



PHILADELPHIA
AUTISM PROJECT

2019 UPDATE REPORT

Welcome to the 2019 Philadelphia Autism Project Update Report

This year highlights the five-year mark in our efforts to ensure that Philadelphia is a top city for people on the spectrum and more broadly, a city of inclusion. Through the leadership of the Office of Councilmember-At-Large Derek S. Green, the Philadelphia Autism Project is guided by stakeholders and the larger Philadelphia community to inform the implementation of initiatives that were identified at the inception of the project. Conceived in 2014 by Former House Speaker and Councilmember-At-Large Dennis M. O'Brien, the Philadelphia Autism Project was created on the foundation of more than 100 initiatives voted on and prioritized by stakeholders.

Philadelphia Autism Project initiatives span a diverse range of projects from community programming to policy changes. Along with concentrating resources on long-term initiatives (such as the development of a Community Autism Peer Specialist Training Program), we continue to foster annual projects, including the Annual Philadelphia Autism Project Conference and Seed Award initiative.

Through our ongoing projects, we have opportunities to engage with diverse groups in the Philadelphia community. These interactions sparked us to reevaluate our tagline and update it from *Guiding the Autism Community* to *Guided by the Autism Community*, to reflect that our efforts have always been and will continue to be driven by the community whom we serve. Additionally, feedback on the importance of identity-first language among self-advocates has led us to update our website and include a language statement on our use of neutral ("on the spectrum") and identity-first ("autistic person") language.

A fundamental component of the Philadelphia Autism Project is our dedication to collaboration and strong partnerships throughout the City of Philadelphia. We thank our collaborators including Philadelphia City Council, the Department of Behavioral Health and Intellectual disAbility Services (DBHIDS), Community Behavioral Health (CBH), the Free Library of Philadelphia, the Philadelphia Museum of Art, and our community stakeholders including self-advocates, family members, educators, service providers, policy and data specialists, researchers and many more.

We are always expanding our network and welcome you to connect with us, and most importantly, with the Philadelphia autism community. Please visit our redeveloped website at www.phillyautismproject.org, and follow us on **Twitter @PhillyAutism**, **Instagram @PhillyAutism**, and **Facebook @PhillyAutism**. We can also be contacted by email at phillyap@drexel.edu.

We are excited to continue our work together and looking forward to an eventful 2020!



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Large and Leader of the
Philadelphia Autism Project



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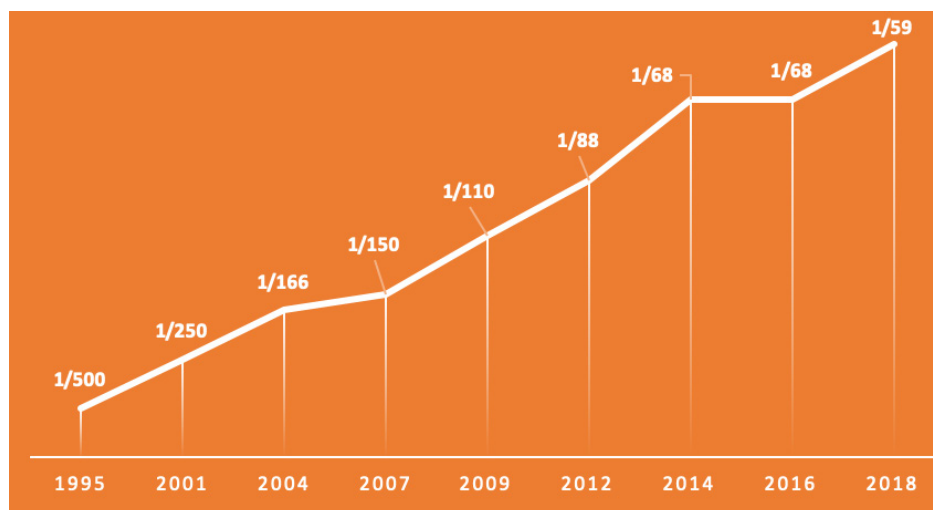
Photo by frank mckenna

Defining the Need and Drawing Comparisons

2017 Philadelphia Autism Project Update Report:

In 2018, the Centers for Disease Control and Prevention (CDC) published an updated estimate that **1 in 59** children are diagnosed with autism spectrum disorder (ASD). Previously, the rate was **1 in 69** children, indicating a **15%** rate increase since 2016.

Autism Prevalence



Source: "Data & Statistics on Autism Spectrum Disorder." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 3 Sept. 2019, <https://www.cdc.gov/ncbddd/autism/data.html>.

TO LEARN MORE about autism prevalence, what it is, how it is measured and why it matters, visit: www.paautism.org/prevalence!



Data from the Pennsylvania Autism Needs Assessment with Philadelphia-specific information will be available in 2020 www.asertneeds.org



Data

In addition to community feedback and stakeholder guidance, the Philadelphia Autism Project uses data from the PA Autism Needs Assessment to inform our approach to initiatives. The Pennsylvania Autism Needs Assessment is a statewide survey distributed by the ASERT Collaborative Eastern Region, to learn more about the self-reported needs of individuals on the spectrum and their caregivers. In 2017, this survey was redistributed as a follow up to the 2011 Pennsylvania Autism Needs Assessment.

2011

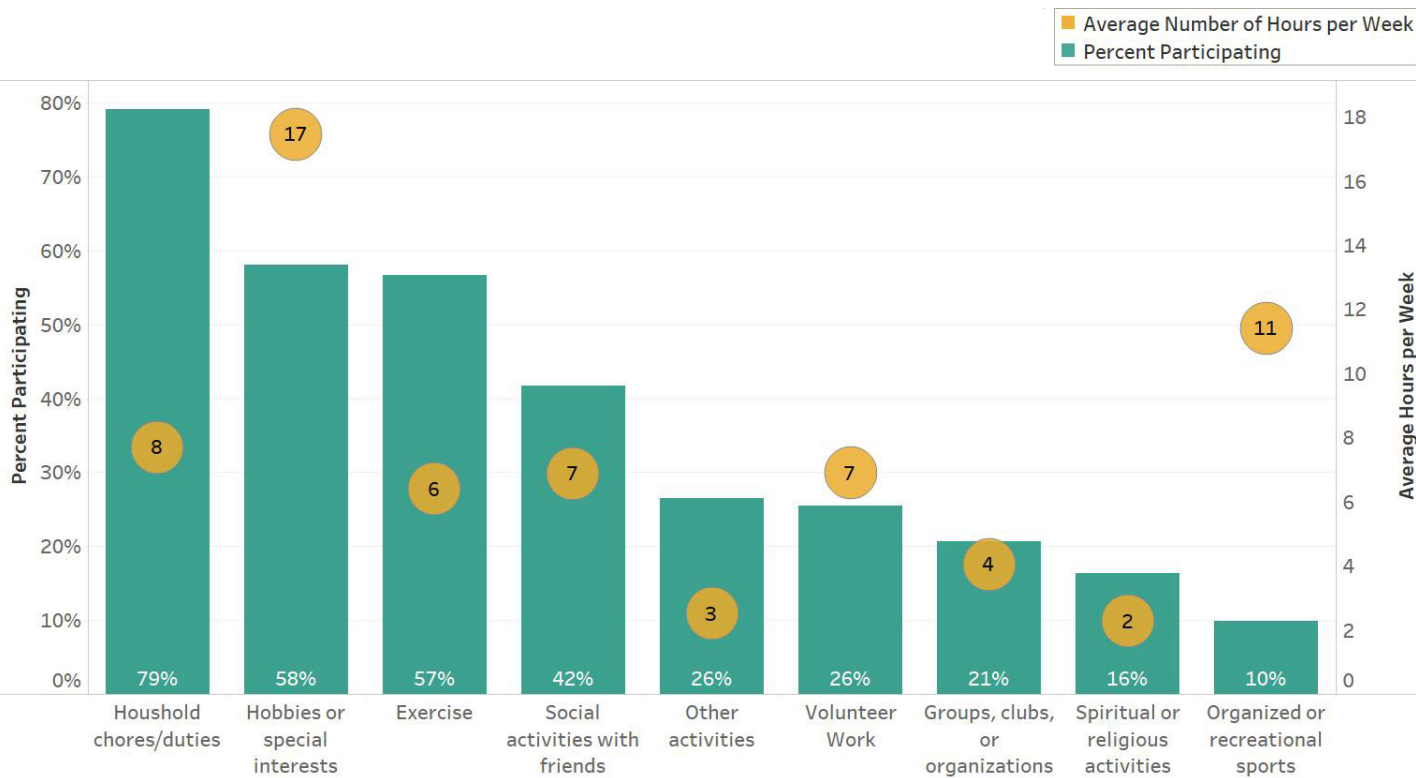


In the 2011 PA Autism Needs Assessment, fewer than **1 in 4 (23%)** of individuals on the spectrum in Philadelphia participated in community activities.

2017

A more detailed look from the 2017 PA Autism Needs Assessment shows that a majority of Philadelphia respondents reported that they participate in Household chores/duties (**79%**), Hobbies or special interests (**58%**) and Exercise (**57%**). Categories in which most respondents reported they do not engage in were: Groups, clubs, or organizations; Organized or recreational sports; and Spiritual or religious activities.

Percentage of Individuals on the Spectrum in Philadelphia that Participate in Community Activities



Source: "PA Autism Needs Assessment." PA ASERT, <https://asertneeds.org/>





Employment

2011

According to the 2011 Pennsylvania Needs Assessment, more than two thirds of adults on the spectrum were unemployed in PA.



More than **1 in 4 adults** on the spectrum report needing, but not receiving vocational training, career counseling or supported employment.



1 in 5 report needing, but not receiving help with transtion planning.

2017

The 2017 PA Autism Needs Assessment shows that **28%** of adults on the spectrum in Pennsylvania were unemployed and looking for work, **30%** reported they were working part-time, and **12%** reported working full-time.

About **1 in 5 adults** on the spectrum in Pennsylvania reported needing, but not receiving career counseling (**26%**), supported employment (**23%**), and vocational training (**21%**).



More than **3 in 4 adults** on the spectrum reported finding employment opportunities to be difficult or very difficult.



2 in 5 reported that getting employers to interview them was very difficult.

What's Next?

A dashboard highlighting Philadelphia-specific insights gained from the PA Autism Needs Assessment will be available online!

Check out our employment resource collection at:
<https://paautism.org/employment>



Justice System Interactions

- The most common interactions reported were having the police called (18%) and stopped and questioned by the police for something other than a traffic violation (9%).



1 in 3 adults on the spectrum had contact with the justice system based on PA Autism Needs Assessment respondents.

In partnership with the Autism Services, Education, Resources and Training (ASERT) Collaborative, the Philadelphia Autism Project continues to increase the knowledge base and awareness of autism for Justice System Professionals. Using feedback collected from the Statewide Autism Survey for Justice System Professionals, top areas of need were identified and integrated through both training and resource dissemination efforts.

Trainings

The Philadelphia Autism Project and ASERT Collaborative provide free trainings to Philadelphia’s police officers as part of their Crisis Intervention Training (CIT) Curriculum. To date, we have completed 20 CIT trainings in Philadelphia, training an estimate of 600 police officers. In addition to the CIT trainings, free autism trainings are offered to professionals working in the justice system, as requested.

▶▶ What’s Next?

The Philadelphia Autism Project will be working with the ASERT Collaborative Eastern Region to support justice-related projects, informed by focus groups and stakeholder feedback.

You can learn more about available justice-related resources on: www.paautism.org/justice.

Examples of resources include:



SIGNS OF AUTISM:
For Justice System Professionals



COMMON PRESENTATIONS:
How Police Officers Can Safely Respond



JUDGE'S GUIDE TO AUTISM:
A Reference Guide

- Statewide Survey Infographic
- Social stories
- Videos of police interactions





Community Programming

Annual Conference

In 2019, the Philadelphia Autism Project hosted the 4th Annual Philadelphia Autism Project Conference, Journey through the Lifespan: Mapping Your Path, on October 18, 2019 at Community Behavioral Health (CBH).

New this year

- Based on community feedback, this year we piloted a call for proposals for two sessions from community presenters
- We offered complementary continuing education credits to support professional education
- Session content is applicable to individuals and families across the life span, therefore tracks are no longer categorized by age
- To provide sustainable resources, participants were given a USB bracelet of resources and interested organizations were able to submit up to two resources for vetting

“

I appreciate the opportunity to obtain college continuation credits to enhance my professional growth. I had never been to one of these before but am very happy I came.

- Conference Attendee

”

“

What a wonderful way to make a very scared family relocating from the south, much more comfortable that moving here is the right thing.

- Conference Attendee

”

What's Next?

The Philadelphia Autism Project will be looking to implement a provider track for the 2020 Annual Conference.

To check out this year's conference and past conferences, visit our website:

[www.phillyautismproject.org/
annual-conference-events/](http://www.phillyautismproject.org/annual-conference-events/)



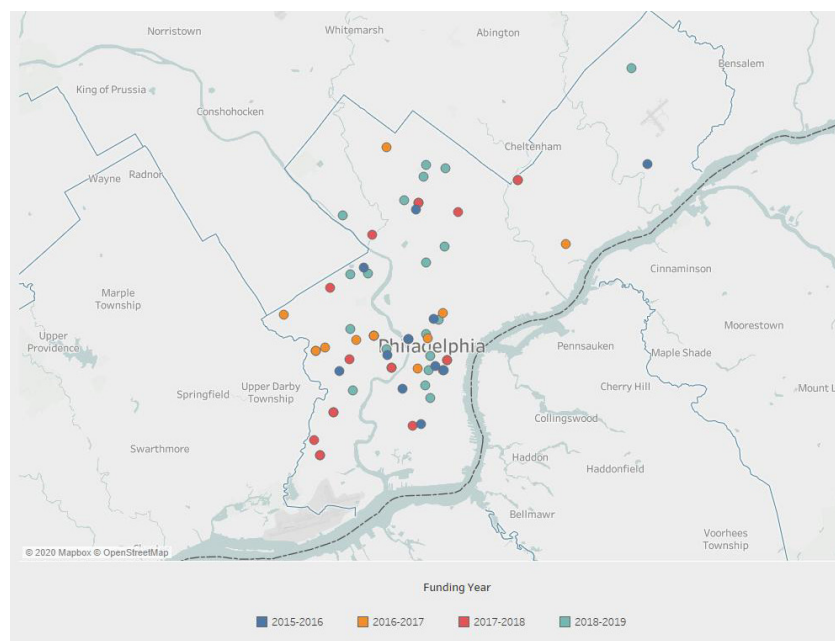


Seed Award Initiative

The Philadelphia Autism Project is proud to provide seed awards to individuals, family members, and organizations to create and/or build upon their existing support groups and programs. Seed awards support underserved and underrepresented populations in the city of Philadelphia by leveraging community leaders, grassroots organizations and existing resources to support mutual engagement.

- In 2018-2019, 34 applications were received with 29 applicants granted seed awards
- Projects spanned creative arts and recreation, raising awareness, creating self-advocacy and support groups, and creating sensory friendly environments, to name a few.

Map of Seed Award Projects across Philadelphia for All Years



“

The seed funding enabled the Autism Advocacy Group to spread awareness through maximizing coverage on media outlets and the funding helped facilitate collaboration with community partners to volunteer at our event. Through collaboration with the Kinney Center for Autism and GetRealGetRaw, the Groothie Pop Up was able to promote healthy living and the abilities and work skills of autistic individuals in Center City Philadelphia.”

- Jefferson Autism Advocacy Group

”

What's Next?

The Philadelphia Autism Project is excited to announce the 2019 – 2020 seed award application is open!

To learn more about each project and to apply:
www.phillyautismproject.org/seed-awards/



COMMUNITY PROGRAMMING
PHILADELPHIA AUTISM PROJECT
 2019 UPDATE REPORT



Community Autism Peer Specialist (CAPS) Program

A top priority initiative voted on by stakeholders was the development of a peer specialist program specific to autism. Based on the Certified Peer Specialist model in mental health, the CAPS program pairs an individual on the spectrum who has completed a peer support training program, with other autistic individuals to achieve personal wellness and community integration goals. Activities are chosen by the participant to build employment and/or post-secondary education and leadership skills, to live independently, care for their own health, navigate interpersonal relationships, use public transportation, engage in the community, and other areas of growth. With Community Behavioral Health (CBH) leading the way in launching this effort, the Philadelphia Autism Project was a partnering stakeholder for this program, which includes:

- A 75-hour training curriculum
- An employment opportunity for individuals on the spectrum
- A service for peers on the spectrum
- An evaluation component to measure outcomes
- To date, over 40 applications received, and 12 participants completed the training program

Stakeholder Involvement

- Self-advocates
- Caregivers
- Peer specialists
- Bureau of Supports for Autism & Special Populations, ODP
- Bureau of Policy, Planning and Program Development, OMHSAS
- Department of Behavioral Health & Intellectual disAbility Services (DBHIDS) and Community Behavioral Health (CBH)
- Policy and Analytics Center, AJ Drexel Autism Institute
 - ASERT Eastern Region
 - Philadelphia Autism Project
- Mental Health Partnerships (MHP)
- TU Collaborative on Community Inclusion

What's Next?

- A long-term goal is to pursue state certification in alignment with current certified peer specialist programs
- We are excited to announce the second training opportunity in 2020!

To learn more about CAPS, visit:
www.phillyautismproject.org/community-autism-peer-specialist-caps-program/



Parks and Recreation

Philadelphia has a rich array of Parks and Recreation sites and programs. The Philadelphia Autism Project's partnership with Parks and Rec. has resulted in:

- Training was provided to parks and recreation staff, with a video training created for future staff
- A survey was disseminated to parks and recreation staff to learn more about strengths and needs
- Partnership with ReBuild efforts to identify opportunities to modify physical sites to be prepared to meet the needs of individuals on the spectrum
- Thank you to our partners: Philadelphia Parks and Recreation, Philadelphia Autism Centers for Excellence (COE) including Special People in Northeast (SPIN), NorthEast Treatment Center (NET) and Child Guidance Resource Center (CGRC), DBHIDS, and Jefferson Occupational Therapy students

What's Next?

The Philadelphia Autism Project received a PA Developmental Disabilities Council Grant and will use funding to support program development and staff training.

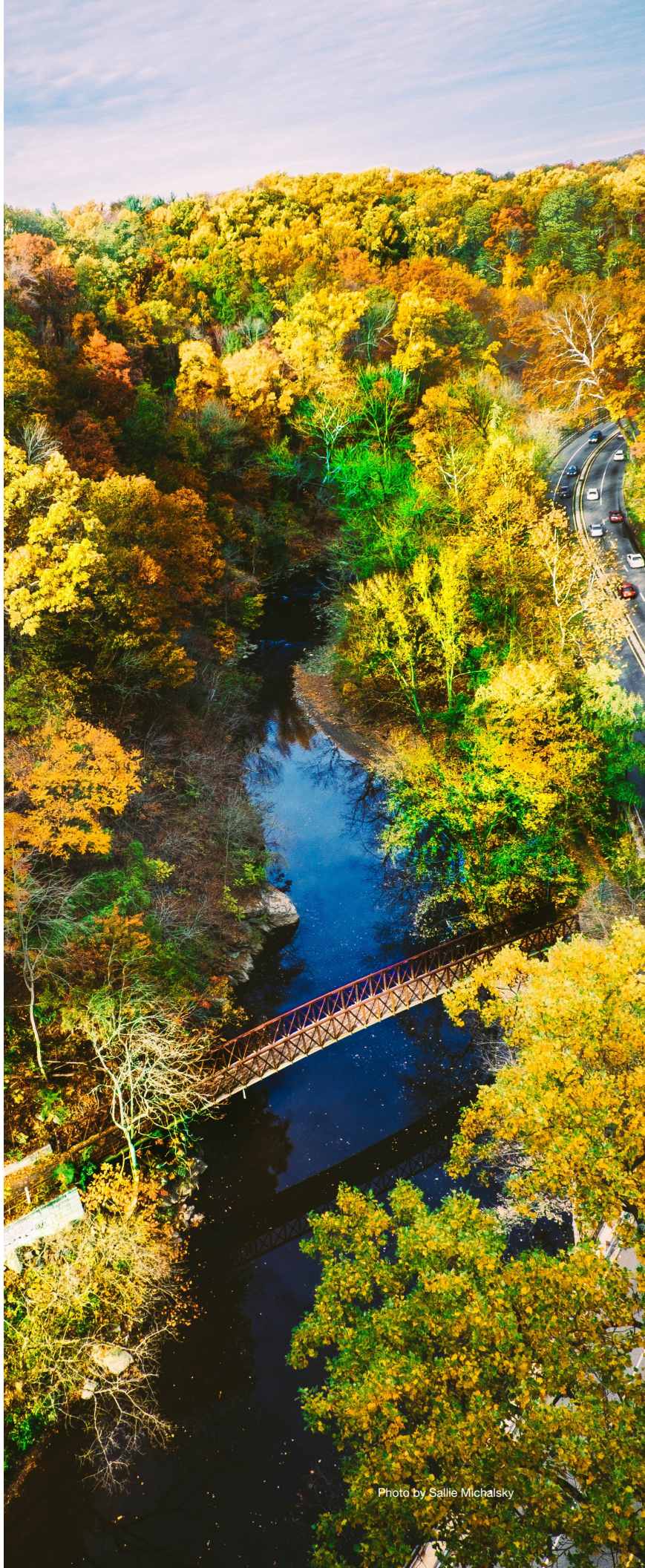


Photo by Sallie Michalsky



Cooking with Confidence

Cooking with Confidence for Individuals on the Spectrum started as a pilot program in collaboration with the Free Library of Philadelphia's Culinary Literacy Center. In hands-on classes, cohorts of 10 participants learn basic cooking skills, including how to follow a recipe and stay safe in the kitchen. Participants prepare a plant-based meal and eat it together at a communal table. Since offering the first class in 2017:

- Classes have expanded from 3 high schools to 9 high school autism support classrooms
- 136 participants to date
- Transition-related resources have been shared with participants, support staff, and other attendees
- Piloted a cooking class using the Free Library's mobile cart at a local library branch

What's Next?

- Expand recipes to reflect participant feedback and daily independent living skills
 - Explore offering classes during the summer time for students
 - The Philadelphia Autism Project submitted an article on this program to the Public Libraries Magazine, with the goal of sharing this information and potential replication across all library branches
-

To learn more about the Cooking with Confidence program, visit: www.phillyautismproject.org/cooking-with-confidence/



Family Navigator

One of the top voted initiatives of the Philadelphia Autism Project is the development of a system navigation model. With system navigation models being implemented in various states and using online, in-person, and other options, the Philadelphia Autism Project held focus groups and a System Navigation Summit to learn more about the feasibility of implementing a system navigation model in Philadelphia.

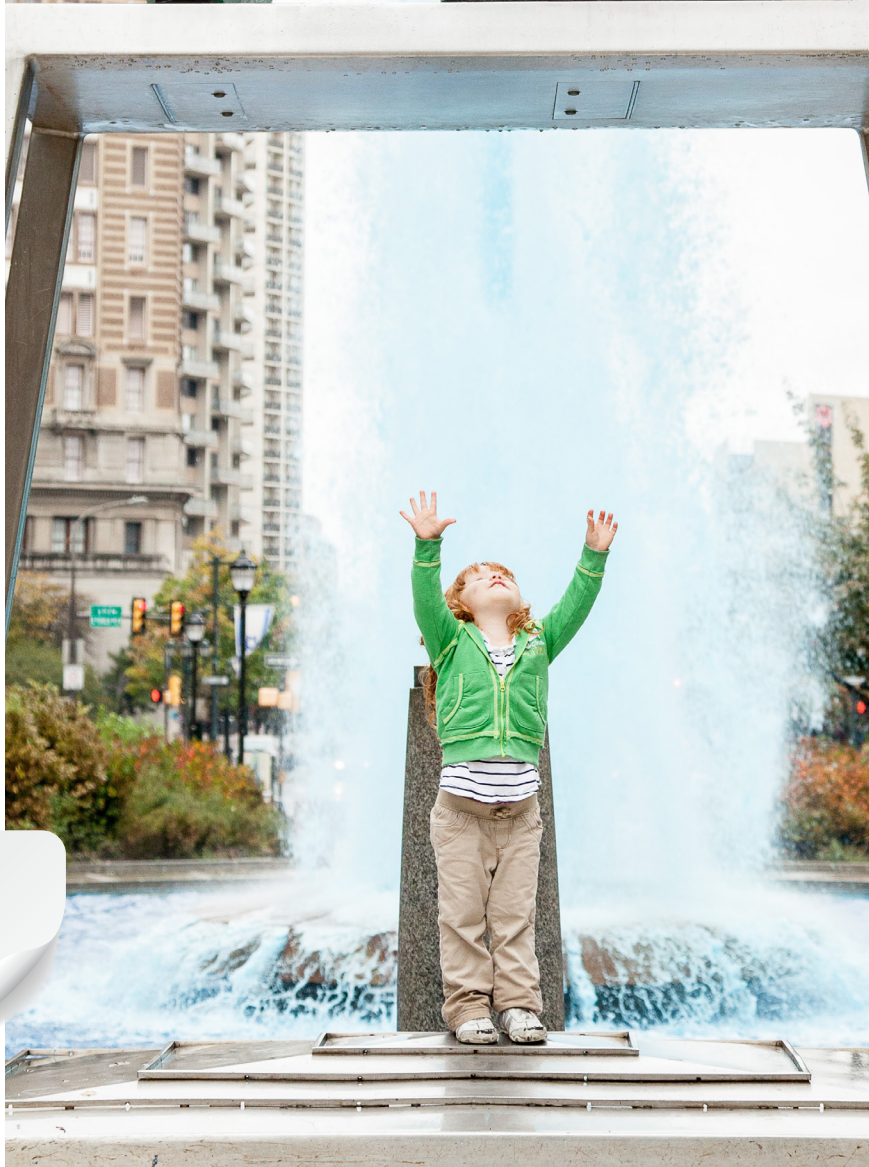
- Held on June 14th, 2018, the *System Navigation Summit: From Cradle to Young Adulthood* was an opportunity to gather information and promote discussion to learn about existing system navigation and family support models, connect with leaders, share their experience navigating the service system, and learn about and plan for a new family organization in Philadelphia.
- We are thankful for the support from the Children with Special Health Care Needs Mini Grant, and in collaboration with the Department of Behavioral Health and Intellectual disabilities Services (DHBIDS) through the System of Care Grant.

What's Next?

- Two reinvestment proposals have been approved through DBHIDS. One reinvestment proposal focuses on developing a system navigator specific to autism resources, and the second reinvestment proposal is focused on navigating services up to age 26.
 - We look forward to keeping you updated and involved in the development of these projects.
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To learn more about the System Navigation Summit:

[www.phillyautismproject.org/
annual-conference-events/](http://www.phillyautismproject.org/annual-conference-events/)





Statewide Changes

The Philadelphia Autism Project works closely with the Autism Services, Education, Resources and Training (ASERT) Collaborative, to ensure areas which have statewide and citywide implications are developed in tandem. Below are some statewide changes since the last update report:

Waivers

Changes in the State Medicaid Waiver Programs have enabled individuals on the spectrum without a co-occurring intellectual disability to apply for the Person/Family Directed Support (PFDS), Consolidated and Community Living Waivers, in addition to the Adult Autism Waiver.

- Visit the waiver resource collection for more information: www.paautism.org/waiver
- Resources describe Medicaid Waivers, a listing of county contacts, checklist with registering with the county, services offered and definition of functional eligibility

Act 62

In Pennsylvania, your child's autism-related services may be covered by private health insurance, Medical Assistance (MA) or the Children's Health Insurance Program (CHIP) under Pennsylvania's Autism Insurance Act (ACT 62). ACT 62 is a statewide insurance mandate specific to services provided to children and adolescents with Autism Spectrum Disorder (ASD).

- Since the passage of Act 62, the PA Supreme Court Case *Burke v. Independence Blue Cross* ruled in favor of John Burke and his family, who fought for their child to receive ABA services in school, and to have those services covered by his insurance.
- To increase awareness of Act 62 and to hear from key players, the Policy and Analytics Center (PAC) held the policy panel event *Autism Insurance in Schools: A Panel Discussion of the Landmark Case of Burke v. IBC* on March 21, 2019.
- To learn more about Act 62, visit: paautism.org/act62

Employment First

Since the passage of Governor Wolf's Employment First Policy to prioritize employment among all individuals, the Philadelphia Autism Project has focused several initiatives on employment, including:

- Collaborated with Self Advocates United as 1 (SAU1) to host a Let's Get to Work! Workshop. For self-advocates and led by self-advocates, topics focused on getting ready to work, looking for and finding a job, applying and interviewing, benefits and who can help.
- Supported Community Integrated Services (CIS) to 1) Develop the Foundations of Community Integrated Employment, a 40 hour, ACRE approved, instructor-led training and 2) Expand benefits counseling to high school students to increase understanding and access of the benefits and services needed for a successful transition.
- Supported Mental Health Partnerships, under the CAPS Training Program, hired 5 peer specialists.





New Resources

Since the last update report, we have worked in tandem with the ASERT Collaborative to generate new and needed resources. Highlights include:

- **PH-95 Checklist:** In Pennsylvania, many children with disabilities are eligible for Medicaid under the PH-95 Category for Children with Special Health Care Needs. Family income does not affect PH-95 eligibility. To apply for Medicaid for a child in the PH-95 Category, there are certain things that need to be submitted with your Medicaid application.
- **Waiver Resource Collection:** A collection of waiver resources that cover: What a Medicaid waiver is, county contact list, checklist for registering for autism services, and more
- **Justice Resource Collection:** A collection of justice-related resources that cover: Signs and common presentations of autism, Judge's Guide to Autism, videos of police interactions, and more
- **Translated Resources:** The Philadelphia Autism Project helped translate Autism 1,2,3 and the Philadelphia Autism Centers for Excellence Service Descriptions.

What's Next?

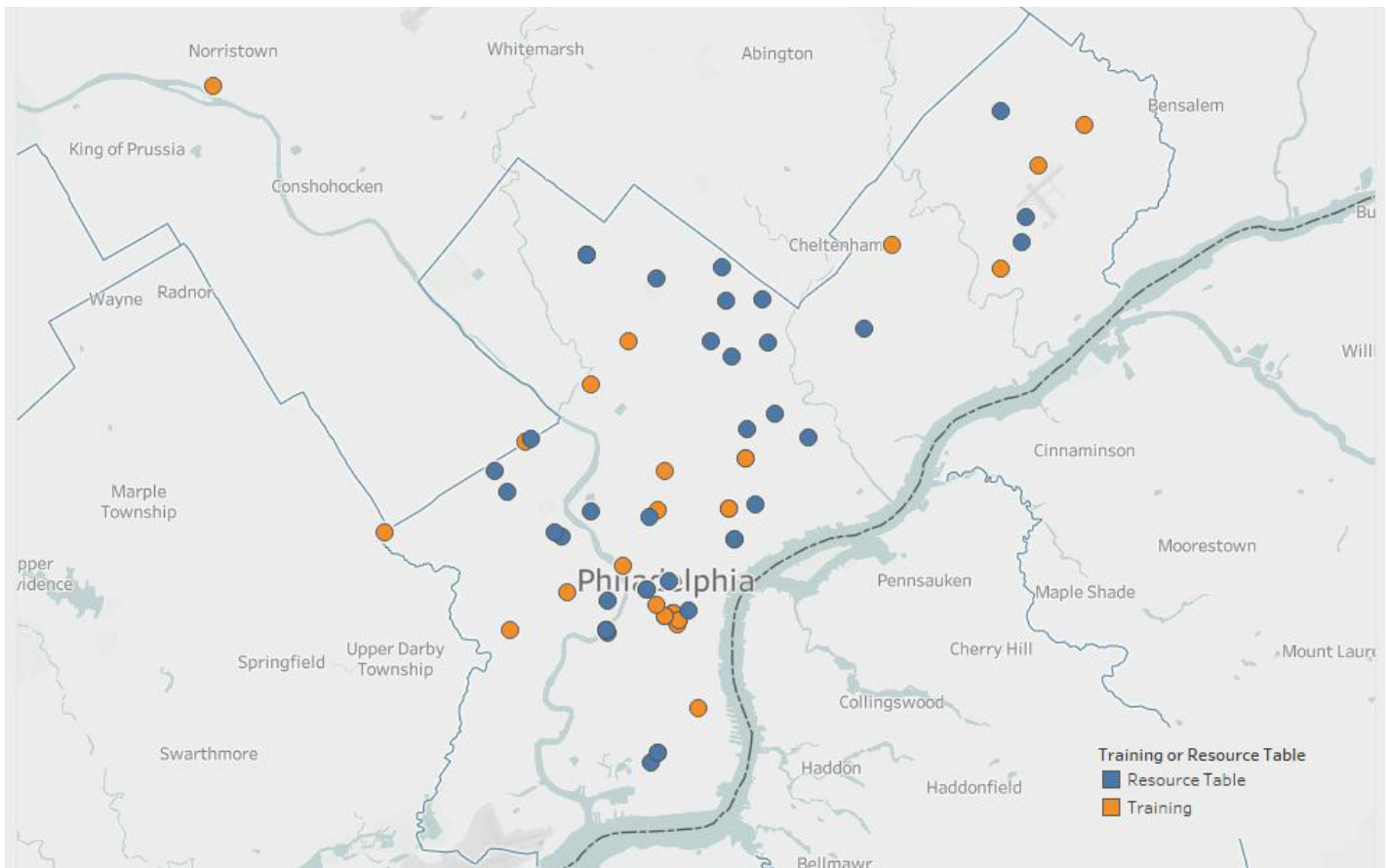
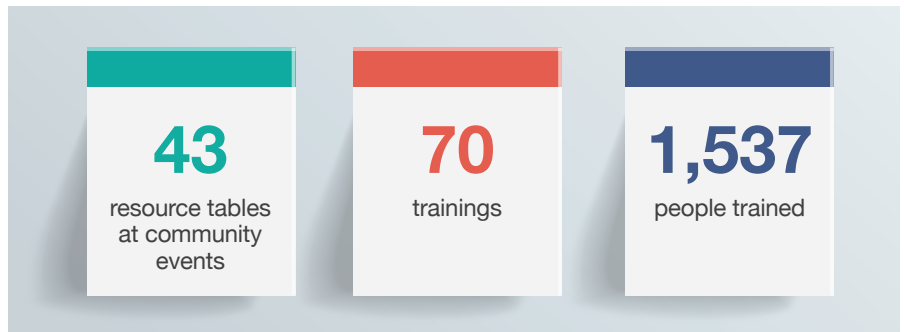
- The Philadelphia Autism Project continues the Philadelphia Autism Network (PAN) Listserv by sharing information and resources to the Philadelphia community through email blasts.
- If you are interested in receiving this information, please email phillyap@drexel.edu with your name, role and email address
- If you are interested in submitting information to share with others, please note our guidelines:
 - The Philadelphia Autism Project makes every effort to assure that the information distributed reflects evidence based practices
 - Avoids posts that sell, recruit or promote individuals, business and programs
 - Encourages information and programs to share events, trainings and information that is accessible both physically and financially to Philadelphia residents
 - Lastly, the Philadelphia Autism Project reserves the right to decide which items to share on this list serve.
- We wish Karen Krivit much success on her next endeavors, value her trust in us, and thank her for everything she has done and created in ensuring that information gets out to the people who need it.



Places We've Been

To Date:

We have trained librarians, parents, church staff, volunteer staff, providers, supports coordinators, social work graduate students, art museum tour guides, police officers, case managers, senior and home care agencies, among others.



What's Next?

- The Philadelphia Autism Project will continue Philadelphia Autism Network (PAN) trainings, by providing a series of trainings throughout the year focused on different topics (such as toilet training, sensory, communication, etc.)
- The Philadelphia Autism Project will continue to provide free autism trainings as requested





thank you

THE PHILADELPHIA AUTISM PROJECT TEAM looks forward to continuing to work on the initiatives outlined by the Philadelphia Autism Project Final Report through the guidance of the Philadelphia community and stakeholders. We are excited to build upon our current efforts, as well as to cultivate new initiatives, programming and engagement opportunities.

We thank all of the individuals on the spectrum, family members, community members, providers, stakeholders, and policymakers who have contributed their guidance and support through out the years. We look forward to future collaborations as we strive to maintain Philadelphia as a top city for people on the spectrum.



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AUTISM PROJECT

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