



**Philadelphia Councilman-At-Large
Dennis M. O'Brien**



Philadelphia
AUTISM PROJECT

FINAL REPORT
January 2015

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This report was prepared by *OPEN MINDS*, in partnership with the Eastern Region ASERT at Drexel University, The Department of Behavioral Health and Intellectual disAbility Services, and Councilman Dennis M. O’Brien’s team.



I. Acknowledgements

The Philadelphia Autism Project is a project of Philadelphia Councilman-At-Large Dennis M. O'Brien, conducted in partnership with the Department of Behavioral Health and Intellectual disAbility Services (DBHIDS). Commissioner Arthur Evans' commitment to this project was vital to its success. This project would not have been possible without the active participation of over 100 talented, committed, and caring individuals who responded to Councilman O'Brien's call to bring together the Autism Spectrum Disorder (ASD) community in Philadelphia in an effort to improve the lives of those living with an ASD and their families. These dedicated individuals comprised the leadership team and stakeholder meeting participants (full list included in Appendices B and C).

In addition, the Philadelphia Autism Project is most appreciative of the following individuals and organizations: Seth Williams, Philadelphia District Attorney, for hosting each of the stakeholder meetings at the District Attorney's Office; Michelle Hazelwood Hyde for donating her time and talent to create the Philadelphia Autism Project logo; Valarie Oulds for serving as the lead point person for DBHIDS; Nina Wall, Director of the Bureau of Autism Services, for providing Commonwealth of Pennsylvania ASD data; Kim Caputo from the Philadelphia School District and David Mandell from the University of Pennsylvania for providing Philadelphia education system data; Craig Newschaffer, Director of the A. J. Drexel Autism Institute, Lindsay Shea, Director of the Autism Services, Education, Resources, & Training Collaborative (ASERT) Eastern Region, and their team including Mary Mathew, Kaitlin Miller and Paul Turcotte for providing Philadelphia specific data on ASD, supporting the organization of stakeholder generated initiatives, creating the Philadelphia Autism Project pre-implementation survey and analyzing the survey results. Finally, special thanks must be given to the self-advocates and family members who participated throughout this process to ensure that their personal experiences, successes, perspectives, and challenges informed and guided this work.

II. Letter From Councilman Dennis M. O'Brien: Announcing Results & Thanking Participants



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COUNCILMAN-AT-LARGE

Dear Reader,

On behalf of City Council, the Department of Behavioral Health and Intellectual disAbility Services, and the stakeholders of the Philadelphia Autism Project, it is a privilege to present you with the Philadelphia Autism Project Final Report. The Philadelphia Autism Project created a citywide task force to examine the quality of and access to services and supports for individuals and families in Philadelphia who are living with autism. Numerous factors warranted the undertaking of this unprecedented initiative at the municipal level. This report represents an action plan for Philadelphia to significantly improve the lives of individuals and families living with autism. I believe this is a critical first step in our process to overcome the identified environmental barriers individuals living with autism deal with on a daily basis.

Autism is a pressing national public health issue. The Center for Disease Control and Prevention estimates that 1 in every 68 children in the United States are on the autism spectrum. Furthermore, the 2014 Pennsylvania Autism Census Report signals a looming crisis as the number of adults with autism in Pennsylvania is projected to increase by 20,000 individuals by the year 2020. This is especially concerning since there are few services currently available for adults. While Pennsylvania was among the first in the nation to create several models to support the adult autism population, access to services is challenging due to limited funding. Lastly, the struggles individuals and families impacted by autism confront on a day-to-day basis has been an area of great importance to me, a cornerstone of my career in public service, and an area that can be vastly improved with the ongoing dedication of our stakeholders.

Philadelphia is recognized as one of the top ten cities to live in if you are diagnosed with autism; however, we realize there continue to be gaps in services and supports, as well as unmet needs that must be addressed. During this process our stakeholders effectively articulated the current state of living with autism in Philadelphia. It is clear tremendous progress has been made in the last two decades. However, individuals with autism are becoming increasingly more involved in the juvenile and criminal justice systems; they face high levels of unemployment; families continue to struggle to navigate a complex world of services; they struggle to secure appropriate housing; best practices continue to be underutilized; and opportunities for true community inclusion are often limited.

On May 12, 2014, the first of three all-day meetings pulled together over 130 diverse community stakeholders including: advocates, self-advocates, family members, administrators, service providers, city agency personnel, educators, policy-makers and researchers. Stakeholders also represented a broad array of community organizations that individuals with autism and their families may have contact with over the course of their lifespan such as: the School District of Philadelphia, the Department of Behavioral Health and Intellectual disAbility Services, the Department of Human Services and the Criminal and Juvenile Justice Systems. These individuals came ready to work and brought with them years of personal and professional experiences that are the heart and soul of this report.

Meeting one began this intensive process and opened with an overview of national, state and local trends to ground our stakeholders in the latest data and information regarding autism. Then stakeholders worked to identify the strengths and weaknesses of the system in Philadelphia. We then generated a list of ten topics that would be the focus of the second meeting. Meeting two was dedicated to having ten work groups identify specific problems and strategies for addressing those challenges. Our stakeholders authored a comprehensive set of more than 100 initiatives. Our third and final meeting was used to gather stakeholder input, where they voted to select top priority initiatives; their recommendations are outlined in this report.

My office has started to map out an implementation plan and will reach out to stakeholders interested in the next phase of this project. Immediate action can be taken on some recommendations, whereas other long-term initiatives will need further development and broader systemic modifications. While many of the recommended initiatives might require significant disruption to the status quo, we are committed to making real change in Philadelphia.

The Philadelphia Autism Project would be impossible without all of the advocacy efforts undertaken at various levels of the system, including the pioneering work of the Pennsylvania Autism Task Force, for which I had the pleasure of serving as the honorary co-chair. The vision and leadership of Estelle Richman, M.A. energized the statewide autism conversation. Dr. David Mandell, Dr. Nancy Minshew, and Nina Wall, M.S.S, L.S.W., worked tirelessly to co-chair the ambitious and model task force laying the foundation for our work here in Philadelphia.

I want to extend my thanks to all of the stakeholders that participated in the Philadelphia Autism Project. Your commitment to this effort is commendable, and I am confident that the time, energy and passion you've shared as part of this process will greatly benefit all Philadelphians living with autism and serve as a national model for other municipalities to replicate. This project would not have been possible without the commitment of several key organizations and individuals. I am grateful to Commissioner Arthur Evans, Ph.D. and his team led by Valarie Oulds, Esq. at the Department of Behavioral Health and Intellectual disAbility Services for partnering with us on this project.

We were also very fortunate to have a leadership team that made a significant commitment of time and resources that was essential to the success of this project. I would like to thank Dr. Annemarie Clarke, Jackie Gallagher, Esq., David Gates, Esq., Dr. Kamilah Jackson, Dr. David Mandell, Terri Matthews, Dr. Jeannette Newman, Dr. Craig Newschaffer, Valerie Oulds, Esq., Dr. Lindsay Shea, and Nina Wall, M.S.S, L.S.W. Additional thanks to Paul Neitman, L.M.S.W., Rennie Joshi and Sabrina Woodlief from Open Minds for their work facilitating the stakeholder and leadership meetings and drafting this report. Finally, I'd like to thank my staff, Matthew Braden, Dr. Katy Kaplan, Margie Caputo, Miriam Enriquez, Esq., Kevin Carroll, Marita Trimmer, and our interns Rachel Hooper and Josh Salzer. Their hard work was essential to making this project a reality.

Sincerely,



Dennis M. O'Brien
Philadelphia Councilman-At-Large

III. Executive Summary

The Philadelphia Autism Project represents the first municipal-level initiative to improve the lives of individuals living with an ASD. Through a series of three stakeholder meetings, 139 initiatives were identified that, if implemented, will substantially improve the quality of life of individuals and families living with an ASD. In order to better understand and develop recommended priorities for implementation these initiatives were organized into the following four categories:

1. **Resources, Outreach, Awareness, Training, and Education:** To assure that individuals and families living with ASD, and those that support them, are continually apprised of the advances in knowledge about ASDs, best practice methods, and the local resources available to bring about the highest quality of life possible.
2. **Infrastructure:** To bring about the necessary changes and increased collaboration/integration of systems that are responsible for supporting individuals and families living with an ASD, as well as other community institutions in Philadelphia, in order to be more responsive and increase access to services and the community as a whole.
3. **Policy:** To explore public policy, local ordinances, and/or practices that will initiate or continue development of more responsive community systems and resources in order to further improve the quality of life for Philadelphians living with an ASD.
4. **Capacity:** To increase the knowledge base, collaboration, responsiveness, and service availability of community institutions whose expertise or services can contribute to an increased quality of life for individuals and families living with an ASD.

Given the process was driven by our stakeholders, it was important to ensure they would have an opportunity to provide clear direction regarding the implementation phase of this project. To this end, we created a pre-implementation survey affording all stakeholders the opportunity to identify their top recommendations for priority initiatives. In the interest of maximizing the efficiency of implementing the initiatives given the varying degrees of resources and time that would be required, three categories of initiatives were created for voting purposes: (i) short term (one year or less) with no new resources required; (ii) short term (one year or less) with new resources required; and (iii) long term (requiring multiple phases in excess of one year to complete).

Below are the top 5 stakeholder recommendations for priorities by category:

1. Short Term (one year or less) with no new resources required

Votes	Initiative #	Description
29	24	Convene ongoing discussions between all payers (Community Behavioral Health, Medicaid, managed care plans, the school district, commercial insurers, Office of Vocational Rehabilitation, etc.) to determine means of braiding funding through common procedure codes, provider qualifications and centralized billing
22	14	Development of “Transition Toolkits” across lifespan for teachers/professionals to use in support of individuals and families living with autism (i.e. – early intervention, school age, 21 and over, seniors)
16	22	Research Medicaid Health Home provision of ACA (§2703 of ACA) and consider the usefulness of this model as an additional funding source; Reach out to Community Behavioral Health, Mental Health Association of Southeastern PA, PA Mental Health Consumers Association, Parents Involved Network, and the Alliance of Community Service Providers to determine interest in a joint Health Home project
16	25	Secure additional autism waiver slots
14	4	Post-Secondary Transition Planning (i.e. – OVR services available, what colleges have programs and supports specific for individuals with an ASD, etc.)

2. Short Term (one year or less) with new resources required

Votes	Initiative #	Description
28	4	Establishing an Annual Philadelphia Autism Conference – conference will be organized by lifespan tracks (i.e. – ages 0-5, school age, 21 and older, older adults) and cover the needs across the spectrum; Conference can also be utilized to organize a grassroots advocacy movement by pulling together a community of individuals with autism, families, providers and researchers to secure more funding, advocate for key legislative changes, etc.
20	2	Creation of Philadelphia Autism Support Group that would utilize a wide range of support strategies including training, webinars, support groups (face-to-face and internet based), peer-to-peer mentoring, etc.
17	30	Professional development of Educators and School Personnel – Assure new teacher coaches get ASD training; Create summer institutes to train teachers and offer financial incentives to participate; Develop a test for autism support teachers, with the requirement that the teacher must pass the test in order to teach; Mandated training for non-teaching assistants, principals and other staff on autism specific issues to ensure an autism friendly school environment; Mandated autism training and continued professional development for teachers in autism support classrooms
16	12	Maintain a database of specialized services and culturally competent providers (culture, languages, etc.) and resources (video, blogs, support groups, etc.)
12	33	Partner with colleges and universities to develop and standardize training programs for teachers and other healthcare professionals interested in working with individuals who have autism, and create more opportunities for internships for allied healthcare professionals, similar to psychology internships

3. Long Term (requiring multiple phases in excess of one year to complete)

Votes	Initiative #	Description
23	1	Creation of “gold standard” centralized resource, possibly a website or the adaption of an existing website, and/or a physical location that can be used to: disseminate existing resources as well as new resources generated; promote awareness initiatives; develop new apps for wider reach and remote access; and establish “connection sites” where information and community experts are brought together to facilitate increased community awareness of ASD and assistance with access to services
16	18	Launch an agency/entity to serve as single, centralized Philadelphia specific portal of entry for access to clinical, behavioral and educational ASD related services that would directly provide initial evaluation/diagnostic services, ongoing multidisciplinary/multisystem care planning and ongoing system navigation whose evaluation and care planning would be accepted across providers/agencies in the city
14	20	Implementation of “Comprehensive Integrated Care Plan” with a “System Navigator” role to assist individuals and their families with successful plan implementation; Explore possibility that the Medicaid Health Home provision of the Affordable Care Act can serve as a potential funding source for System Navigator
14	49	Create Vocational Autism Work Group that can develop a strategic plan to increase internships within City departments and non-profits, and tax incentives for private business internships
12	15	City Wide Task Force of providers from across the lifespan to develop a Universal Multi-Disciplinary/Multi-System Care Plan protocol (Individual Services Plan, Universal Services Plan, etc.) that meets the requirements of all funding systems. The protocol should emphasize use of best practices documenting the appropriate intervention at each age group for specific needs. Additionally it should identify the role of the various professionals and their ability to identify what an individual with autism needs.

Philadelphia is nationally recognized as one of the “Ten Best Cities” for those living with an ASD (Autism Speaks, Ten Best Places to Live if You Have Autism, April 1, 2011). However, there are still gaps and unmet needs for individuals with an ASD and their families who live in Philadelphia. The 15 initiatives listed above were recommended by the stakeholders as a starting point for the Philadelphia Autism Strategic Plan, which will further improve the lives of people with an ASD and provide them with needed support.

IV. Introduction

The Philadelphia Autism Project was sponsored by Philadelphia Councilman-At-Large Dennis M. O'Brien and was conducted in partnership with DBHIDS. Councilman O'Brien sought to build upon the strengths of services and supports available in Philadelphia while also addressing concerns and challenges facing individuals living with an ASD and their families. Katy Kaplan, his Director of Human Services and Special Initiatives, was charged with leading a diverse group of stakeholders (see Figure 1) in the first ever municipal level initiative to build a strong community support system for individuals and families living with an ASD. *OPEN MINDS* was selected to support this effort by facilitating the process and writing a final report based upon the work of the Stakeholders Group and Leadership Team.



Figure 1. Philadelphia Autism Project Stakeholders

A. Background & Purpose

In a 2011 *Autism Speaks* national survey, Philadelphia ranked in the Top Ten of best cities to raise children with an ASD. Philadelphia has a wealth of world class medical facilities, universities, and colleges that are actively involved in ASD research and advocacy. There is a system of service providers who are able to provide a wide range of services for both children and adults with an ASD. Philadelphia also has a network of community members (i.e. – government officials, community institutions, employers, etc.) who are responsive to the need to create an inclusive community and to improve the quality of life for Philadelphians living with an ASD.

State and local leadership has been instrumental in advancing awareness of and support for individuals and families living with an ASD. The Bureau of Autism Services (BAS), through the Pennsylvania Department of Human Services (DHS), is a state-level government entity with two direct service programs to support adults with an ASD; the Adult Autism Waiver and the Adult Community Autism Program (ACAP). A third initiative, The ASERT Collaborative is a statewide initiative, funded by BAS, which provides support to individuals with an ASD and their families through resources, training, and other projects. Act 62 (the Autism Insurance Mandate), mandates private insurance companies cover services for individuals diagnosed with an ASD. These initiatives have led to improved services, enhanced quality of life, and expanded opportunities for Philadelphians with an ASD.

Despite statewide and localized efforts, Councilman O’Brien understands that there are continuing needs and challenges for Philadelphians with an ASD and their families. In response to the needs of his constituency of individuals impacted by an ASD, Councilman O’Brien sought to develop a first of its kind municipal level, comprehensive *Strategic Plan* to improve the lives of Philadelphians with an ASD, their family members, and others who comprise their support network. In order to develop the plan, Councilman O’Brien created an inclusive process that relied upon self-advocates, family members, policy makers, researchers, service providers, educators, and other key stakeholders to design a more effective, efficient, and comprehensive system of care for individuals with an ASD and their families.

B. Trends in Services to Individuals Living with Autism

In order for project stakeholders to examine current practices and make recommendations for the future, participants were provided with the latest national, state, and city trends, detailed in the sections below. These trends focused on the increased incidence of an ASD, the need for early diagnosis and intervention, better coordination of funding and services, improved outreach to underserved communities, more attention to the transition of youth to adulthood, increased access to adult services, and the need for support to family members of individuals with an ASD.

1. National Trends

The challenges and needs of individuals living with an ASD have increasingly been recognized as a national public health concern over the past two decades. There is an increased awareness of the prevalence, impact, and needs of those living with an ASD, as well as the needs of family members and others who support them. Current research and practice has offered a more comprehensive understanding of ASD, including strategies to support and improve quality of life.

Incidence

According to the Center for Disease Control (CDC) and National Institute for Health (NIH):

- ASD has become more prevalent in the national health policy discussion as research has indicated increased incidence and prevalence of individuals with an ASD.
- In 2012, the NIH estimated about 36,500 of every 4 million children born each year in the United States will have autism.
- In the past fifteen years, due in part to increased awareness and surveillance methods, the incidence of an ASD has increased from 1 in 150 in 2000, to the most recent Center For Disease Control report of 1 in 68 in March of 2014.
- Boys are almost five times more likely to be diagnosed with an ASD when compared to girls.
- Currently, nearly half of all children with an ASD have average or above-average intellectual ability (defined as an IQ above 85), compared to one-third of children diagnosed a decade ago.

Costs

As reported in “Costs of Autism Spectrum Disorders in the United Kingdom and the United States” (Buescher, AV., Cidav Z., Knapp, M., Mandell, DS. “Costs of Autism Spectrum Disorders in the United Kingdom and the United States.” *JAMA Pediatrics*. 168-8 (August 2014): 721-728.)

- Autism costs the United States a total of \$236 billion annually for the services and supports needed by the estimated 3.5 million adults and children diagnosed with an ASD.
- The annual per person cost averages \$67,428, but varies depending on the person’s age, and whether or not the person also has an intellectual disability. The estimated costs also accounts for out-of-pocket costs paid by families and the reduction in productivity by families due to lost or disrupted employment in order to provide informal care.
- Among children with an ASD, the greatest costs were for special education services and parental productivity loss.
- Among adults with an ASD, the greatest costs were for residential care or supportive living accommodations and individual productivity loss.
- Medical costs were higher for adults than for children. About 40% of individuals with an ASD also have an intellectual disability.

Awareness

As indicated by the 2012 National Conference of State Legislatures (NCSL) Autism Legislation Database:

- Many states in the U.S. have convened efforts to organize constituents and stakeholders focused on ASD in the last 15 years.
- These efforts have resulted in substantial movement in some states to dedicate a unit, entity or a subsection of a unit or entity to focus on ASD.
- The need to expand services and support to families in their efforts to secure and pay for needed services was also highlighted through these efforts.
- Increasing evidence documenting disparities in the diagnosis and care of children with an ASD, who are from underrepresented and underserved communities, indicates a need to increase access to services, public education, and awareness in these communities.
- “Population Health” models are emerging which recognize the importance of an integrated physical/mental health approach to more comprehensively address the needs of those living with an ASD (Association of Maternal and Child Health Programs, AMCHP ISSUE BRIEF: The Affordable Care Act and Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities, May 2012).

Funding

- Almost 40 states in the U.S. have enacted legislation mandating autism-specific health insurance coverage.
- Many states have Medicaid waivers allowing children, adolescents, and/or adults with an ASD to receive services. These waivers are generally intended to provide care in communities rather than in inpatient settings and most are focused on children. Pennsylvania is one of the only states with a specific [adult ASD waiver](#).
- According to the 2014 Autism Speaks States Initiatives report, there are thirty-eight states plus the District of Columbia and US Virgin Islands with enacted autism insurance reform laws; six states with Autism Speaks-endorsed bills for 2014; and one state pursuing insurance reform in 2014.

As evidenced in a Kaiser Foundation Issue paper (*Medicaid and the Uninsured, February 2012*):

- Passage of the Affordable Care Act (ACA) and subsequent Medicaid Expansion in about half of states has increased access to health care for millions of Americans.
- The ACA is especially important to underprivileged families given the increasing incidence of ASD in African American, Hispanic, and other minority populations, many of whom are economically challenged.

Community Inclusion

- Young adults with an ASD have poorer employment outcomes compared to other peers with disabilities, with only 53.4% who reported having worked for pay within eight years following high school (Roux, Anne M., et al. "Postsecondary employment experiences among young adults with an autism spectrum disorder." *Journal of the American Academy of Child and Adolescent Psychiatry* 52.9 (2013): 931-939).
- Young adults with an ASD from poorer households are more likely to be disengaged in services and supports, which can be essential to securing and maintaining a job (Roux, Anne M., et al. "Postsecondary employment experiences among young adults with an autism spectrum disorder." *Journal of the American Academy of Child and Adolescent Psychiatry* 52.9 (2013): 931-939).
- When compared to other adults with disabilities, adults with an ASD are less likely to have ever lived independently and more likely to be living with a parent or guardian (Anderson, Kristy A., et al. "Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder." *Autism* (2013): 1362361313481860).

Increased awareness of ASDs has brought significant changes in assessment, treatment, and funding. The impact of ASDs on individuals, their families, and care providers is substantial. Important research focused on children with an ASD is growing and more work is needed to understand the parallel needs of adolescents, adults, and their families, as well. Additional work to scaffold increasing knowledge with local efforts that are germane to communities is essential to truly creating changes for individuals with an ASD and their families.

2. Pennsylvania Trends

Pennsylvania was an early leader in recognizing and addressing ASDs as an emerging public health issue. This work included an improved understanding of Pennsylvanians living with an ASD, establishing structures for improved research and public education models, and investigating alternatives to support families both emotionally and financially. These efforts were spearheaded by the state legislature which brought together existing key public institutions, the university community, advocates, and other stakeholder groups. After its inception, the Bureau of Autism Services (BAS) began to execute the work commissioned by the PA Autism Task Force, including the Adult Community Autism Program and the Adult Autism Waiver. BAS also created the [Autism Services, Education, Resources and Training \(ASERT\) Collaborative](#), which executes a variety of initiatives, including the Pennsylvania Autism Census.

Prevalence

Findings from the 2014 Pennsylvania Autism Census:

- As of 2011, the Pennsylvania Autism Census reported that an estimated 55,830 children, adolescents, and adults with an ASD were receiving services in Pennsylvania.
- If the CDC prevalence rate of 1 in 68 were applied to the Pennsylvania population, an additional 130,000 individuals with an ASD may be undiagnosed, misdiagnosed, or not receiving services.
- Overall there was a **181%** increase in the number of individuals with an ASD receiving services in PA from 2005 to 2011.
- There was a **334%** increase in adults (21+) receiving services and this trend is expected to continue, with a projected number of adults receiving services reaching over **35,000** in 2020.

Policy

- Pennsylvania was one of the first states to create an Autism Task Force and one of only four states to have a specific entity focused on ASD, the Pennsylvania Bureau of Autism Services.
- Services are funded by a variety of entities including the Department of Human Services, local school systems, and private insurance among others.

- The Adult Autism Waiver (AAW) and Adult Community Autism Program (ACAP) were among the first in the country to provide ASD-specific services to adults.
- Pennsylvania was among the first to mandate private insurance companies to cover ASD services through Public Act 62.

Service Challenges

According to the 2010 Needs Assessment:

- Pennsylvanians of all ages with an ASD and their families are struggling to find the services they need and are often dissatisfied with the services that are provided.
- As individuals with an ASD grow into adulthood, the need for support and services often increases, although services become less accessible.
- A lack or shortage of providers is the most common barrier to accessing services.
- The lack of effective interventions for challenging behaviors and mental health problems often leads to preventable crises.
- Although children are being diagnosed at younger ages, diagnosis and follow-up care is still a long and difficult process.
- Most adults with an ASD often are unemployed or underemployed because the necessary supports are not available.
- Caring for an individual with an ASD often takes an economic and emotional toll on families.

Pennsylvania trends for children, adolescents, and adults living with an ASD mirrored many of the national trends. The state responded by creating the Bureau of Autism Services (BAS) to bring increased focus and resources to those living with an ASD.

3. Philadelphia Trends

Despite being recognized as one of the “Ten Best Cities” in the country to raise a child living with an ASD, individuals and their families residing in Philadelphia are challenged with similar service and funding trends faced across the country.

- From 2005 to 2011, there was a **116%** increase in the number of Philadelphians with an ASD who were receiving services. (2014 Pennsylvania Autism Census)
- In 2011, approximately 15% of all Pennsylvania children with an ASD who enrolled in Early Intervention resided in Philadelphia. (2014 Pennsylvania Autism Census)
- Of Philadelphia children with an ASD receiving educational support through the Pennsylvania Department of Education, 50.6% were receiving autistic support services, 6.3% emotional

support services, 27.2% learning services, 7.8% life skills, 4.1% multiple disabilities, 2.9% speech/language services, and 1.1% “other” services. (2014 Pennsylvania Autism Census)

- Comorbid psychiatric diagnoses increase in childhood and continue to increase across the lifespan for most individuals with an ASD.
- The number of school children with an ASD receiving services between ages 5-17 years has been increasing over time in Philadelphia schools.
- The rate of individuals with an ASD who are coming into contact with the juvenile and criminal justice systems has increased over time with professionals requesting tools, training, and support to meet the needs of this growing population. (2014 Pennsylvania Autism Census)
- ASD targeted support programs at colleges/universities face specific hurdles, including limited funding, staff capacity/training, student funding support, college/university buy-in, knowledge of socialization needs and collaboration with stakeholders.

Understanding and responding to the needs of Philadelphians living with an ASD continues to be a top priority in Philadelphia. This has led to seeking to improve educational services, initiatives targeted at creating a more inclusive community living environment, and supportive local leadership to assure continuing state efforts to improve the lives of all Pennsylvanians living with an ASD. Despite these considerable efforts, local leadership and other key stakeholders continue to work to further improve the quality of life for Philadelphians living with an ASD so they can reach their full potential.

Much has been learned about individuals living with an ASD in the last 15 years. It is now known that diagnosis is possible as early as two years old, and early diagnosis and intervention is related to more positive future outcomes for these children. As greater numbers of children living with an ASD are transitioning into adulthood, more needs to be done to support this transition, as well as the need for services to support adults living with an ASD. Federal and state public policy, directly and indirectly, has brought about increased funding to assist families in securing services and supports. However, families continue to need practical, emotional and financial supports to achieve a higher quality of life.

Philadelphia has been a leader at the state and national levels in creating a more comprehensive system of supports for residents living with an ASD. These include, but are not limited to increased employment opportunities, strategies to increase community inclusion and an overall local political and business community that is responsive to improving the quality of life for all Philadelphians. Despite all that has been accomplished to assist those living with an ASD, community leaders in Philadelphia saw the need to do more to support these individuals and their families.

Demographic Considerations for Implementation

- Table 1 highlights the race and income statistics of Philadelphia County, in comparison to the rest of Pennsylvania. The race and ethnicity statistics demonstrate that Philadelphia has a more diverse population than Pennsylvania. The percentage of people in Philadelphia living below the poverty level is double that of Pennsylvania. The 2014 Pennsylvania Autism Census has identified that approximately three-quarters of the individuals receiving autism services in Philadelphia are non-white. Therefore, programs and community outreach to individuals with an ASD and their families in Philadelphia will require culturally and linguistically competent approaches for these diverse communities.

Table 1. Race/Ethnicity and Poverty for Philadelphia and Pennsylvania

	Philadelphia (%)	Pennsylvania (%)
White Alone (not Hispanic or Latino)	36	78
Black or African American Alone	44	12
Asian Alone	7	3
Hispanic or Latino	13	6
Median Household Income	\$37,016	\$52,267
Persons below poverty level, 2008-2012	26	13

- The number of individuals with an ASD who are receiving services by zip code is presented in Figure 2. This data from the 2014 PA Autism Census indicates where the majority of individuals with an ASD, who are receiving services in Philadelphia, reside. Services here are inclusive of: behavioral supports, early intervention, school district support, behavioral health rehabilitation services, Office of Developmental Waiver systems, Bureau of Autism services, including any Medicaid reimbursed services. Further inquiry is warranted regarding communities with lower rates of individuals receiving ASD services to explore possible issues of access to information, services, and supports. Additional information on rates of poverty, crime, service utilization, as well as resource mapping of communities, will be needed to further inform planning and implementation efforts.

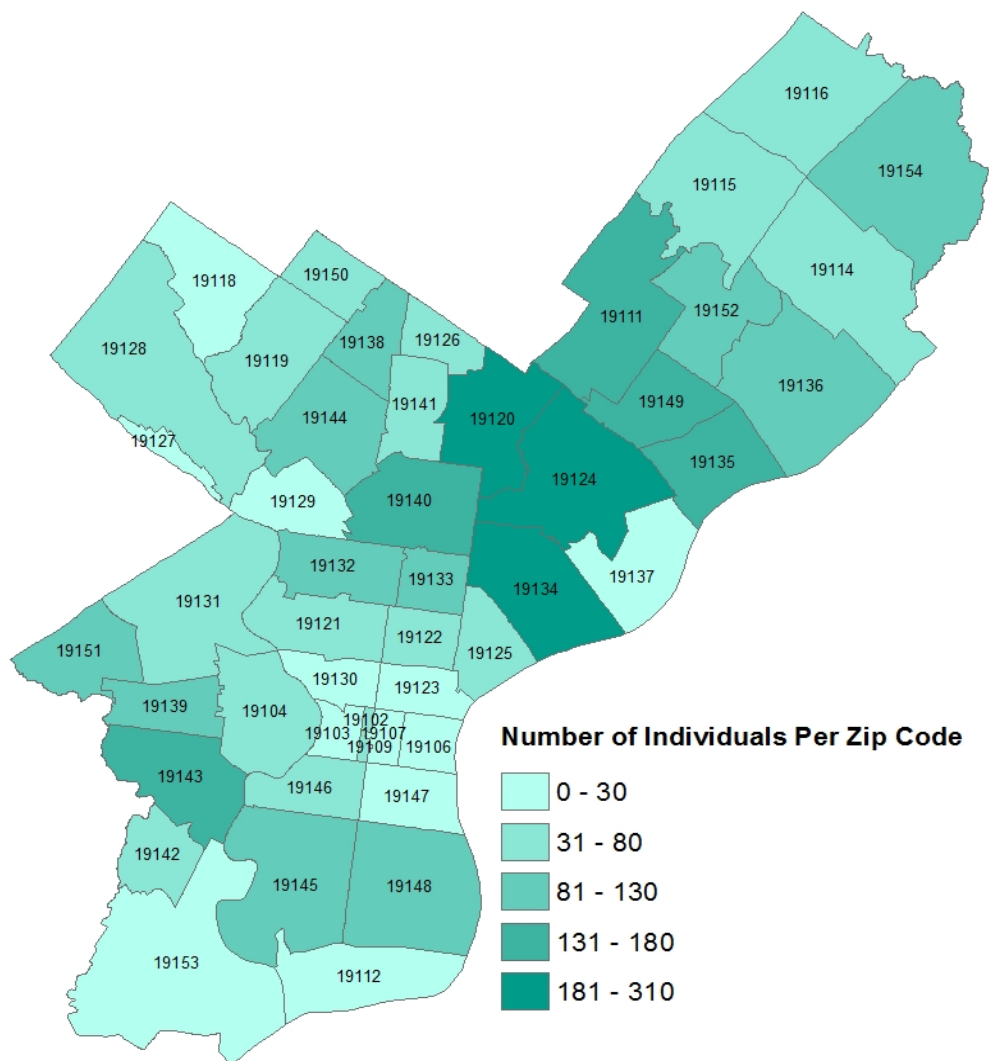


Figure 2: Number of Individuals with an ASD Receiving Services by Zip Code in Philadelphia

- The number of educational institutions including public entities, private nonpublic entities, and postsecondary and higher education entities from the Educational Names and Addresses (EdNA) database is shown in Figure 3. Identifying where potential educational supports are in place can help determine where and how services and supports for individuals with an ASD are implemented, as well as how best to leverage these resources citywide.

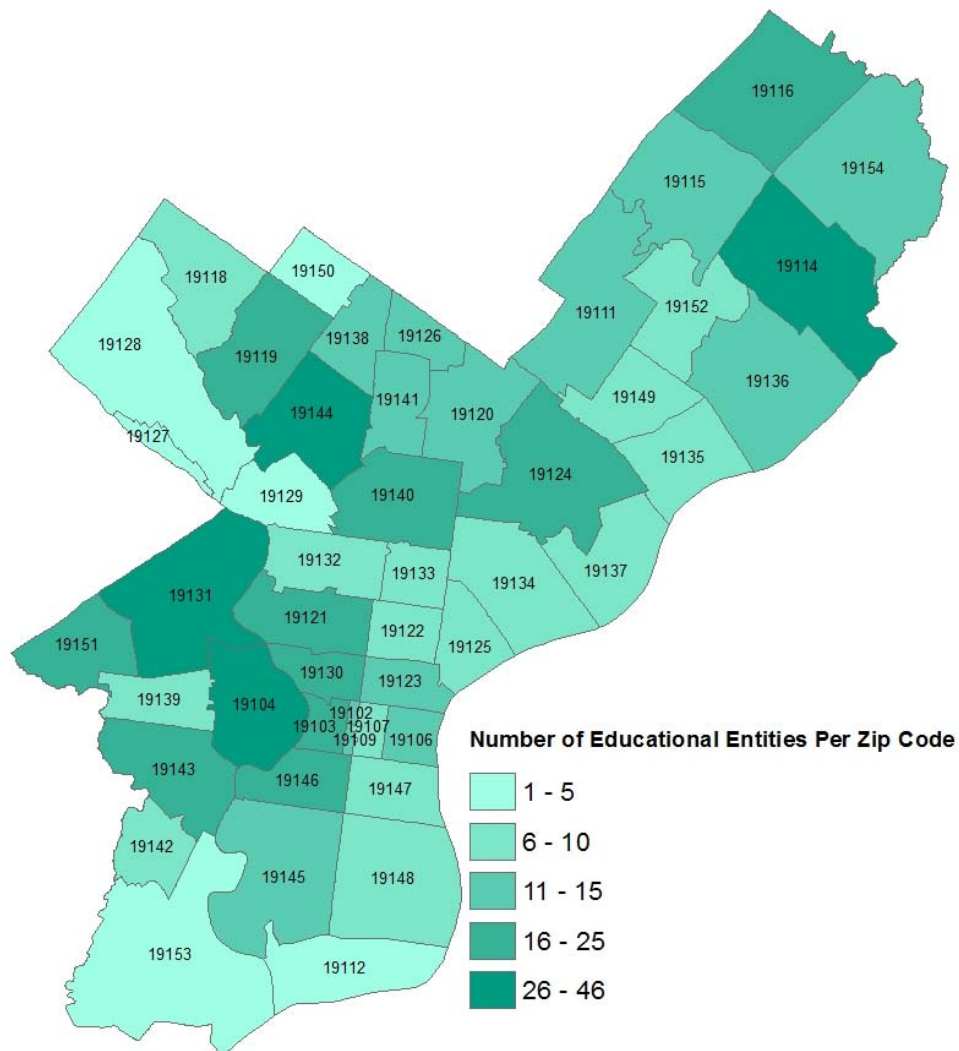


Figure 3. Number of Educational Entities by Zip Code in Philadelphia

C. Development of the Philadelphia Strategic Plan

The Philadelphia Strategic Plan for improving the quality of life for individuals living with an ASD and their families was developed during three large group stakeholder meetings over the course of five months under the guidance and direction of the project leadership team. The following is a summary of the planning process. A full description of the methodology used to develop the process is included in Appendix D of the report.

The first of three meetings identified many strengths in the current system, but also noted areas where improvements are needed. These improvements would add to the quality of life of those living with an ASD. They would also provide support for families and other caregivers who are often exhausted by the demands of caring for, seeking services for, and finding ways to pay for required services and supports of those living with an ASD.

The Philadelphia stakeholder group identified ten “Themes for Improvement” that, if successfully addressed, would improve the quality of life for individuals with an ASD and bring greatly needed support to family members and others responsible for their care. The “Themes for Improvement” are:

1. **Clinical Concerns Across The Lifespan** – Developing solutions to support individuals and families as they navigate the system to receive needed services and as they transition from one system to the next as the family member with an ASD grows older. This theme also involves the identification of best practices in diagnosis, early intervention, and ongoing treatment as an individual with an ASD ages into adulthood.
2. **Family Support** – Identifying solutions to support families educationally, emotionally, socially, and financially to meet the needs of their family member with an ASD and address the impact it has on all family members.
3. **Post-Secondary Educational & Employment Opportunities** – Addressing the need to design employment preparation and job opportunities for young adults and adults with an ASD that are rewarding, challenging, and take full advantage of the individual’s potential and strengths while fostering self-determination.
4. **Underserved Communities** – Identifying barriers and creating solutions for the needs of individuals and their families in communities that are underserved, because of culture, language barriers, poverty, unsafe neighborhoods, etc. Solutions include community awareness, access to diagnosis, early intervention, and the full array of needed services that are culturally and linguistically appropriate.

5. **Capacity Building & Workforce Development** – Developing solutions to promote more ASD-specific competencies for all professionals who work with the ASD population (educators, health care, behavioral health, etc.). Solutions must support the training and professional development needs of these professionals and work to assure the number of professionals required are available (recruiting and retaining highly qualified professionals) to meet current and future needs of individuals with an ASD and their families.
6. **Enhancing Community Inclusion For Individuals & Families With An ASD** – Identifying specific areas (daycare, respite, transportation, recreation, social, entertainment, family living, etc.) and solutions to create a more inclusive community living environment for individuals living with an ASD and their families across the lifespan.
7. **Supports for Adults** – Creating solutions to address the complex needs of adults with an ASD from ages 21+ throughout adulthood. This includes, but is not limited to, developing independent living skills, access to post-secondary educational and vocational training opportunities, and developing a continuum of appropriate and adequate housing alternatives, etc.
8. **Child Welfare & Criminal Justice Systems**
 - a. Child Welfare & Juvenile Justice – Identifying the needs and solutions to address the special needs of children and youth with an ASD who are in the juvenile justice and child welfare systems.
 - b. Adult Criminal Justice System – Identifying needs and solutions for adults with an ASD who come into contact with the criminal justice system, from initial identification, through sentencing, rehabilitation, and reentry to the community.
9. **Education** – Developing strategies that increase the use of best practices in classrooms, create more mainstream opportunities for students with an ASD, improve the Individual Educational Plan (IEP) process for families, retain high quality teachers, and increase awareness among all staff.
10. **Blending Of Funding Streams** – Identifying strategies for blending funding from various systems (education, public, and private insurance) to create more integrated and coordinated services offered to individuals with an ASD and their families.

Through discussion of these ten themes at stakeholder meeting #2, meeting attendees developed an initial list of 139 strategic initiatives. The leadership team examined these initiatives to ensure clarity and avoid duplication and generated a final list of 119 initiatives. Then the leadership team devised a method for combining and prioritizing initiatives in order to

increase the likelihood of implementation success. The initiatives were categorized based on the time and resources required for successful implementation. Specifically, initiatives were placed into one of three categories: Category 1: Short term (less than one year) and no new resources; Category 2: Short term (less than one year), with new resources required; and Category 3: Long term (more than one year), with new resources required. In stakeholder meeting #3, the initiatives were “voted” on by stakeholders and represent their recommendation of how the initiatives should be prioritized for implementation.

Selection of the final prioritized initiatives for year one implementation will be chosen based on the following factors:

1. Guiding Influences

- A. Guiding principles of the stakeholder meetings
- B. Commitment to focus on issues across the lifespan and across the spectrum
- C. The leadership team

2. Prioritization Process

- A. Recommendations from stakeholders
- B. Input from the leadership team
- C. Ability to allocate or secure funding resources
- D. Ability to develop strategic relationships
- E. Adjusting priorities over time based upon new information or changing community needs

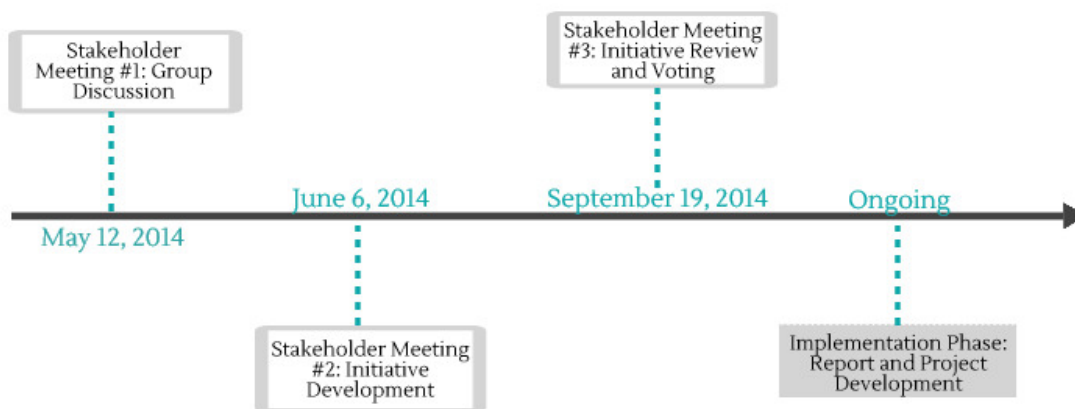


Figure 4. Timeline of Philadelphia Autism Project

V. Strategic Initiatives

The final recommendations for implementation of the Philadelphia Autism Project initiatives were determined through a process of stakeholder voting. Listed below are the initiatives stakeholders identified as priorities for initial implementation:

1. Short Term (one year or less) with no new resources required

Votes	Initiative #	Description
29	24	Convene ongoing discussions between all payers (Community Behavioral Health, Medicaid, managed care plans, the school district, commercial insurers, Office of Vocational Rehabilitation, etc.) to determine means of braiding funding through common procedure codes, provider qualifications and centralized billing
22	14	Development of "Transition Toolkits" across lifespan for teachers/professionals to use in support of individuals and families living with autism (i.e. – early intervention, school age, 21 and over, seniors)
16	22	Research Medicaid Health Home provision of ACA (§2703 of ACA) and consider the usefulness of this model as an additional funding source; Reach out to Community Behavioral Health, Mental Health Association of Southeastern PA, PA Mental Health Consumers Association, Parents Involved Network, and the Alliance of Community Service Providers to determine interest in a joint Health Home project
16	25	Secure additional autism waiver slots
14	4	Post-Secondary Transition Planning (i.e. – OVR services available, what colleges have programs and supports specific for individuals with an ASD, etc.)

2. Short Term (one year or less) with new resources required

Votes	Initiative #	Description
28	4	Establishing an Annual Philadelphia Autism Conference – conference will be organized by lifespan tracks (i.e. – ages 0-5, school age, 21 and older, older adults) and cover the needs across the spectrum; Conference can also be utilized to organize a grassroots advocacy movement by pulling together a community of individuals with autism, families, providers and researchers to secure more funding, advocate for key legislative changes, etc.
20	2	Creation of Philadelphia Autism Support Group that would utilize a wide range of support strategies including training, webinars, support groups (face-to-face and internet based), peer-to-peer mentoring, etc.
17	30	Professional development of Educators and School Personnel – Assure new teacher and coaches get ASD training; Create summer institutes to train teachers and offer financial incentives to participate; Develop a test for autism support teachers, with the requirement that the teacher must pass the test in order to teach; Mandated training for non-teaching assistants, principals and other staff on autism specific issues to ensure an autism friendly school environment; Mandated autism training and continued professional development for teachers in autism support classrooms
16	12	Maintain a database of specialized services and culturally competent providers (culture, languages, etc.) and resources (video, blogs, support groups, etc.)
12	33	Partner with colleges and universities to develop and standardize training programs for teachers and other healthcare professionals interested in working with individuals who have autism, and create more opportunities for internships for allied healthcare professionals, similar to psychology internships

3. Long Term (requiring multiple phases in excess of one year to complete)

Votes	Initiative #	Description
23	1	Creation of “gold standard” centralized resource, possibly a website or the adaption of an existing website, and/or a physical location that can be used to: disseminate existing resources as well as new resources generated; promote awareness initiatives; develop new apps for wider reach and remote access; and establish “connection sites” where information and community experts are brought together to facilitate increased community awareness of ASD and assistance with access to services
16	18	Launch an agency/entity to serve as single, centralized Philadelphia specific portal of entry for access to clinical, behavioral and educational ASD related services that would directly provide initial evaluation/diagnostic services, ongoing multidisciplinary/multisystem care planning and ongoing system navigation whose evaluation and care planning would be accepted across providers/agencies in the city
14	20	Implementation of “Comprehensive Integrated Care Plan” with a “System Navigator” role to assist individuals and their families with successful plan implementation; Explore possibility that the Medicaid Health Home provision of the Affordable Care Act can serve as a potential funding source for System Navigator
14	49	Create Vocational Autism Work Group that can develop a strategic plan to include an increase internships with City departments and non-profits, and tax incentives for private business internships
12	15	City Wide Task Force of providers from across the lifespan to develop a Universal Multi-Disciplinary/Multi-System Care Plan protocol (Individual Services Plan, Universal Services Plan, etc.) that meets the requirements of all funding systems. The protocol should emphasize use of best practices documenting the appropriate intervention at each age group for specific needs. Additionally it should identify the role of the various professionals and their ability to identify what an individual with autism needs.

For a more in-depth look at the Philadelphia Autism Project survey results, see Appendix K.

VI. Next Steps

The completion of this final report officially ends the formal process for strategic plan development. The implementation phase of the Philadelphia Autism Project will begin immediately and will involve:

- Sharing of the report with the Philadelphia Autism Project stakeholders and the larger autism community
- Sharing of the report with community institutions, and other key stakeholders
- Formation of implementation team work groups and committees
- Ongoing stakeholder group and key constituency updates via email

Katy Kaplan, Director of Human Services and Special Initiatives for Councilman Dennis M. O'Brien, will be responsible for directing the implementation phase of the Philadelphia Autism Project in collaboration with other members of Councilman O'Brien's office and the implementation team represented by a wide range of stakeholders. Together, they will work to create an environment where individuals living with an ASD have an even greater opportunity to reach their full potential and be fully active and contributing members of the Philadelphia community.

VII. Appendices

Appendix A – Councilman Dennis M. O’Brien’s Letter of Invitation



CITY OF PHILADELPHIA
CITY COUNCIL

DENNIS M. O'BRIEN
ROOM 582, CITY HALL
PHILADELPHIA, PA 19107
(215) 686-3440 or 3441
Fax No. (215) 686-1929
Email: dennis.o'brien@phila.gov

COUNCILMAN-AT-LARGE

April 17, 2014

Hello,

I'm writing to invite you to participate in the Philadelphia Autism Project. This is an exciting opportunity to positively impact the lives of individuals living with autism and their families, in Philadelphia. We will create a city-wide taskforce, consisting of families, individuals living with autism, clinicians, administrators, educators, researchers, and advocates who will employ their personal and professional experiences to develop a strategic plan for advancing access to and quality of services and supports to individuals living with autism across the lifespan.

The Philadelphia Autism Project will result in a set of recommendations designed to identify and address the needs of individuals with an autism spectrum disorder and their families over their lifetime. Our goals are to utilize existing innovative approaches to support individuals and families that can be sustained, foster a comprehensive approach resulting in better coordination of services between different service systems, and generate novel approaches to maximize quality of life and positive outcomes. We acknowledge that although we've made great progress, where Philadelphia has been recognized as a national leader in the area of autism services, many individuals living with autism and their families remain underserved and underrepresented. Therefore, we are committed to more fully supporting all individuals and families.

If you agree to join us you will be participating in a cutting-edge project designed to improve services and support to individuals and families impacted by autism. We believe a project such as this has never been done before on a county level. For that reason, we are asking you to make the following commitments:

1. Attend the three all day face-to-face stakeholder meetings;
2. Actively participate in these meetings by sharing your personal experiences and professional knowledge as we work to generate a strategic plan and corresponding set of initiatives; and
3. Engage with your assigned subcommittee. This engagement will be via email and conference calls between stakeholder meetings to ensure the final strategic plan is of high quality.

The stakeholder meetings will begin at 8:30am and run until 4:30pm, with a break for lunch. Breakfast and lunch will be provided.

- Kick Off Meeting – Monday May 12th
 - Office of the District Attorney
Ray Harley Training Room
Three South Penn Square
Corner of Juniper and South Penn Square
Philadelphia, PA 19107-3499
- Second Stakeholder Meeting – Friday June 6th
 - Drexel University
Paul Peck Alumni Center
3141 Chestnut Street
Philadelphia, PA 19104
- Final Stakeholder Meeting – Monday July 28th
 - Location – To be determined

I hope you are able to join us for this meaningful endeavor, as you have come recommended to us and we believe you have a great deal to contribute to this important initiative. One of our goals is to generate new relationships that will be sustained over time; the Philadelphia Autism Project is just the starting point for pushing forward meaningful positive change in Philadelphia. Please RSVP by email or phone to Margie Caputo (Margie.caputo@phila.gov, 215-686-3440) by Friday May 2nd. If you have any questions please contact Katy Kaplan (katy.kaplan@phila.gov, 215-686-3440).

Sincerely,


Dennis M. O'Brien
Philadelphia Councilman-At-Large

Appendix B – Stakeholders

The following list identifies the individual stakeholders who participated in The Philadelphia Autism Project:

- Judy Anderson, School District of Philadelphia, Office of Specialized Services, Autism Coordinator
- David Armbrister, Self-Advocate
- Keith Arrington, School District of Philadelphia, Principal/Marshall School
- David Ayers, District Attorney's Office, Mental Health Administrator
- Julia Barol, Networks for Training and Development, Coordinator of Business Development
- Marilyn Benoit, Devereux, Chief Medical Officer, Psychiatrist
- Eric Berger, Center City Pediatrics, Pediatrician
- Renay Boyce, School District of Philadelphia, Office of Specialized Services, Interventions Coordinator
- Matthew Braden, City Council, Office of Councilman Dennis M. O'Brien, Chief of Staff
- Joel Bregman, The Center for Autism, Medical Director, Director of Psychiatry
- Benjamin Brock, City Council, Office of Councilwoman Jannie L. Blackwell, Director of Education Policy
- Ann Brown, School District of Philadelphia, Principal/Nebinger School
- Jenny Broz, Defender Association of Philadelphia, Social Worker
- Lindsay Burger, Philadelphia International Airport, ADA Compliance/Autism Access
- Michael Calderone, School District of Philadelphia, Principal/Harding Middle School
- Margie Caputo, City Council, Office of Councilman Dennis M. O'Brien, Director of Constituent Services
- Kimberly Caputo, School District of Philadelphia, Office of Specialized Services, Deputy Chief
- Annemarie Clarke, SPIN, Corporate Officer
- Nick Claxton, Philadelphia Department of Public Health, Maternal, Child and Family Health, Program Director
- Kelly Colvin, Temple University, Center of Regional Politics, Associate Director
- James Connell, Drexel University, A.J. Drexel Autism Institute, Clinical Core Director
- William Cooney, Juvenile Probation, Deputy Director
- Kathleen Copeland, Child Guidance Resource Centers, Supervisor of Specialized Services

- James Coplan, Neurodevelopmental Pediatrics of the Main Line, Pediatrician; University of Pennsylvania School of Medicine, Clinical Professor of Psychiatry
- Charles Cunningham, Defender Association of Philadelphia, Attorney
- Anne Deaner, Community Behavioral Health, Interim Director of Psychology
- Lauren DellaCava, Community Behavioral Health, Program Development and Implementation Manager
- Roy Diamond, Parent; Autism Living and Working Inc., Board President
- Dante DiBello, Self-Advocate
- Elizabeth DiDonato, Philadelphia Police Department
- Michele Dowell, Philadelphia Mental Health Care Corporation, Crisis Intervention Team Coordinator
- Joyce Dukes, School District of Philadelphia, Office of Specialized Services, Interventions Coordinator
- Miriam Enriquez, City Council, Office of Councilman Dennis M. O'Brien, Director of Legislation
- Gloria Eposito, Parent
- Timene Farlow, Department of Human Services - Juvenile Justice Services, Deputy Commissioner
- Jackie Gallagher, Esq., Parent
- David Gates, Pennsylvania Health Law Project, Director of Policy Senior Attorney,
- Shaakira Gillette, Parent; Department of Behavioral Health and Intellectual disAbility Services, Post Arrest Crisis Screener
- Brenda Golden, Public Health Management Corporation, ChildFind Coordinator
- Amy Goldman, Temple University, Institute on Disabilities, Co-Executive Director
- Lissette Gonzales, HUNE, Hispanos Unidos Para Ninos Excepcionales, Board Co-Chair, Social Worker
- Patrick Graff, Self-Advocate
- Kathy Grasela, Philadelphia Court of Common Pleas, Family Division, Chief of Court Operations
- Derek Green, Parent; City Council, Office of Councilwoman Tasco, Special Counsel
- Ryan Hammond, St. Joseph's University, Kinney Center for Autism Education and Support, Executive Director

- Francis Healy, Philadelphia Police Department, Captain
- Sharon Heileman, SPIN, Director of Autism Programs
- Jim Hence, School District of Philadelphia, Autism Support Teacher 6-8
- Renee Henderson, Parent; Community Behavioral Health, Deputy Chief Financial Officer
- Rachel Hooper, City Council, Office of the Council President, Fellow
- Charles Hoyt, Philadelphia Adult Probation & Parole Officer, Chief
- Felicia Hurewitz, Parent
- Matthew Hurford, Department of Behavioral Health and Intellectual disAbility Services/Community Behavioral Health, Chief Medical Officer
- Roger Ideishi, Temple University, Department of Rehabilitation Sciences, Associate Professor
- Kamillah Jackson, Community Behavioral Health, Child & Adolescent Services, Associate Medical Director
- Rennie Joshi, *OPEN MINDS*, Research Analyst
- Katy Kaplan, City Council, Office of Councilman Dennis M. O'Brien, Director of Human Services and Special Initiatives
- Sonja Kerr, Public Interest Law Center of Philadelphia, Disability Rights, Director
- Gayle Keyes, School District of Philadelphia, Autism Support Teacher 3-5
- Wendy Kohler, Community College of Philadelphia, Center on Disability, Director
- Karen Krivit, Elwyn, SEEDS, Training and Resource Specialist
- Ashlee Lamson, Elwyn, SEEDS, Director
- Jeanne Lehrer, NorthEast Treatment Centers, Youth Services Division, Vice President
- Mandi Levine, NorthEast Treatment Centers, PACE, Program Manager
- Dustin Lowry, *OPEN MINDS*, Consulting Practice Operations, Vice President
- Tara Macatee, Kaleidoscope Family Solutions, Inc., Executive Director
- David Mandell, University of Pennsylvania, Center for Mental Health Policy and Services Research, Director; The Children's Hospital of Philadelphia, Center for Autism Research, Associate Director
- Rosemarie Manfredi, Chestnut Hill College, Assistant Professor; Faculty & Curriculum Coordinator of ASD Programs

- Mary Mathew, Drexel University, A.J. Drexel Autism Institute, Eastern Region ASERT, Policy Coordinator
- Terri Matthews, Parent; Jaden's Voice, Founder and CEO
- Mary Maurer, Parent
- Kate Maus, Department Human Services, Substance Affected Family Evaluation Unit, Director
- Gary McCormick, Parent
- Linda McCullough, Parent
- Jayne McGinley, School District of Philadelphia, Autism Support Teacher, High School
- Michele McKeone, Philadelphia School District, Autism Support Teacher, High School; Autism Expressed, Founder
- Judith Miller, Children's Hospital of Philadelphia, Center for Autism Research, Director of Clinical Training
- Kaitlin Miller, Drexel University, A.J. Drexel Autism Institute, Eastern Region ASERT, Policy Coordinator
- Michelle Montgomery, Parent
- Sherry Moyer, Keystone Autism Services, Adult Community Autism Program, Executive Director
- Paul Neitman, *OPEN MINDS*, Senior Associate
- Pia Newman, Bureau of Autism Services, Assistant Director
- Jeannette Newman, Department of Behavioral Health and Intellectual disAbility Services, Philadelphia Infant Toddler Early Intervention, Policy & Planning Specialist
- Craig Newschaffer, Drexel University, A.J. Drexel Autism Institute, Director
- Dennis M. O'Brien, City Council, City Councilman-At-Large
- Erin O'Brien, District Attorney's Office, Family Violence & Sexual Assault Unit, Assistant Chief
- Meredith Ouimette, Rethink, Director of Professional Services
- Valarie Oulds, Parent; Department of Behavioral Health and Intellectual disAbility Services, Program Manager
- Emilio Pacheco, Parent; Vision for Equality, Associate Director
- Navjyot Parmar, Drexel University, School of Public Health, Graduate Student

- Jennifer Plumb, Drexel University, A.J. Drexel Autism Institute, Outreach Core, Director
- Allison Potter Proto, ASPIRA of PA Charter School, Autistic Support Teacher
- Tanya Regli, Parent; The Arc of Philadelphia, Executive Director
- Michele Reichow, Parent; Public Interest Law Center of Philadelphia, Special Education Administrator
- Tom Reinke, Parent
- Christi Rinehart, Department of Human Services, Support Center, Acting Director
- Khyllil Robinson, Self-Advocate
- Cathy Rocchia-Meier, Parent; Elwyn SEEDS, Parent Partnership Program
- Wendy Ross, Center for Pediatric Development, Director; Autism Inclusion Resources, Founder
- Gina Ross, Temple University, Department of Rehabilitation Sciences, Recreation Therapy Graduate Student
- Kerey Ruggiero, Philadelphia Mental Health Center, CEO
- Jacqueline Russo, School District of Philadelphia, Autism Support Teacher K-2
- Aimee Salas, Child Guidance Resource Centers, Clinical Services, Vice President
- Josh Salzer, City Council, Office of Councilman Dennis M. O'Brien, Intern
- Roseann Schaaf, Thomas Jefferson University Hospital, Department of Occupational Therapy, Chair & Professor
- Susan Schonfeld, Community Integrated Services, Executive Director
- Jessica Shapiro, Department of Human Services, Chief of Staff
- Steve Shaud, Elwyn, SEEDS, Program Director
- Lindsay Shea, Drexel University, A.J. Drexel Autism Institute, Eastern Region ASERT, Director
- Charlene Smurtwaite, Parent
- Margaret Souders, Children's Hospital of Philadelphia, Center for Autism Research, Researcher; University of Pennsylvania, School of Nursing, Assistant Professor
- Cathleen Spinelli, St. Joseph's University, Special Education Programs, Director
- Kathleen Stengel, Clarity Service Group, CEO
- Cecelia Thompson, Parent
- Ilene Toll, Elwyn, SEEDS, Autism Services, Director
- Sabra Townsend, Parent; The Arc, Adult Advocacy, Director

- Wayne Trout, Office of Vocational Rehabilitation, Philadelphia District Administrator
- Paul Turcotte, Drexel University, A.J. Drexel Autism Institute, Eastern Region ASERT, Data Analyst
- Sandy Vasko, Department of Behavioral Health and Intellectual disAbility Services, Office of Mental Health, Director
- Nina Wall, Parent; Bureau of Autism Services, Director
- Natasha Washington, Community Behavioral Health, Clinical Care Manager
- Andre Watson, Community Behavioral Health, Psychiatrist
- Jordan Weisman, Philadelphia Mental Health Center, Psychologist
- Keri White, Parent
- Dana Wolfe, Elwyn, SEEDS, Clinical Services, Director
- Lisa Wood, Greentree, Special Education, Supervisor
- Sabrina Woodlief, *OPEN MINDS*, Research Analyst

Appendix C – Leadership Team

The following identifies the individual leadership team members who participated in The Philadelphia Autism Project:

- Annemarie Clarke, SPIN, Corporate Officer
- Jackie Gallagher, Parent
- David Gates, Pennsylvania Health Law Project, Director of Policy, Senior Attorney,
- Kamillah Jackson, M.D., Community Behavioral Health, Child & Adolescent Services, Associate Medical Director
- Katy Kaplan, City Council, Office of Councilman Dennis M. O’Brien, Director of Human Services and Special Initiatives
- Lindsay Shea, Drexel University, A.J. Drexel Autism Institute, Eastern Region ASERT, Director
- David Mandell, University of Pennsylvania, Center for Mental Health Policy and Services Research, Director; The Children’s Hospital of Philadelphia, Center for Autism Research, Associate Director
- Terri Matthews, Parent; Jaden's Voice, Founder and CEO
- Jeannette Newman, Department of Behavioral Health and Intellectual disAbility Services, Philadelphia Infant Toddler Early Intervention, Policy & Planning Specialist
- Craig Newschaffer, Drexel University, A.J. Drexel Autism Institute, Director
- Dennis M. O’Brien, City Council, City Councilman-At-Large
- Valarie Oulds, Parent; Department of Behavioral Health and Intellectual disAbility Services, Program Manager
- Nina Wall, Parent; Bureau of Autism Services, Director

Appendix D - Methodology

The Philadelphia Autism Project was designed collaboratively by Councilman Dennis M. O'Brien's staff and the project leadership team with facilitation support by *OPEN MINDS*. Planning began in April of 2014 with a face-to-face meeting of the leadership team. The project consisted of three stakeholder meetings, which resulted in the development and prioritization of the strategic initiatives that will guide community improvements. The purpose and themes for these meetings are described below:

Purpose of Stakeholder Meetings

To create an inclusive process that relied upon self-advocates, family members, policy makers, researchers, service providers, educators and other key stakeholders to design a more effective, efficient, and comprehensive system of care for individuals with an ASD and their families.

Themes of Stakeholder Meetings

1. Describing today and creating a vision for the future.
2. Identifying the need and creating solutions.
3. Prioritizing solutions, establishing timelines and indicators of success.

These three stakeholder meetings comprised the planning phase of the Philadelphia Autism Project. The proposed result of these meetings was the development of a Philadelphia Strategic Plan for improving the lives of Philadelphians living with an ASD. This plan will be the basis for the work of an implementation team charged with bringing about the recommended changes from stakeholder meetings.

Appendix E – Guiding Principles

In addition, the leadership team developed a set of guiding principles for project work that was used to insure a best practices and inclusive process:

1. **Self Determination:** Meaningful participation and choice regarding in all aspects of life for individuals with an ASD and their families.
2. **Independence/Fullest Potential:** Independence and the ability for individuals with an ASD to achieve their fullest potential in accordance with their hopes and dreams.
3. **Safety:** The safety and well-being of individuals with an ASD is the responsibility of the entire community.
4. **Inclusion, Access & Full Participation in Community:** Individuals with an ASD are supported to the extent necessary to live, learn, work, and socialize in their communities of choice.
5. **Individualized Approaches, Services & Supports:** Services and supports in all systems are individualized to the specific needs, culture, dreams, and potential of each person and their family.
6. **Early Intervention:** Early identification of an ASD and early intervention services are key for positive outcomes for young children with an ASD.
7. **Family Support & Involvement:** Family members of individuals with an ASD receive the information and supports they need.
8. **Inclusive, Collaborative Service/Support Teams & Services:** Providers, educators, and systems work collaboratively and in partnership with the individual and his/her family.
9. **Best Practices & Innovative Approaches:** Evidence-based practices and innovative approaches are utilized.
10. **Equitable Access to Information, Support & Services:** Information supports and services are accessible to individuals and their families across the city's culturally and linguistically diverse communities.
11. **Holistic Approaches to Care:** The system of care for individuals with an ASD is designed to enhance and support the development and well-being of the whole person.

Appendix F – Stakeholder Meeting #1

In April, Councilman O’Brien issued a written request for participation in the Philadelphia Autism Project (Appendix A). In response, over one hundred stakeholders participated in Meeting #1 held at the Philadelphia District Attorney’s Office on May 12, 2014. In order to assure that all stakeholders were afforded the same level of basic information about ASDs, the morning session primarily focused on basic data and trend information regarding ASDs. The presentations included overviews of:

- National ASD Policy, Service, and Funding Trends: presented by *OPEN MINDS*
- State of Pennsylvania ASD Trends: presented by Nina Wall, Director, Pennsylvania Bureau of Autism Services
- City of Philadelphia Trends: presented by Lindsay Shea, Drexel University, ASERT
- City of Philadelphia Education Trends: presented by David Mandell, University of Pennsylvania

Several common trends were noted during this informational session: (According to the Center for Disease Control (CDC))

- The documented incidence of ASD continues to rise and is now estimated to be 1 in 68 children.
- There is an increasing awareness of ASD as a critical public health concern.
- Parity, the Affordable Care Act, and state-level mandated insurance legislation has the potential to increase access to services and help to lessen the financial burdens on families of children, youth, and adults with an ASD.
- There is an increasing awareness of ASD being a public health concern across the lifespan as more and more children with an ASD grow into adolescence and adulthood.

After the informational session, stakeholder participants were assigned to ten heterogeneous groups (a mix of family members, educators, treatment providers, researchers, policy officials, etc.) to begin the process of identifying the current system of care in Philadelphia. This process involved noting what is currently available, the current strengths, the areas needing improvement, the gaps in services, etc. This nearly five hour process resulted in over 150 pages of group notes.

Through leadership team review and discussion this resulted in the development of ten “Themes for Improvement”. The identified themes were:

1. **Clinical Concerns Across The Lifespan** – Developing solutions to support individuals and families as they navigate the system to receive needed services and as they transition from one system to the next as the family member with an ASD grows older. This theme also involves the identification of best practices in diagnosis, early intervention, and ongoing treatment as an individual with an ASD ages into adulthood.
2. **Family Support** – Identifying solutions to support families educationally, emotionally, socially, and financially to meet the needs of their family member with an ASD and address the impact it has on all family members.
3. **Post-Secondary Educational & Employment Opportunities** – Addressing the need to design employment preparation and job opportunities for young adults and adults with an ASD that are rewarding, challenging, and take full advantage of the individual’s potential and strengths while fostering self-determination.
4. **Underserved Communities** – Identifying barriers and creating solutions for the needs of individuals and their families in communities that are underserved, because of culture, language barriers, poverty, unsafe neighborhoods, etc. Solutions include community awareness, access to diagnosis, early intervention, and the full array of needed services that are culturally and linguistically appropriate.
5. **Capacity Building & Workforce Development** – Developing solutions to promote more ASD-specific competencies for all professionals who work with the ASD population (educators, health care, behavioral health, etc.). Solutions must support the training and professional development needs of these professionals and work to assure the number of professionals required are available (recruiting and retaining highly qualified professionals) to meet current and future needs of individuals with an ASD and their families.
6. **Enhancing Community Inclusion For Individuals & Families With An ASD** – Identifying specific areas (daycare, respite, transportation, recreation, social, entertainment, family living, etc.) and solutions to create a more inclusive community living environment for individuals living with an ASD and their families across the lifespan.
7. **Supports for Adults** – Creating solutions to address the complex needs of adults with an ASD from ages 21+ throughout adulthood. This includes, but is not limited to, developing independent living skills, access to post-secondary educational and vocational training opportunities, and developing a continuum of appropriate and adequate housing alternatives, etc.

8. **Child Welfare & Criminal Justice Systems**

- a. Child Welfare & Juvenile Justice – Identifying the needs and solutions to address the special needs of children and youth with an ASD who are in the juvenile justice and child welfare systems.
- b. Adult Criminal Justice System – Identifying needs and solutions for adults with an ASD who come into contact with the criminal justice system, from initial identification, through sentencing, rehabilitation, and reentry to the community.

9. **Education** – Developing strategies that increase the use of best practices in classrooms, create more mainstream opportunities for students with an ASD, improve the Individualized Education Plan (IEP) process for families, retain high quality teachers, and increase awareness among all staff.

10. **Blending Of Funding Streams** – Identifying strategies for blending funding from various systems (education, public, and private insurance) to create more integrated and coordinated services offered to individuals with an ASD and their families.

Appendix G – Stakeholder Meeting #2

Stakeholder Meeting #2 was held June 6, 2014 and the assignment for Meeting #2 was to discuss the ten “themes for improvement.” This involved identifying and establishing “initiatives” with timelines to address the issues outlined for each theme. For this discussion, Councilman O’Brien encouraged the groups to use their expertise to identify needed improvements and not be inhibited by the barriers to change. Councilman O’Brien gave this guidance because he wanted to use the plan of action developed during this meeting to work with others and bring about the resources required to successfully implement the recommended improvement initiatives.

Stakeholder Meeting #2 began with a brief review of the overall goals of the project, accomplishments of Meeting #1, and the goals for Meeting #2. After, the workgroups spent the rest of the day completing work on their assigned theme for improvement. Since the “Themes for Improvement” required content-specific expertise, members were assigned based upon their background and experience. Groups were also organized so all of them had sufficient numbers to successfully complete their assignments.

Stakeholder Meeting #2 was concluded prior to workgroups having completed a final full version of their worksheet. The meeting was ended with a brief summary of the day, reminder of their assignment to complete work sheets and turn them in by June 27, 2014, and an overview of the role and purpose of the third and final Stakeholder Meeting: prioritization of recommended initiatives.

Appendix H – Stakeholder Meeting #3

Stakeholder Meeting #3 was originally scheduled for July 2014. However, a lengthy process was utilized to assure that all 139 initiatives developed by the various groups at Stakeholder Meeting #2 were included and accurately described. This process involved a verification with the stakeholder workgroup chairs and offering opportunities for feedback to all workgroup members. Additionally, the number of initiatives required the creation of a categorization and feedback process that would simplify stakeholder's ability to recommend priority initiatives. For these reasons, the originally scheduled Stakeholder Meeting #3 in July was utilized as a Leadership Team Meeting to prepare and organize initiatives in order to allow stakeholders an efficient process for voting on them. Stakeholder Meeting #3 was rescheduled for September 19, 2014.

In preparation for the September 19th stakeholder meeting, Katy Kaplan with Councilman O'Brien's office, Valerie Oulds of the Philadelphia Department of Behavioral Health, and Lindsay Shea's team at Drexel's ASERT Collaborative, drafted the final process for organizing initiatives and voting on priority recommendations. Through a series of reviews a final categorization and prioritization process was agreed upon and formed the basis for organizing and structuring Stakeholder Meeting #3.

Stakeholder Meeting #3 was held on September 19, 2014 at the Philadelphia District Attorney's training center. The meeting began with a review of overall project goals and the accomplishments of the first two meetings. The final categorization of initiatives and the process for making recommendations for priority initiatives was described to all stakeholders. This process is outlined below:

- A final total of 119 initiatives were developed after consolidation of repeat initiatives and elimination of some by the respective stakeholder workgroups.
- Four categories were identified to sort initiatives:
 1. **Resources, Outreach, Awareness, Training, and Education:** To assure that individuals and families living with an ASD, and those that support them, are continually apprised of the advances in knowledge about ASD, best practice methods, and the local resources available to bring about the highest quality of life possible.
 2. **Infrastructure:** To bring about the necessary changes and increased collaboration/integration of systems that are responsible for supporting individuals and families living with an ASD, and other community institutions in Philadelphia, in order to be more responsive and increase access to services and the community as a whole.

3. **Policy:** To explore public policy legislation, local ordinances, and/or practices that will initiate or continue development of more responsive community systems and resources in order to further improve the quality of life for Philadelphians living with an ASD.
4. **Capacity:** To increase the knowledge base, collaboration, responsiveness, and service availability of community institutions whose expertise or services can contribute to an increased quality of life for individuals and families living with an ASD.

Three categories of initiatives were utilized to offer stakeholders a method for recommending priority initiatives:

1. Short Term Initiatives (one year or less) requiring no new resources to implement.
2. Short Term Initiatives (one year or less) requiring new resources to implement.
3. Long Term Initiatives (over one year) requiring several phases and new resources to implement.

Following the description of the categorization and prioritization processes, individual stakeholders were given a survey to generate stakeholder recommendations for priority initiatives. Afterwards, stakeholders were then given an opportunity to work individually and in small groups for a final review of all initiatives to check the wording, intent, and that a complete list of all initiative recommendations were included. During this time, the ASERT Team entered the voting data to offer preliminary results by the end of the meeting.

During the afternoon session, small group feedback was shared and while there were additions and deletions noted, the basic initiatives were approved. Afterwards, the final report outline was shared, as well as next steps in the process.

Next Steps: Final Report

1. Finalize survey results with input from Stakeholders unable to attend September 19th, meeting.
2. Complete the Final Report and disseminate to all stakeholder and larger ASD community.

Next Steps: Selection of Priorities

1. Guiding influences:

- a. Project guiding principles
- b. Commitment across the lifespan, across the spectrum
- c. Contributions from leadership team

2. Prioritization of Initiatives

- a. Recommendations from stakeholders
- b. Guidance from Leadership Team
- c. Ability to allocate/secure necessary funding/resources
- d. Ability to develop strategic relationships
- e. Adjusting priorities based on new information or changing community needs

Next Steps: Implementation of the Strategic Plan

1. Formation of workgroups/committees

2. Ongoing communication with stakeholders

The ASERT Team conducted the final presentation of the meeting on the preliminary report of the survey results. The “Top Five” recommendations in each category (Short Term - No New Resources; Short Term - New Resources Required; Long Term) were presented and briefly described. However, meeting participants were reminded that these results were preliminary since a significant number of stakeholders were not able to attend the meeting. In particular, it was noted that many from the educational community were unable to attend the September 19th meeting since school was in the early weeks of its new year. An online version of the voting survey was provided to these stakeholders after the meeting.

The meeting concluded with a closing message from Councilman O’Brien talking about the importance of the work of the stakeholder’s group and the great success of the planning portion of the project. He also offered his thanks for the dedicated efforts of the group, and asked for their continued commitment through the implementation stage of the project.

Appendix I – Philadelphia Autism Project Initiatives



Philadelphia Autism Project Initiatives

I. Resources, Outreach, Awareness, Training, and Education

- A. Materials:** Develop print and web based materials to provide information on the topics listed below. Materials will be disseminated broadly to the following groups when relevant: families, individuals living with autism, professionals (i.e. - childcare providers, early interventionists, educators, behavioral health providers, child welfare providers, members of the judiciary, etc.). These materials will build upon existing city and state wide resources (28, 29, 30, 45, 52, 85, 93, 97, 128, 129).
1. General Information regarding ASD, including available services across the lifespan
 2. Early Intervention
 3. Legal/Juvenile Justice (for both victims and offenders who are living with ASD and have contact with the juvenile justice or criminal justice systems)
 4. Post-Secondary Transition Planning (i.e. – OVR services available, what colleges have programs and supports specific for individuals with ASD, etc.)
 5. Adult Services (i.e. how to apply for waiver; should I apply, etc.)
 6. Child Protective Services and Foster Care
 7. Housing
 8. Creation of an easily read informational packet for individuals and families of individuals living with Autism
 9. Develop a list of Post-Secondary programs/supports
 10. Develop a “Welcome Packet” that can be used to stimulate meaningful dialogue between teacher and parents at beginning of school year.
 11. Develop list of all parent groups, including online support groups.
 12. Develop a list of advocates with knowledge of best practices for educational interventions for children with autism.
 13. Create a Transition “Roadmap”.
 14. Development of “Transition Toolkits” across the lifespan for teachers/professionals to use in support of individuals and families living with autism (i.e. – early intervention, school age, 21 and over, seniors)

- B. Hubs:** Creation of a “gold standard” centralized resource, possibly a website or the adaption of an existing website, and/or a physical location that can be used to: disseminate existing resources as well as new resources generated; promote awareness initiatives; develop new apps for wider reach and remote access; and establish “connection sites” where information and community experts are brought together to facilitate increased community awareness of ASD and assistance with access to services (1, 10, 28, 54)
- C. Connection Opportunities/Support Groups:** Create a comprehensive system of support groups for individuals with ASD and their families that are flexible to address various community needs and stakeholders; includes a comprehensive approach to advocacy, mentorship and support of families using technology; and provides technical assistance to self-advocates around local, state and national advocacy efforts. Specific initiatives can include the (23, 24, 69, 125):
1. Creation of a more effective advocacy/support group network along the lines of Leukemia and Lymphoma Society (23)
 2. Creation of the Philadelphia Autism Support Group that would utilize a wide range of support strategies including trainings, webinars, support groups (face-to-face and internet based), peer to peer mentoring, etc. (24)
 3. Mentoring of new families by peer families; ongoing peer support among families (parents, siblings, etc.); create Family Voices structure and borrow mental health model (69)
 4. Start parent partnership model with independent contractors that are neutral, but accountable to both parents and staff; expand existing parent coordinator functions (125)
- D. Events/Meetings:** Create additional opportunities for information gathering, as well as advocacy efforts through local meetings and events. Initiatives can include:
1. Establishing an annual Philadelphia Autism Conference – conference will be organized by lifespan tracks (i.e. Ages 0-5, School Age, 21 and older, older adults) and cover the needs across the spectrum (12, 17, and 18); Conference can also be utilized to organize a grassroots advocacy movement by pulling together a community of individuals with autism, families, providers and researchers to secure more funding, advocate for key legislative changes, etc.
 2. Town Hall Meetings – provide updates on Philadelphia Autism Project initiatives and create advocacy opportunities to push for additional funding, services, and supports to individuals with autism and their families
- E. Consultative Services:** Increase the availability of consulting services in the following areas: clinical, juvenile justice, housing, and legal. Initiatives can include:
1. Partner with Bar Association and DBH to create increased access to ASD specific legal/life planning (e.g. financial planning, etc.) services (25)

2. Examine existing consultative structure offered by ASERT (i.e. – case consultation) for delivery to probation officers (94)
3. Examine existing consultative services provided by ASERT for families and providers and determine how to modify for families who've come into contact with the child welfare, juvenile justice or criminal justice systems (98)
4. Establish or strengthen an organization which provides counseling on legal, financing and personal issues in setting up independent housing for persons with ASD (90)

F. Awareness/Training/Education: Provide training and education to address the lack of awareness that exists among teachers, parents and professions regarding a variety of services and supports that exists for individuals and families impacted by autism. Specific initiatives are:

1. Training for high school/alternative school teachers and personnel responsible for transition planning, on waivers and other programs such as the Office of Vocational Rehabilitation's Early Reach Program (33)
2. Development of a strategy that will create increased opportunities for community-wide desensitization activities to increase meaningful community inclusion of individuals and families living with autism (71)
3. Outreach to community via trainings and community based programs, including those employed in public service, university settings, employment training, etc. (53)
4. Comprehensive community wide trainings in autism specific language, environmental accessibility and accessible materials (82)
5. Target the needs of underserved populations accessible in existing key community hubs
6. Create a system of "Community Based Ambassadors" indigenous to the community who could be employed by the "Hub" to educate community residents (46)

G. Campaigns

Utilizing the Media

1. Partner with Comcast to run Public Service Announcements (PSAs) educating individuals and families impacted by autism about available resources such as ASERT and local initiatives like the Philadelphia Autism Project and the newly established Philadelphia Autism Conference (14)
2. Create a specialized ASD awareness campaign around transition to adulthood and adults with ASD using general public awareness strategies (16)
3. Development of Public Awareness Campaign specifically targeted for underserved communities---utilize existing community institutions---clinics, doctor's offices, churches, community centers, etc. (48)

4. Development of a public awareness campaign focused on eliminating myths and reducing the stigma associated with ASD (49)

Targeting Business/Commerce

1. Campaign to raise awareness of need for employment opportunities with large community employers (e.g. - Aramark, sports stadiums, Sodexo, TastyKake, etc.) (37)
2. Campaign to raise awareness in the local small business market (40)
3. Acknowledge autism friendly businesses by creating “badges” and include in business ratings; support efforts through training and awareness programs for businesses(68, 72)

II. Infrastructure

A. Service Creation: Development of new services and programs to meet existing gaps in service.

1. City Task Force of providers of ASD providers from across the lifespan, to develop a Universal Initial ASD Evaluation Protocol that meets the requirements of all funding systems (4)
2. City Wide Task Force of providers from across the lifespan to develop a Universal Multi-Disciplinary/Multi-System Care Plan protocol (Individual Service Plan, Universal Service Plan, etc.) that meets the requirements of all funding systems. The protocol should emphasize use of best practices documenting the appropriate intervention at each age group for specific needs. Additionally it should identify the role of various professionals and their ability to identify what an individual with autism needs (6)
3. Development of a tool to assess the qualification strengths and deficiencies in families and their immediate support network; develop specific programs to strengthen an individuals’ family and support network so they can more successfully manage the responsibilities required for in-home services
4. Development of Autism Inclusive childcare services (83)
5. Launch an agency/entity to serve as a single, centralized Philadelphia specific portal of entry for access to clinical, behavioral and educational ASD related services that would directly provide initial evaluation/diagnostic services, ongoing multidisciplinary/multisystem care planning and ongoing system navigation whose evaluations and care planning would be accepted across providers/agencies in the City (5)
6. Establish a dedicated caseworker from 0-5 that will follow the child from diagnosis through transition to the School District
7. Implementation of a “Comprehensive Integrated Care Plan” with a “System Navigator” role to assist individuals and their families with successful plan implementation (7); Explore possibility that the Medicaid Health Home provision

of Affordable Care Act can serve as a potential funding source for System Navigator

8. Support Office of Vocational Rehabilitation with development of autism specific services (22)
9. Creation of more local in-home supports and options for aging parents and their adult children with ASD, (see models identified under the “Housing” section of the State Task Force Plan) (91)
10. Creation of autism specific tracks within the First Judicial District Mental Health Court to offer diversion program options for individuals with autism who are court involved (101)
11. Expand the Adult Community Autism Program to Philadelphia County
12. Development of a “Bio Behavior Unit”(102)
13. Create access to screenings by a wide range of professionals (ER, MDs, pharmacists, schools, pre-schools, ministers, etc.) and provide with a centralized phone number to access resources (57)

B. Workforce

1. Increase the number of ASD specialists by making this position a viable, long term career for a diverse workforce through fellowship opportunities, trainee stipends, loan forgiveness, scholarships, career ladders, and other incentives (58, 60)
2. Establish quality improvement, practice guidelines, and standards, as well as ongoing review of licenses to obtain/keep city contracts and study impact on quality of care (59)
3. Develop practice guidelines for the use and coordination of evidence based practice within and between systems, e.g., Infant Toddler Early Intervention and CBH, School District and CBH.

C. Universal Database

1. Create a workgroup (including privacy, IT experts) to develop and launch an information sharing solution that would support a commonly accessible “core record” (including a subset of information of high use utility across providers/agencies in Philadelphia) for individuals with ASD (7, 102)
2. Create contacts between probation and investigators and those who can provide training and create an assessment tool (100)
3. Develop “data dashboards” for sharing child-level and aggregate data (113)
4. Create structures for inter-provider, inter-system awareness of common approaches to services, treatment, planning, etc. in order to create a more coordinated system of care for individuals with ASD and their families (8)
5. Maintain a database of specialized services and culturally competent providers (culture, languages, etc.) and resources (videos, blogs, support groups, etc.) (47)

III. Policy

A. Analysis/Research

1. Underserved community assessment of ASD awareness and needed supports (55)
2. Study of how “underserved” ASD population in other cities are identified and served (use of graduate students)(56)
3. Analysis of existing funding streams
4. Comprehensive review of regulations and funding for persons with disabilities to ensure policies and programs accommodate their needs (34)
5. Identify existing models for 6-year high schools to learn about models of excellence (121)
6. Research Medicaid Health Home provision of Affordable Care Act (§2703 of ACA) and consider the usefulness of this model as an additional funding source (130); Reach out to Community Behavioral Health, Mental Health Association of Southeastern PA, PA Mental Health Consumers Association, Parents Involved Network, and the Alliance of Community Service Providers to determine interest in joint Health Home project
7. Advocate with Department of Public Welfare’s Office of Mental Health and Substance Abuse Services to submit a Philadelphia specific Health Home Medicaid state plan amendment to the federal government for persons with autism and persons with serious and persistent mental illness (the allowable target populations)
8. Study process of “portability” of services and funding---funding follows the individual (look into models of self-directed care in mental health) (132)
9. Evaluate a pilot project where services that are typically provided in school buildings are provided outside of classrooms with shortened academic day, to ensure coverage of services by private insurers (133)
10. Examine models in other states/counties that represent best practices for inclusion
11. Convene ongoing discussions between all payers (Community Behavioral Health, Medicaid managed care plans, the school district, commercial insurers, Office of Vocational Rehabilitation, etc.) to determine means of braiding funding through common procedure codes, provider qualifications and centralized billing (131)
12. Work with Community Behavioral Health and Department of Behavioral Health to fund autism centers or contract with qualified providers to assure they receive adequate reimbursement for comprehensive evaluation/preparation of treatment plan and report/reimbursement for time spent coordinating multi-disciplinary evaluation team (13)
13. Development of a consortium of researchers and service providers that could identify opportunities for meaningful research-to-practice projects that could be carried out in partnership with a goal of having more evidence-supported practices being adopted.
14. Secure additional autism waiver slots

B. Legislation

1. Make it a legal requirement that the transition roadmap be distributed to families receiving early intervention (i.e. 0-3, 3-5) services, or are students in the Philadelphia School District or a Charter Schools (linked to initiative under Resources/Materials – creation of a transition roadmap) (29)
2. Tax incentives for entities that promote awareness of autism (15)
3. Enact local ordinance to require all City contractors or subcontractors to include youth with disabilities in internship and apprenticeship programs (118)
4. Explore a wide range of housing and housing support options based upon the State Task Force Report and initiatives in other states (87)
5. Funnel public money through one agency (similar to Philadelphia Corporation for the Aging) by enacting legislation for coordination of resources to serve individuals/families (11)

C. Mandated Training/Care

1. Add a required autism training component to the summer academy for Principals and Special Education Liaisons and include autism as an aspect of teacher induction (105)
2. Develop policies to strongly incentivize multi-agency/multi-provider coordinated care and/or to make agencies/providers accountable for care coordination

IV. Capacity

A. Individual Choice

1. Expand the project Councilman O'Brien has been working on with PHL Airport to create employment opportunities to include other industries (39)
2. Create SEPTA fare exemption program to increase access to services (89)
3. Expand "Work Ready" program to include ASD kids (20)
4. Creation of paid City internship program for ASD youth/adults (36) and support paid internships with community employers (38)
5. Increased access to self-determined community recreation (81)
6. Develop supportive college program for students with ASD (academic, social skills, etc.) (43)
7. Develop college courses for more severe ASD youth and adults who are interested (44)
8. Development of transportation training program (80)
9. Increase access to faith based opportunities (86)
10. Development of technology training programs that serve to increase employment opportunities, social networks and access to information (84)

B. Family

1. Examine existing consultative services for families and providers to determine necessary modifications (98)

C. Community

1. Replicate Middle Bucks Institute of Technology's approach that utilizes a multi-disciplinary environment so students are exposed to a variety of occupations (19)
2. Replicate program similar to College of New Jersey's "College and Community Program" (42)
3. Assess the ability and willingness of the business community and unions to provide vocational/employment services and opportunities (135)

D. Professional

1. Develop a strategy to train Child Welfare Workers on ASD (96)
2. Develop partnerships with universities and providers to offer observational opportunities to increase the number of ASD specialists (63)
3. Partner with universities to develop required skill sets for effective ASD teaching and outcome measures (134)
4. Provided trainings to promote use of peer role models and create opportunities for interaction between peers with ASD and typically developing peers in schools and the community (75)
5. Professional Development of Educators and School Personnel - Assure new teacher coaches get ASD training (107); Create summer institutes to train teachers and offer financial incentives to participate (64); Develop test for autism support teachers, with the requirement that the teacher must pass the test in order to teach (108); Mandated training for non-teaching assistants, principals and other support staff on autism specific issues to ensure an autism-friendly school environment (109/110); Mandated autism training and continued professional development for teachers in autism support classrooms
6. Contract to develop a supplemental curriculum for a range of life/soft skills for higher grades, allowing for flexible content; and develop a policy for content selection (120)
7. District wide push for greater inclusion, with specific training and in-school supports/consultation on how to include students with autism (124)
8. Recruit training sites at hospitals, community providers, etc. to insure adequate practice learning sites and offer incentives to participate (61)
9. Expand the opportunities available for psychiatry residents to rotate through community providers to increase the number of psychiatrists with capability to diagnosis ASD (62)
10. Partner with colleges and universities to develop and standardize training programs for teachers and other healthcare professionals interested in working



with individuals who have autism, and create more opportunities for internships for allied healthcare professionals, similar to psychology internships (65, 104)

11. Develop demonstration teacher program in which highly skilled teachers have certified interns placed with them who take over classrooms one day a week while the demonstration teacher provides support to other teachers in the learning network (117)
12. Develop and mandate IEP writing workshops (126)
13. Research existing partnerships with business and include these topics in summer leadership academies (122)
14. Establish ongoing review of training and expertise for Behavior Specialist Consultant certification by developing ongoing training institutes (66); Review trainings offered to Broad Certified Behavior Analysts for the inclusion of trainings offered to BSCs to further enhance the skill set of a BSC

E. System

1. Partner with Senior Centers to extend support services to older adults with ASD (136)
2. Create a Vocational Autism Work Group that can develop a strategic plan to include increased internships with City departments and non-profits, and tax incentives for private business internships (21)
3. Replicate “Project Search” model in Philadelphia (31)
4. Define and enforce disciplinary process for students with ASD. Implement school wide positive behavior support plans in all schools as one strategy for avoiding inappropriate discipline of students with ASD (123)
5. Replicate the Certified Peer Specialist model from mental health for individuals with ASD (70/74)
6. Develop an ASD specific Sexuality Training Program (26)
7. Advocate for adding Special Education Liaisons back into budget and training personnel to provide training and consultation in autism (106)
8. In order to support the formation, operation and endurance of independent housing developed by families for adults with autism, establish a private, non-profit membership organization which provides technical assistance and a safety net for independent housing which is in financial trouble including purchasing efficiencies, establishment of standards and outcome measures (92)
9. Create a standardized, uniform protocol for transition planning in schools with ongoing professional development and designation of a “Transition Coordinator” and staff in each school (27)
10. Improve the capacity, quality, duration and intensity of evidence-supported, behaviorally-based Early Intervention services
11. Host information forums and exchanges among systems including Infant Toddler Early Intervention, Behavioral Health, and other interested systems

Appendix J – Pre-Implementation Survey

	 	
PHILADELPHIA AUTISM PROJECT PRE-IMPLEMENTATION SURVEY		
Part 1	Name:	
	Email:	
	Phone:	
	Stakeholder Type [Check all that apply]:	
	<input type="checkbox"/> Individual (with ASD) <input type="checkbox"/> Family Member <input type="checkbox"/> Provider <input type="checkbox"/> Teacher/Educator <input type="checkbox"/> Government Staff <input type="checkbox"/> Researcher <input type="checkbox"/> Advocate <input type="checkbox"/> Other, please specify:	
	Your responses to Questions 1 – 3 will identify your top recommendations to prioritize the initiatives and tasks for implementation. Place a checkmark next to your choices for the top 3 initiatives in each category listed below:	
	Category 1: Initiatives that build on existing resources and are less than one year to complete. Put a check next to your top 3 initiatives.	
	<i>Initiative</i>	<i>Check Here</i>
	1. General Information - regarding ASD, including available services across the lifespan	
	2. Early Intervention	
	3. Legal/Juvenile Justice (for both victims and offenders who are living with ASD and have contact with the juvenile justice or criminal justice systems)	
	4. Post-Secondary Transition Planning (i.e. – OVR services available, what colleges have programs and supports specific for individuals with ASD, etc.)	
	5. Adult Services (i.e. how to apply for waiver; should I apply, etc.)	
	6. Child Protective Services and Foster Care	
	7. Housing	
8. Creation of an easily read informational packet for individuals and families living with autism		
9. Develop a list of post-secondary programs/supports		
10. Development of a “Welcoming Packet” that can be used to simulate meaningful dialogue between teacher and parents at beginning of school year		
11. Develop list of all parent groups, including online support groups		
12. Develop a list of advocates with knowledge of best practices for educational interventions for children with autism		
13. Create a Transition “Roadmap”		
14. Development of “Transition Toolkits” across the lifespan for teachers/professionals to use in support of individuals and families living with autism (i.e. – early intervention, school age, 21 and over, seniors)		
15. Training for high school/alternative school teachers and personnel responsible for transition planning, on waivers and other programs such as the Office of Vocational Rehabilitation’s Early Reach Program (33)		

16. Development of strategy the will create increased opportunities for community-wide desensitization activities to increase meaningful community inclusion of individuals and families living with autism (71)	
17. Outreach to community via trainings and community based programs, including those employed in public service, university settings, employment training, etc. (53)	
18. Study of how “underserved” ASD population in other cities are identified and served (use of graduate students)(56)	
19. Analysis of existing funding streams	
20. Comprehensive review of regulations and funding for persons with disabilities to ensure policies and programs accommodate their needs (34)	
21. Identify existing models for 6-year high schools to learn about models of excellence (121)	
22. Research Medicaid Health Home provision of Affordable Care Act (§2703 of ACA) and consider the usefulness of this model as an additional funding source (130); Reach out to Community Behavioral Health, Mental Health Association of Southeastern PA, PA Mental Health Consumers Association, Parents Involved Network, and the Alliance of Community Service Providers to determine interest in joint Health Home project	
23. Examine models in other states/counties that represent best practices for inclusion	
24. Convene ongoing discussions between all payers (Community Behavioral Health, Medicaid managed care plans, the Philadelphia School District, commercial insurers, Office of Vocational Rehabilitation, etc.) to determine means of braiding funding through common procedure codes, provider qualifications and centralized billing (131)	
25. Secure additional autism waiver slots	
26. Explore a wide range of housing and housing support options based upon the State Task Force Report and initiatives in other states (87)	
27. Examine existing consultative services for families and providers to determine necessary modifications (98)	
Category 2: Initiatives that require new resources but take less than one year to complete. Put a check next to your top 3 initiatives.	
<i>Initiative</i>	<i>Check Here</i>
1. Creation of a more effective advocacy/support group network along the lines of Leukemia and Lymphoma Society (23)	
2. Creation of the Philadelphia Autism Support Group that would utilize a wide range of support strategies including trainings, webinars, support groups (face-to-face and internet based), peer to peer mentoring, etc. (24)	
3. Mentoring of new families by peer families; ongoing peer support among families (parents, siblings, etc)-create Family Voices structure and borrow mental health model (69)	
4. Establish an annual Philadelphia Autism Conference organized by tracks that cover the lifespan (i.e. Ages 0-5, School Age, 21 and older, older adults) as well as address the needs of individuals with Autism across the spectrum (12, 17, and 18); Utilize Philadelphia Autism Conference to organize a grassroots advocacy community of individuals with autism, families, and providers to advocate for increased funding, service enhancements, etc.	

5. Utilize Town Hall Meetings to provide updates on Philadelphia Autism Project, as well as to advocate for additional funding, services and supports to individuals with autism and their families	
6. Examine existing consultative structure offered by ASERT (i.e. – case consultation) for delivery to probation officers (94)	
7. Examine existing consultative services provided by ASERT for families and providers and determine how to modify for families who've come into contact with the child welfare, juvenile justice or criminal justice systems (98)	
8. Comprehensive community wide trainings in autism specific language, environmental accessibility and accessible materials (82)	
9. Support Office of Vocational Rehabilitation with development of autism specific services (22)	
10. Creation of autism specific tracks within the First Judicial District Mental Health Court to offer diversion program options for individuals with autism who are court involved (101)	
11. Create contacts between probation and investigators and those who can provide training and create an assessment tool (100)	
12. Maintain a database of specialized services and culturally competent providers (culture, languages, etc) and resources (videos, blogs, support groups, etc.) (47)	
13. Underserved community assessment of ASD awareness and needed supports (55)	
14. Advocate with Department of Public Welfare's Office of Mental Health and Substance Abuse Services to submit a Philadelphia specific Health Home Medicaid state plan amendment to the federal government for persons with autism and persons with serious and persistent mental illness (the allowable target populations)	
15. Study process of "portability" of services and funding---funding follows the individual (look into models of self-directed care in mental health) (132)	
16. Enact local ordinance to require all City contractors or subcontractors to include youth with disabilities in internship and apprenticeship programs (118)	
17. Add a required autism training component to the summer academy for Principals and Special Education Liaisons and include autism as an aspect of teacher induction (105)	
18. Expand the project Councilman O'Brien has been working on with PHL Airport to create employment opportunities to include other industries (39)	
19. Expand "Work Ready" program to include ASD kids (20)	
20. Creation of paid City internship program for ASD youth/adults (36) and support paid internships with community employers (38)	
21. Increased access to self-determined community recreation (81)	
22. Development of transportation training program (80)	
23. Increase access to faith based opportunities (86)	
24. Development of technology training programs that serve to increase employment opportunities, social networks and access to information (84)	
25. Assess the ability and willingness of the business community and unions to provide vocational/employment services and opportunities (135)	
26. Develop a strategy to train Child Welfare Workers on ASD (96)	
27. Develop partnerships with universities and providers to offer observational opportunities to increase the number of ASD specialists (63)	

28. Partner with universities to develop required skill sets for effective ASD teaching and outcome measures (134)	
29. Provided trainings to promote use of peer role models and create opportunities for interaction between peers with ASD and typically developing peers in schools and the community (75)	
30. Professional Development of Educators and School Personnel - Assure new teacher coaches get ASD training (107); Create summer institutes to train teachers and offer financial incentives to participate (64); Develop test for autism support teachers, with the requirement that the teacher must pass the test in order to teach (108); Mandated training for non-teaching assistants, principals and other support staff on autism specific issues to ensure an autism-friendly school environment (109/110); Mandated autism training and continued professional development for teachers in autism support classrooms	
31. Recruit training sites at hospitals, community providers, etc to insure adequate practice learning sites and offer incentives to participate (61)	
32. Expand the opportunities available for psychiatry residents to rotate through community providers to increase the number of psychiatrists with capability to diagnosis ASD (62)	
33. Partner with colleges and universities to develop and standardize training programs for teachers and other healthcare professionals interested in working with individuals who have autism, and create more opportunities for internships for allied healthcare professionals, similar to psychology internships (65, 104)	
34. Develop and mandate IEP writing workshops (126)	
35. Replicate "Project Search" model in Philadelphia (31)	
36. Develop an ASD specific Sexuality Training Program (26)	
37. Host information forums and exchanges among systems including Infant Toddler Early Intervention, Behavioral Health, and other interested systems	
Category 3: Initiatives that require new resources and will take more than one year to complete. Put a check next to your top 3 initiatives.	
<i>Initiative</i>	<i>Check Here</i>
1. Creation of a "gold standard" centralized resource, possibly a website or the adaption of an existing website, and/or a physical location that can be used to: Disseminate existing resources, as well as new resources generated; Promote awareness initiatives; Develop new apps for wider reach and remote access; and Establish "Connection Sites" where information and community "experts" are brought together to facilitate increased community awareness of ASD and assistance with access to services (1, 10, 28, 54)	
2. Start parent partnership model with independent contractors that are neutral, but accountable to both parents and staff; expand existing parent coordinator functions (125)	
3. Partner with Bar Association and DBH to create increased access to ASD specific legal/life planning (e.g. financial planning, etc.) services (25)	
4. Establish or strengthen an organization which provides counseling on legal, financing and personal issues in setting up independent housing for persons with ASD (90)	
5. Target the needs of underserved populations accessible in existing key community hubs	

6. Create a system of “Community Based Ambassadors” indigenous to the community who could be employed by the “Hub” to educate community residents (46)	
7. Partner with Comcast to run Public Service Announcements (PSAs) educating individuals and families impacted by autism about available resources such as ASERT and local initiatives like the Philadelphia Autism Project and the newly established Philadelphia Autism Conference (14)	
8. Create a specialized ASD awareness campaign around transition to adulthood and adults with ASD using general public awareness strategies (16)	
9. Development of Public Awareness Campaign specifically targeted for underserved communities---utilize existing community institutions—clinics, doctor’s offices, churches, community centers, etc (48)	
10. Development of a public awareness campaign focused on eliminating myths and reducing the stigma associated with ASD (49)	
11. Campaign to raise awareness of need for employment opportunities with large community employers (e.g. - Aramark, sports stadiums, Sodexo, TastyKake, etc.) (37)	
12. Campaign to raise awareness in the local small business market (40)	
13. Acknowledge autism friendly businesses by creating “badges” and include in business ratings; support efforts through training and awareness programs for businesses(68, 72)	
14. City Task Force of providers of ASD providers from across the lifespan, to develop a Universal Initial ASD Evaluation Protocol that meets the requirements of all funding systems (4)	
15. City Wide Task Force of providers from across the lifespan to develop a Universal Multi-Disciplinary/Multi-System Care Plan protocol ((Individual Service Plan, Universal Service Plan, etc.) that meets the requirements of all funding systems. The protocol should emphasize use of best practices documenting the appropriate intervention at each age group for specific needs. Additionally it should identify the role of various professionals and their ability to identify what an individual with autism needs (6)	
16. Development of a tool to assess the qualification strengths and deficiencies in families and their immediate support network; develop specific programs to strengthen an individuals’ family and support network so they can more successfully manage the responsibilities required for in-home services	
17. Development of Autism Inclusive childcare services (83)	
18. Launch an agency/entity to serve as a single, centralized Philadelphia specific portal of entry for access to clinical, behavioral and educational ASD related services that would directly provide initial evaluation/diagnostic services, ongoing multidisciplinary/multisystem care planning and ongoing system navigation whose evaluations and care planning would be accepted across providers/agencies in the City (5)	
19. Establish a dedicated caseworker from 0-5 that will follow the child from diagnosis through transition to the School District	
20. Implementation of a “Comprehensive Integrated Care Plan” with a “System Navigator” role to assist individuals and their families with successful plan implementation (7); Explore possibility that the Medicaid Health Home provision of Affordable Care Act can serve as a potential funding source for System Navigator	

21. Creation of more local in-home supports and options for aging parents and their adult children with ASD, (see models identified under the "Housing" section of the State Task Force Plan) (91)	
22. Expand the Adult Community Autism Program to Philadelphia County	
23. Development of a "Bio Behavior Unit"(102)	
24. Create access to screenings by a wide range of professionals (ER, MDs, pharmacists, schools, pre-schools, ministers, etc.) and provide with a centralized phone number to access resources (57)	
25. Increase the number of ASD specialists by making this position a viable, long term career for a diverse workforce through fellowship opportunities, trainee stipends, loan forgiveness, scholarships, career ladders, and other incentives (58, 60)	
26. Establish quality improvement, practice guidelines, and standards, as well as ongoing review of licenses to obtain/keep city contracts and study impact on quality of care (59)	
27. Develop practice guidelines for the use and coordination of evidence based practice within and between systems, e.g., Infant Toddler Early Intervention and CBH, School District and CBH.	
28. Create a workgroup (including privacy, IT experts) to develop and launch an information sharing solution that would support a commonly accessible "core record" (including a subset of information of high use utility across providers/agencies in Philadelphia) for individuals with ASD (7, 102)	
29. Develop "data dashboards" for sharing child-level and aggregate data (113)	
30. Create structures for inter-provider, inter-system awareness of common approaches to services, treatment, planning, etc. in order to create a more coordinated system of care for individuals with ASD and their families (8)	
31. Evaluate a pilot project where services that are typically provided in school buildings are provided outside of classrooms with shortened academic day, to ensure coverage of services by private insurers (133)	
32. Work with Community Behavioral Health and Department of Behavioral Health to fund autism centers or contract with qualified providers to assure they receive adequate reimbursement for comprehensive evaluation/preparation of treatment plan and report/reimbursement for time spent coordinating multi-disciplinary evaluation team (13)	
33. Development of a consortium of researchers and service providers that could identify opportunities for meaningful research-to-practice projects that could be carried out in partnership with a goal of having more evidence-supported practices being adopted.	
34. Make it a legal requirement that the transition roadmap be distributed to families receiving early intervention (i.e. 0-3, 3-5) services, or are students in the Philadelphia School District or a Charter Schools (linked to initiative under Resources/Materials – creation of a transition roadmap) (29)	
35. Tax incentives for entities that promote awareness of autism (15)	
36. Funnel public money through one agency (similar to Philadelphia Corporation for the Aging) by enacting legislation for coordination of resources to serve individuals/families (11)	
37. Develop policies to strongly incentivize multi-agency/multi-provider coordinated care and/or to make agencies/providers accountable for care coordination	

38. Create SEPTA fare exemption program to increase access to services (89)	
39. Develop supportive college program for students with ASD (academic, social skills, etc.) (43)	
40. Develop college courses for more severe ASD youth and adults who are interested (44)	
41. Replicate Middle Bucks Institute of Technology's approach that utilizes a multi-disciplinary environment so students are exposure to a variety of occupations (19)	
42. Replicate program similar to College of New Jersey's "College and Community Program" (42)	
43. Contract to develop a supplemental curriculum for a range of life/soft skills for higher grades, allowing for flexible content; and develop a policy for content selection (120)	
44. District wide push for greater inclusion, with specific training and in-school supports/consultation on how to include students with autism (124)	
45. Develop demonstration teacher program in which highly skilled teachers have certified interns placed with them who take over classrooms one day a week while the demonstration teacher provides support to other teachers in the learning network (117)	
46. Research existing partnerships with business and include these topics in summer leadership academies (122)	
47. Establish ongoing review of training and expertise for Behavior Specialist Consultant certification by developing ongoing training institutes (66); Review trainings offered to Broad Certified Behavior Analysts for the inclusion of trainings offered to BSCs to further enhance the skill set of a BSC	
48. Partner with Senior Centers to extend support services to older adults with ASD (136)	
49. Create a Vocational Autism Work Group that can develop a strategic plan to include increased internships with City departments and non-profits, and tax incentives for private business internships (21)	
50. Define and enforce disciplinary process for students with ASD. Implement school wide positive behavior support plans in all schools as one strategy for avoiding inappropriate discipline of students with ASD (123)	
51. Replicate the Certified Peer Specialist model from mental health for individuals with ASD (70/74)	
52. Advocate for adding Special Education Liaisons back into budget and training personnel to provide training and consultation in autism (106)	
53. In order to support the formation, operation and endurance of independent housing developed by families for adults with autism, establish a private, non-profit membership organization which provides technical assistance and a safety net for independent housing which is in financial trouble including purchasing efficiencies, establishment of standards and outcome measures (92)	
54. Create a standardized, uniform protocol for transition planning in schools with ongoing professional development and designation of a "Transition Coordinator" and staff in each school (27)	
55. Improve the capacity, quality, duration and intensity of evidence-supported, behaviorally-based Early Intervention services	

Part 2	<p>We'd like to continue to engage interested stakeholders in this phase of the project by identifying your areas of interest and expertise, as well as your desired level of involvement during the implementation phase. Please review the topic areas listed below and select the topics you would like to work on with us during implementation.</p> <p>For each topic you select please choose whether you are willing to take a leadership role, an active role as a member of a committee/work group, or if you're unable to actively participate but are willing to share resources and disseminate information.</p>			
	<p><i>If you are not able to be involved in any of the implementation phases, please check here → <input type="checkbox"/></i></p>			
		<p>Take a leadership role (Check your top 3)</p>	<p>Participate as member of a committee/work group (Check your top 3)</p>	<p>Share resources and/or disseminate information (Check your top 3)</p>
	Clinical Concerns Across the Lifespan (i.e. – diagnosis, system navigation, treatment planning, early intervention and ongoing treatment)			
	Support (i.e. – families and individuals living with ASD)			
	Education			
	Post-secondary Education			
	Employment			
	Housing			
	Underserved Communities			
	Capacity Building & Workforce Development			
	Funding Streams			
	Child Welfare & Criminal Justice Systems			
Community Inclusion (i.e. – social roles, leisure & recreation, religion & spirituality, transportation)				

Appendix K – Final Survey Results

Following the September 19, 2014 stakeholder meeting, Katy Kaplan led an effort to ensure that all original stakeholders had an opportunity to cast a “vote” for selecting priority initiatives. Over the course of three weeks, numerous phone calls, conference call meetings, and access to surveys online were made to obtain as many respondents as possible. In the end, eighty surveys were completed and the following results were recorded by the ASERT Team:



Philadelphia Autism Project Survey Results

Overview

The top ten initiatives for each survey category are listed below with their corresponding number and the initiative description. The top 5 responses are separated by color shading. In addition, the responses for being a leader, member, or sharing resources for the implementation categories are outlined. In total, 80 survey responses were collected from the Philadelphia Autism Project.

Top Ten Responses in Each Category:

Category 1: Initiatives that build on existing resources and are less than one year to complete:

Votes	Initiative #	Description
29	24	Convene discussions between all payers to determine funding braiding, e.g. centralized billing
22	14	Development of “Transition Toolkits” across lifespan for teachers/professionals to use
16	22	Research Health Home provision of ACA, reach out to stakeholders for interest in joint home model
16	25	Secure additional autism waiver slots
14	4	Post-Secondary Transition Planning
11	13	Create a Transition “Roadmap”
10	23	Examine models across country for best practices for inclusion
9	3	Legal/Juvenile Justice resources for victims and offenders
9	16	Develop strategy for community-wide desensitization activities for individuals and their families
8	1	General Information-regarding ASD, including available services across lifespan

Category 2: Initiatives that require new resources but take less than one year to complete:

Votes	Initiative #	Description
28	4	Establish Annual Philadelphia Autism Conference organized by tracks that cover lifespan
20	2	Creation of Philadelphia Autism Support Group utilizing wide range of support strategies
17	30	Professional development of Educators and School Personnel
16	12	Maintain a database of specialized services and culturally competent providers
12	33	Partner with colleges and universities to develop and training programs for teachers /professionals
11	9	Support OVR with development of autism specific services
10	14	Advocate DPW-OMHSAS for Philadelphia specific Health Home amendment
9	10	Creation of autism track in Philadelphia Mental Health Court for diversionary purposes
9	17	Add required autism component to summer academy for Principals and Special Ed. Liaisons
9	18	Expand Councilman O’Brien’s Phila. Airport project to create opportunities in other industries

Category 3: Initiatives that require new resources and will take more than one year to complete:

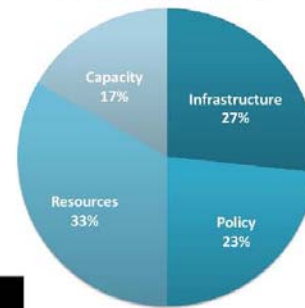
Votes	Initiative #	Description
23	1	Creation of "gold standard" centralized resource, possibly a website and/or physical location
16	18	Launch agency/entity to serve as single centralized portal of entry for access to services
14	20	Implementation of "Comprehensive Integrated Care Plan" with "System Navigator" role
14	49	Create Vocational Autism Work Group, develop strategic plan to increase internships/employment
12	15	City Wide Task Force of providers to develop Universal Multi-Discipline/Multi-System care plan
10	14	City Task Force of providers to develop a Universal Initial ASD Evaluation Protocol
9	17	Development of Autism Inclusive childcare services
8	25	Increase the number of ASD specialists by making position a more viable long term career
7	5	Target the needs of underserved populations accessible in existing key community hubs
7	33	Development of consortium of researchers/providers to increase evidence based practices

The highest voted initiative was number 24, which dealt with funding braiding. Thirty-six percent of the participants voted for this initiative. The second highest initiative was number 4 with 35% of participants voting in favor.

Initiative Response Area

The top ten responses in each category were matched to their initial topic areas. The majority of the top initiatives were Resource related, followed by Infrastructure, Policy, and Capacity. This provides a broader overview in what areas stakeholders deemed most in need of improvement or change.

Topic Area Proportions



Implementation Involvement

Category	Leader	Member	Share	Total Resources
Clinical Concerns Across the Lifespan	12	20	19	51
Support	12	17	15	44
Education	12	20	13	55
Post-secondary Education	7	15	7	29
Employment	4	15	12	31
Housing	1	5	8	14
Underserved Communities	8	10	11	29
Capacity Building & Workforce Development	11	16	11	38
Funding Streams	5	13	5	23
Child Welfare & Criminal Justice Systems	5	14	12	31
Community Inclusion	12	18	12	42
Total	89	163	114	

Respondents could indicate their interest to participate in three topic areas under the roles identified. The most desired participation was shown in the categories for Education, Clinical Concerns, Support, and Community Inclusion.

Overall, most respondents wanted to participate as a member of a committee/work group across all categories.

The Autism Services, Education, Resources and Training Collaborative (ASERT) is a statewide initiative funded by the Bureau of Autism Services, PA Department of Public Welfare.

Appendix L - Glossary of Terms

ABA: Applied Behavior Analysis – A method of teaching designed to analyze and change behavior in a precisely measurable and accountable manner. Also called behavior modification. Skills are broken down into their simplest components and then taught to the child through a system of reinforcement.

ACA: Affordable Care Act – Recently enacted federal legislation to comprehensively expand health care coverage to more Americans.

ASD: Autism Spectrum Disorder or Autism (DSM V) – A complex brain disorder typically appearing in early childhood characterized by (i) persistent deficits in social communication and social interaction across multiple contexts, and (ii) restricted, repetitive patterns of behavior, interests, or activities. Includes individuals diagnosed with the following disorders listed in the prior DSM-IV: Autistic Disorder, Asperger’s and Pervasive Developmental Disorder (PDD-NOS)

ASERT: Autism Services, Education, Resources, & Training Collaborative – A statewide initiative that provides support to individuals with an ASD and their families through resources, training, and other projects.

Assessment – A collecting and bringing together of information about a child’s needs, which may include social, psychological, and educational evaluations used to determine services and supports.

AT: Assistive Technology – A generic term that includes assistive, adaptive, and rehabilitative devices and the process used in selecting, locating, and using them. AT promotes greater independence for people with disabilities by enabling them to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to or changed methods of interacting with the technology needed to accomplish such tasks.

Augmentative Communication – A special device that provides an alternative for spoken language. For example, photographs and picture exchange communication.

Autism – A complex neurological disorder that affects, in varying degrees, language and social skill development, characterized by challenges in communication and social interactions, repetitive behaviors and movement, and self-stimulatory patterns.

Autism Waiver – A Medicaid waiver program designed to provide long-term services and supports for community living, tailored to the specific needs of adults age 21 or older with an ASD. The program is designed to help adults with an ASD participate in their communities in the way they want to, based upon their identified needs.

BCBA: Board Certified Behavior Analyst - Master's level trained person who has received additional specific graduate training in Applied Behavioral Analysis and passed the qualifying exam for this licensure.

BHRS: Behavioral Health Rehabilitation Services – Short-term community-based clinical services for children who have severe emotional or behavioral difficulties, and their family members, including children with an ASD. The main goal of BHRS is to reduce behavioral health challenges, while helping family and other key people in a child's life learn skills that will help a child do well. The treatment team may consist of an individual or a combination of the following professionals/services: Behavior Specialist Consultant, Mobile Treatment, and/or Therapeutic Support Services, as and to the extent determined to be medically necessary.

BSC: Behavior Specialist Consultant – Master's trained clinician whose role it is to design the treatment plan based upon the individualized needs of a child and family. This includes writing goals, suggesting techniques, and implementation of the treatment plan.

BSP: Behavior Support Plan/(BIP) - Behavior Intervention Plan – Multi-component behavior intervention plans, with multiple layers of support, based on the results of the Functional Behavioral Assessment and designed to promote the acquisition of new skills and/or to decrease problem behaviors. Specific strategies include changing elements of students' environment to promote positive behavior, teaching new skills to replace problem behavior and to increase social and academic competencies, and the use of positive reinforcement to strengthen desirable behavior.

Early Intervention Services – Available to children from birth to 5 years of age who are discovered to have or be at risk of developing special needs due to a developmental delay or disability that may adversely delay or affect their development (physical, cognitive, communication, social development). Early intervention programs may be center-based, home-based, hospital-based, or a combination. Services range from identification – that is, hospital or school screening and referral services – to diagnostic and direct intervention programs.

FBA: Functional Behavioral Assessment – A specific type of assessment conducted to help to find out the reason or purpose of a specific behavior. This information is used by the therapist in developing specific treatment goals and recommending appropriate types of interventions to decrease behaviors. A FBA consists of interviews with parents, caregivers and teachers, direct observation, and may include a survey to find out what motivates or interests the individual child.

IDEA: Individuals with Disabilities Education Act – Federal legislation (Public Law 105-17) passed in 1997 as a reauthorization of the Education of the Handicapped Act (EHA) passed in 1975. IDEA provides a mandate and some funding for certain services for students who have disabilities.

IEP: Individualized Education Plan – A yearly education plan written by teachers, therapists, psychologists, etc. and the child’s parents for school age children with disabilities who are determined to require special education. The IEP outlines the student’s specific needs and the educational supports and other services required to meet those needs.

IFSP: Individualized Family Service Plan – An education plan written by teachers, therapists, psychologists, etc. and the child’s parents for a child birth through 2 years old with disabilities.

Inclusion – Children with disabilities are educated and receive services in their home and in school, in the same classroom with children without disabilities. Inclusion classes often require a special assistant to the classroom teacher to modify and/or create differentiated curriculum and learning strategies.

LRE: Least Restrictive Environment – A federal mandate that a child should be educated in the least restrictive environment for his or her disability which meets his or her needs. LRE is an educational setting which gives students with disabilities a place to learn to the best of their ability in an inclusive environment with children without disabilities.

MA: Medical Assistance/Medicaid – A public insurance system that provides free health insurance (for physical and behavioral health) to persons who are financially eligible. In Pennsylvania, children with special needs, including autism, may be eligible for MA regardless of the income level of the family.

Mainstreaming – Placement of child with disabilities with non-disabled peers in a regular classroom, such that some or all of the child’s day is spent in a regular inclusive classroom.

MT: Mobile Therapist - Master’s trained individual who provides therapeutic services to a child and family in community settings (home, school, and daycare) other than at a provider agency office. Therapy will be child-centered and family focused to help caregivers and teachers learn ways to respond more therapeutically to a child’s needs.

PaTTAN: Pennsylvania Training and Technical Assistance Network – An initiative of the Pennsylvania Department of Education, Bureau of Special Education. PaTTAN supports the PA Department of Education’s efforts to lead and serve the educational community by offering professional development that builds the capacity of local educational agencies to meet students’ needs. PaTTAN’s primary focus is special education. However, services are also provided to support Early Intervention, student assessment, tutoring and other partnership efforts, all designed to help students succeed.

Respite Care – Child care for a child with special needs that may be provided in the child’s home or another qualified setting in order to afford the parents a break from care giving.

Service Coordinator – Someone who acts as a coordinator of infant or toddler services, working in partnership with the family and providers of special programs; service coordinators may be employed by the early intervention agency.

TSS: Therapeutic Staff Support – Supervised by BSC they provide direct interventions, structure activities for a child and assist in development of appropriate skills.