Councilman Oh.

19 COUNCILMAN OH: Thank you very
20 much.

21 I don't have a question. I
22 just have a comment and, that is, number
23 one, thank you for your testimony, all
24 the witnesses, very valuable testimony.
25 I want to thank Chairman, Councilman, and

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2 Former Speaker of the House, Denny
3 O'Brien, for this wonderful hearing.
4 This is fantastic work.

5 I think the issue of
6 implementation is critical, and one of
7 the most frustrating things that we
8 face -- I'm sure all of you as well as
9 all of us over here -- is best practices.
10 We see them. Trying to implement them is
11 so, so very different in so many areas,
12 but the advocacy of this implementation,
13 getting this group together, having this
14 report really provides a very clear and
15 credible message and opportunity to
16 advance in a very integrated way with our
17 city and our state, our federal
18 government, our private and non-profit
19 sectors the best possible method of
20 helping people at this critical time. So
21 for this blueprint and this opportunity,
22 thank you very much and, Councilman
23 O'Brien, thank you for your great work.

24 COUNCILMAN O'BRIEN: Thank you.

25 Councilwoman Blackwell.

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2 COUNCILWOMAN BLACKWELL: Thank
3 you. I'd like to certainly reiterate
4 what Councilman Oh has said. Thank you
5 all. And certainly I'm sure you must
6 know were it not for Councilman O'Brien,
7 we would not be here, and he, from the
8 moment he came to this Council, has
9 focused on this issue and has, with your
10 help, he has brought us this far.

11 So we want to say thank you to
12 you and we want to commend him on his
13 leadership and his commitment to this
14 issue.

15 Thank you.

16 COUNCILMAN O'BRIEN: Well, I
17 want to thank you, Councilwoman. And I
18 think Councilman David Oh and I are
19 newbies to this conversation, but
20 everywhere I go, the loudest voice that
21 champions -- or gives voice to the most
22 vulnerable in the City is yours, and I'm
23 looking forward to partnering with you in
24 your advocacy for individuals in the
25 educational system so that we can bring

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2 this conversation and merge that as we
3 have with Kim and the wonderful new
4 leadership at the School District of
5 Philadelphia so that we can build
6 advocacy and systems that are consistent
7 and inclusive so that you can move freely
8 from one system to the other.

9 And, Nina, as you said, the
10 supports that an individual needs to be
11 successful in the bigger world, whether
12 it's furthering their education or
13 achieving gainful employment,
14 unfortunately we as policymakers look and
15 say we want you to be gainfully employed,
16 but if you're gainfully employed, we're
17 going to pull your MA supports. So that
18 you can't be gainfully employed because
19 you can't survive in that environment.
20 And these are conversations that
21 hopefully the Philadelphia Autism Project
22 can bridge between the federal, state,
23 and local governments so that we can take
24 these recognizable barriers and mediate
25 them with realistic assessments of what

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2 has to be done so that individuals
3 primarily can be successful in these
4 conversations going forward.

5 So, again, I am very grateful
6 for all the hard work from all of the
7 stakeholders that participated in making
8 the Philadelphia Autism Task Force -- or
9 the Philadelphia Autism Project report a
10 reality. But now as I look around the
11 room with all the people that made this
12 successful, the implementation over the
13 next year is going to be critical. And,
14 again, this is an announcement for
15 those -- we need people who are leaders
16 in your own community that can help
17 identify those supports. And I know I'm
18 going to miss some people who are here
19 today, but as I look around the room, Kim
20 Caputo, AnneMarie Clarke, who was here
21 and left, Roy Diamond, Jackie Gallagher,
22 Karen Krivit, Mary Mathew, Terry
23 Matthews, Mary O'Brien-Mower, the mother
24 of Christopher Mower, Pia Newman, Valarie
25 Oulds, Jennifer Plumb, Tanya Ragali,

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2 Khyllil. Is Khyllil still here? We're so
3 grateful for his participation today.
4 And Kathy Guchia-Meyer, Lindsay Shea,
5 Kathleen Stengel, Cecelia Thompson, Paul
6 Turcotte, Kaitlin Miller, and Nina Wall.
7 We want to thank you for your
8 participation in the Philadelphia Autism
9 Project, even to the point that we
10 created this wonderful logo that uses the
11 Liberty Bell. Thank you for that
12 contribution. Again, for all my
13 wonderful staff.

14 And I would just like to
15 acknowledge that we have copies of the
16 final report. So if you leave, you're
17 welcome to take a copy and share it,
18 analyze it, and come back with
19 constructive comments. They're all
20 welcome.

21 Now, is there anyone else here
22 that wishes to testify?

23 (No response.)

24 COUNCILMAN O'BRIEN: Seeing
25 none, then there being no further

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2 business before this Committee on the
3 Disabled and Special Needs today, the
4 public hearing on Resolution No. 150026
5 is recessed until the call of the Chair.

6 Thank you all very much for
7 your attendance and thank you to my
8 colleagues for your patience and
9 listening to this wonderful testimony.
10 Thank you.

11 COUNCILWOMAN BLACKWELL: I
12 would like to make a motion that the
13 Committee on the Disabled and Special
14 Needs adopt the Philadelphia Autism
15 Project Final Report.

16 COUNCILMAN O'BRIEN: Is there a
17 second?

18 (Duly seconded.)

19 COUNCILMAN O'BRIEN: All those
20 in favor?

21 (Aye.)

22 COUNCILMAN O'BRIEN: The motion
23 carries. The report is adopted.

24 Thank you, Councilwoman
25 Blackwell, for that.

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2 (Committee on the Disabled and
3 Special Needs concluded at 12:55 p.m.)

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CERTIFICATE

I HEREBY CERTIFY that the
proceedings, evidence and objections are
contained fully and accurately in the
stenographic notes taken by me upon the
foregoing matter, and that this is a true and
correct transcript of same.

MICHELE L. MURPHY
RPR-Notary Public

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