# The Philadelphia Autism Project Model: Lessons Learned from Developing a Citywide Autism Initiative

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## ABSTRACT

**Background:** Autism prevalence is rising, leading to increased initiatives and research, yet autistic individuals are not always included. The Philadelphia Autism Project (PhillyAP) was developed by people with lived experience, community input and multi-system stakeholders.

**Objectives:** To examine the development, key partnerships, lessons learned and impact of a citywide autism project using an ecological framework and community-academic approach.

**Methods:** PhillyAP was developed using a community-academic partnership approach, engaging autistic individuals, families, and multi-system stakeholders. An ecological framework guided the analysis of stakeholder roles, governance structures, and sustainability efforts to assess the project's implementation and impact.

**Lessons Learned:** Four key lessons emerged: 1) mobilize diverse champions, 2) plan for sustainability, 3) dedicate time to foster trust, and 4) ensure collaborative governance and power sharing.

**Conclusions:** The Philadelphia Autism Project model fostered meaningful collaborations to support autistic individuals from an ecological framework and offers an approach for replication.


**KEYWORDS:** Power sharing, Health promotion, Process issues, Cities, Urban Health, Autism, Ecological Model, Public Health, Community

**Background**

The prevalence of autism has seen a steady rise over time[1]. To meet growing service needs, there has been a surge in autism-related initiatives, research, and other efforts. However, individuals on the spectrum are not always included in these endeavors. This exclusion led the autistic community to embrace the phrase used widely in the fight for the Americans with Disabilities Act, "Nothing About Us Without Us", which underscores the importance of including autistic individuals in discussions concerning autism as the outcomes of initiatives and research formulated without their input may be unfavorable[2]. For instance, a systematic review of stakeholder perspectives on priorities for autism research found that priorities vary significantly amongst different stakeholder groups[3]. Autistic adults highlighted key priorities centered on skill development, enhancing life outcomes, increasing awareness and understanding of autism, and inclusion in research and community spaces. In contrast, parents, clinicians, and researchers emphasized the importance of early autism identification, genetic factors, interventions, and access to services and resources. Additionally, the review identified that research samples had six times as many family members and more than twice as many professionals as individuals on the spectrum. This begs to question whether the chosen priorities are actually reflective of the autistic community. Community-Academic Partnerships (CAP) are a viable solution to connect researchers, professionals, and the community, empowering the autistic community to have equitable influence in addressing the issues that impact them[4]. CAPs are defined by shared decision-making, a focus on issues that are primarily significant to the community, and clear objectives aimed at achieving specific goals[4].

This paper aims to contribute to the growing body of knowledge on Community-Academic Partnerships and describes partnerships and lessons learned from the development of the Philadelphia Autism Project (PhillyAP), a citywide autism initiative. It highlights our effort to incorporate the voices of the autistic community, ensuring their priorities and perspectives shape the direction of autism support and services. Lessons learned may serve as a practical guide for researchers, community members, and academic institutions interested in fostering meaningful collaborations to better support autistic individuals and their families and/or those who wish to replicate the PhillyAP model.

**Methods**

*Study Population*

The CDC estimates that 1 in 36 children are diagnosed with autism[1]. While city-specific data is unavailable, applying this rate to Philadelphia's population (1,603,797) suggests approximately 2,582 children aged 5 to 9 are on the spectrum[5]. Similarly, applying national estimates of 1 in 45 adults with autism[6] to Philadelphia data, suggests there are approximately 27,949 adults aged 18 and older in Philadelphia who are on the spectrum[5]. However, the actual number of autistic adults in Philadelphia may exceed these estimates due to missed diagnoses, particularly among women, people of color, and those with co-occurring conditions[7-8]. As a result, many may navigate life without adequate support, underscoring the need for accessible services.

Understanding Philadelphia's diverse communities is also essential to shaping our approach. As Pennsylvania's largest city, Philadelphia has significantly greater racial and ethnic diversity than the state overall[9]. The Black population comprises 39% of the city compared to 10% statewide, while Hispanic (16%) and Asian (8%) populations are nearly double or more

than double their state proportions[9]. Additionally, 15.7% of residents are immigrants. Philadelphia also faces high poverty rates (21.7% vs. 11.8% statewide) and major challenges affecting quality of life, including underfunded schools, public transportation deficits, high crime, and an opioid crisis[10]. Given these diverse needs, PhillyAP prioritizes listening, learning, and tailoring its approach to meet communities where they are.

*Approach*

PhillyAP processes utilize strategies grounded in Community-Academic Partnership (CAP) principles, and functions within an ecological framework. This article will describe some of the processes that facilitate collaborative partnerships, including the inclusion of diverse voices, working towards a shared vision[4], fostering respect among partners[4], authentic engagement[11], open and frequent communication to support cyclical and iterative processes for systems development[4,12] and a commitment to long term sustainability.

Affirming that people do not function in isolation, the model's implementation process is embedded within an ecological framework which explores the reciprocal interactions between individuals and their environment. It includes multiple levels starting from the individual, or intrapersonal level, to interpersonal, organizational, community, and public policy levels. It is suggested that successful intervention programs and services will be more effective when they consider and support influences at multiple levels[13]. PhillyAP exemplifies this approach through its unique collaboration with partners.

*Development of the Philadelphia Autism Project*

There were several factors that contributed to this model's development. As a national public health issue, children were diagnosed at a rate of 1 in 68 children in the US at the time the project was developed and the 2014 PA Autism Census was showing a looming crisis with youth

aging into adulthood and adult service systems not equipped to support them[14-15]. Additionally, project champions had a personal connection to autism. Thus, this initiative was developed to work with stakeholders to examine the services and support in Philadelphia for autistic individuals and their families. Utilizing the Pennsylvania Autism Task Force framework[16], a planning process of over 130 diverse community stakeholders comprised of autistic individuals, family members, administrators, service providers, city agency personnel, educators, policymakers and researchers met to discuss building autism capacity in Philadelphia. The planning process resulted in a Final Report[17] outlining 139 initiatives across four categories: Resources, Outreach, Awareness, Training, and Education; Infrastructure; Policy; and Capacity. Through training and technical assistance, these initiatives aim to:

- Inform and support autistic individuals and their support networks through resource hubs and educational materials.

- Enhance infrastructure by improving service accessibility and system collaboration.

- Advance policy through legislation, researching best practices and models, and multi-system coordination.

- Build capacity by expanding services, employment opportunities, informational forums, and community partnerships.

*Project Implementation*

The PhillyAP model implements initiatives using a cyclical and iterative process, a principle that is reflected in how communication is structured to gather diverse voices and experiences[18]. Continuous feedback loops include convening workgroups, an Advisory Board, and Planning Committees, as well as channels to learn more about community needs outside of

convenings. Please see Figure 1 for the different feedback loops that inform project implementation.



**Figure 1: Philadelphia Autism Project Feedback Loops**

**Workgroups** evolve based on agency staffing and priorities. One workgroup initially focused on blending funding but later shifted to focusing on autism-related navigation supports. Membership expanded to include representatives from healthcare, education, autism services, and funding/governing bodies, such as Philadelphia City Council and the Department of Behavioral Health and Intellectual disAbilities Services (DBHIDS) and Community Behavioral Health (CBH). The **Advisory Board**, established in 2020, includes autistic individuals, parents/caregivers, and community members. It shares project updates and gathers community feedback on topics like information dissemination and PhillyAP's stance on key issues. **Planning**

**Committees** oversee initiative implementation, consisting of governing partners, autistic individuals, community members, and professionals. They oversee PhillyAP's Annual Conference and the Seed Award community-focused mini-grant process. The conference committee shapes speakers, themes, and format, while the Seed Award Review Committee evaluates grant applications based on merit, impact, fiscal responsibility, and sustainability— ensuring lived experience informs funding decisions. Membership varies annually, with many serving in dual roles as both individuals with a lived experience and/or professional. Members are compensated for their time with gift cards.

PhillyAP integrates feedback loops to engage voices beyond planning committees. Through calls, emails, social media, events, meetings, and listening sessions, staff connect with communities where they are. This two-way communication ensures initiatives are co-created with those most impacted, driving continuous improvement and lasting change. This approach has led to successful programmatic shifts in Philadelphia, detailed in the Outcomes section.

*Outcomes from an Ecological Approach*

PhillyAP's ecological approach fosters awareness, education, and empowerment across multiple systems. Figure 2 (Ecological Model) illustrates how the project leverages partnerships, processes, and programs to create impact across individual and environmental levels, with people with lived experience engaged throughout. At the individual level, PhillyAP increases autism awareness and acceptance, informs people of their rights, and supports informed decision-making through its website and ASERT Resource Center. As of January 1, 2025, PhillyAP handled 2,212 resource requests, trained 6,336 people and attended 99 community events. Training participants include community members, service providers, daycare workers, first responders, and families, ensuring a broad impact across sectors.

**Figure 2: Philadelphia Autism Project Ecological Model**

At the interpersonal level, PhillyAP worked with stakeholders to support the launch of two innovative services: Medicaid-reimbursed autistic peer support and the Autism Family Navigator role. These services strengthen support networks by connecting individuals with shared experiences for mutual support and resource sharing. To date, PhillyAP has trained 43 autistic individuals as peer supporters and 5 participants as Autism Family Navigators.

At the community level, PhillyAP fosters inclusive decision-making, ensuring diverse voices shape projects from development to implementation. Key initiatives include:

- Seed Awards – Grants supporting new or expanded programs, such as sensory-friendly story times at Free Library branches and voting rights campaigns for the disability community. To date, 189 community grants have been awarded from 251 applications.

- Annual Conference – A space for connection and learning, with 9 conferences held, 1,650 attendees, and 66% first-time participants last year. The conference format has evolved from on-site to virtual, hybrid, and fully in-person post-pandemic, ensuring accessibility and continued growth.

At the organizational level, PhillyAP leverages the Managed Care Organization partnership by convening cross-systems workgroups with Intellectual disAbility Services, Federally Qualified Health Centers, the School District of Philadelphia, Crisis Services, Criminal Justice, child welfare professionals, and autism treatment providers. These providers offer behavioral, developmental, and psychological services for autistic individuals. To date, PhillyAP has overseen five workgroups focused on Clinical Concerns, Birth to Five services, Education, Funding, and Community Inclusion. The model also establishes standards for embedding lived experience in project development through guiding principles, Advisory Board processes, and workgroup expectations, available as shareable resources in the Supplement 1.

At the environmental and policy level, PhillyAP has leveraged Philadelphia City Council partnership to collaborate with city-funded entities such as faith-based organizations, Federally Qualified Health Centers, the Free Library, School District of Philadelphia, and Parks and Recreation. One example of this collaboration is working with Parks and Recreation and autism treatment providers to gather feedback from families, service providers, and parks staff on programming and accessibility in recreation spaces. These efforts aligned with the passage of the Philadelphia Beverage Tax, which funded the ReBuild Program to improve parks, recreation centers, and libraries.

*Partnerships*

PhillyAP's strength lies in its extensive local and statewide partnerships, allowing it to leverage resources, expertise, and networks beyond its private university setting. Decision-making is a collaborative process, incorporating partner feedback, community concerns, and shared implementation efforts.

At the city level, PhillyAP collaborates with Philadelphia City Council, the Department of Behavioral Health and Intellectual disAbility Services (DBHIDS), and Community Behavioral Health (CBH), as well as agencies across Pennsylvania. At the state level, PhillyAP works in tandem with the ASERT Collaborative, which connects medical centers, autism research and service organizations, universities, and providers (such as Health Care Quality Units) to enhance care and resources for autistic individuals and their families. Working with ASERT's Eastern Region fosters bi-directional communication on policy changes, innovative programs, and community needs.

Through City Council partnerships, PhillyAP engages with city-funded entities such as Parks and Recreation Centers, Federally Qualified Health Centers (FQHCs), the Free Library of Philadelphia, and the School District of Philadelphia. PhillyAP also receives funding from DBHIDS, which oversees divisions focused on trauma, equity, and community, including CBH, a nonprofit managing Medicaid-funded mental health and substance use services for Philadelphia County[19-20].

Beyond institutional partnerships, PhillyAP works with community organizations and individuals with lived experience, including self-advocacy groups, family-led organizations, and independent voices. This broad network enables PhillyAP to integrate diverse perspectives from autistic individuals, caregivers, treatment providers, intellectual disability services, crisis response, child welfare, and criminal justice.

**Lessons Learned**

Being able to witness the evolution of this project from development through implementation across the years, there are four lessons learned that would be helpful to consider in replicating this model. These lessons include 1) mobilize diverse champions, 2) plan for sustainability, 3) dedicate time to foster trust, and 4) ensure collaborative governance and power sharing.

*Lesson #1: Mobilize diverse champions*

Community-based research builds on existing strengths, resources, and relationships[18]. The PhillyAP model succeeded by mobilizing diverse champions—individuals with lived experience, system knowledge, policy influence, and community leadership—to identify service barriers, secure funding, and advocate for policy change. Through stakeholder convenings, these champions mapped service gaps, shaped implementation strategies, and connected policymakers with personal stories to drive funding decisions. For successful replication, engaging a broad network of leaders is essential. Their ability to bridge sectors, foster collaboration, and adapt to leadership changes ensures long-term sustainability, while a shared vision keeps momentum and impact strong.

*Lesson #2: Plan for sustainability*

Sustainability is a key principle of community-academic partnerships[18]. The PhillyAP model ensures long-term impact by securing recurring funding within DBHIDS county budget, avoiding the limitations of time-bound grants. Additionally, PhillyAP's collaborations with the City and CBH enabled the project to reinvest Medicaid cost savings into developing and piloting innovative service models for autistic individuals and their families. This is important to highlight, as it can encourage other counties and states to explore similar approaches with

Medicaid funds. Sustainability is also built into the Seed Award community grant process, where applicants must demonstrate their capacity to maintain projects beyond initial funding. However, ongoing advocacy, impact measurement, and communication remain essential, as system priorities, leadership, and staffing evolve over time. It is important to adapt to the ever-changing landscape of services and supports to better meet community needs. This includes evolving workgroups, updating processes, and incorporating an advisory board, as discussed earlier. These changes help ensure that services remain effective and relevant over time.

*Lesson #3: Dedicate time to foster trust.*

In research and academic settings, there is often tension between the time needed to build community trust and the urgency of funding timelines or stakeholder priorities. Systemic change—especially when working across diverse partners—requires time, as priorities and communication styles vary. Creating space for collaboration ensures the work is guided by those most impacted.

Building trust requires accessibility, transparency, empathy, and respect[21], along with flexibility in scheduling and engagement. Time-intensive processes include stakeholder outreach, aligning priorities, adapting to staffing changes, and disseminating information. Fostering buy-in requires ongoing assessment: Are partners engaged? Do they have capacity? How can burdens be eased? Considerations like meeting formats, compensation, accessibility, and incentives (e.g., food, parking, childcare) should be factored into budgets and planning.

For PhillyAP, it took a year to convene stakeholders and develop the Final Report guiding implementation. Initiative timelines vary—some take under a year, while others require long-term investment. For example, the Seed Award community grant takes six months to implement, an annual conference requires a year of planning, and developing an autistic-led peer

support program took four years. Please see Figure 3 Timeline of the major initiatives and processes.
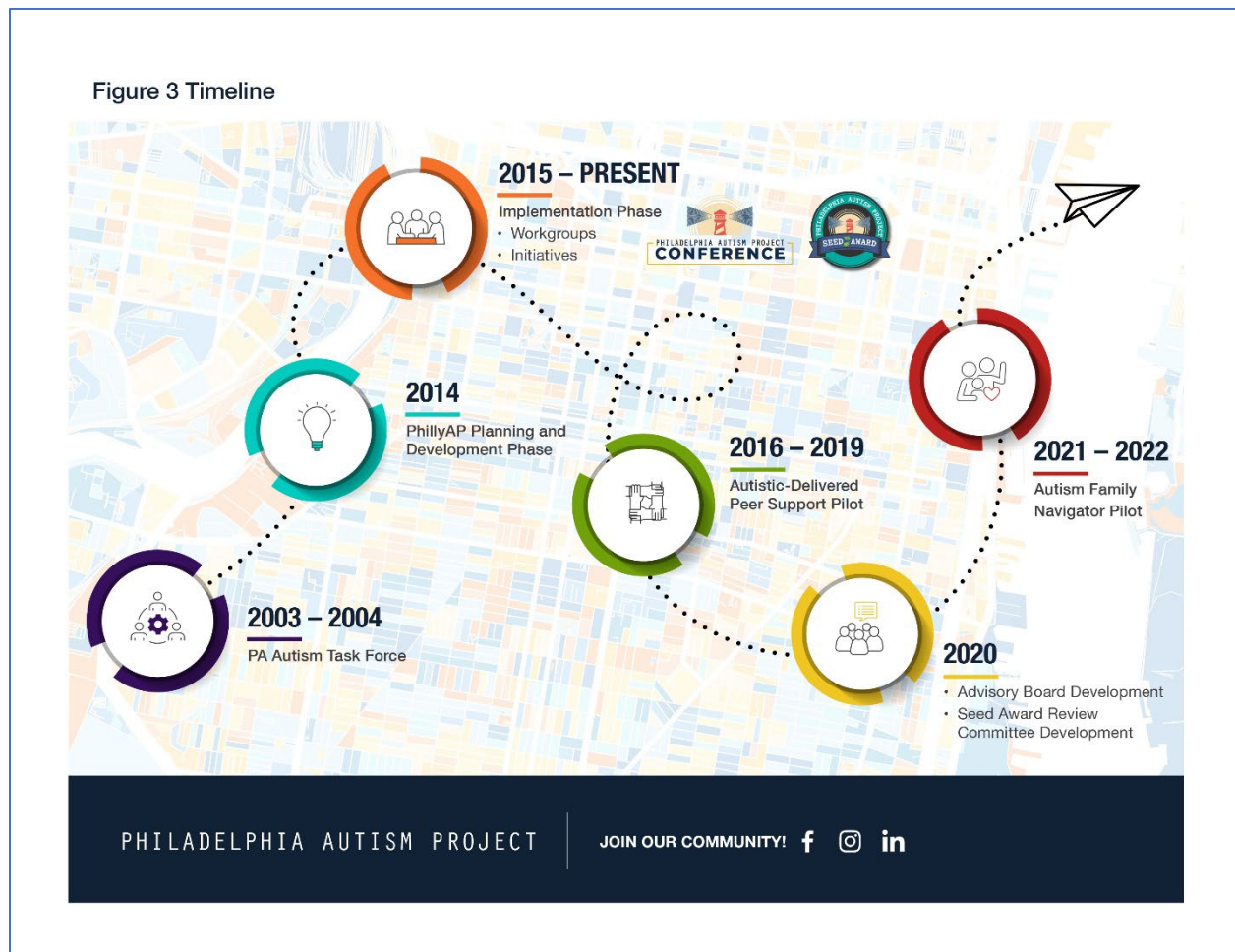


**Figure 3: Timeline**

*Lesson #4: Ensure collaborative governance and power sharing*

The PhillyAP model brings together partners with diverse roles and power dynamics, including its own staff. Acknowledging the privilege of these roles is essential in shaping communication, decision-making, and engagement. Effective collaboration requires bidirectional communication, shared decision-making, and valuing lived experience alongside professional

expertise[21-22]. PhillyAP operates in a space where perspectives sometimes align but often conflict. Key discussions include whose voices are prioritized in autism support (autistic individuals, caregivers, or others), language use, and treatment approaches. To foster collective governance, power must be shared, and decisions communicated transparently. In practice, this means:

- Identifying who needs to be informed about concerns, both internally and externally.

- Seeking input from partners and experts when more information is needed.

- Clearly articulating the project's stance on contentious issues, even when it differs from the larger organization.

- Ensuring representation of lived experience, assessing who is missing, tracking role representation and creating space for more diverse backgrounds and levels of support.

- Providing flexibility for those unable to participate consistently or who prefer one-on-one engagement.

PhillyAP continuously evaluates its processes, sometimes pausing committees or boards to seek broader input. While PhillyAP strives to include autistic voices in all aspects of its work, it recognizes the need to make additional efforts to incorporate more autistic individuals from diverse backgrounds for better representation, including those with varying levels of support needs and individuals who use alternative communication methods. By tracking role representation at every meeting, staff can better quantify equitable participation. Acknowledging that maintaining diverse representation at all times can also be challenging due to the diverse and evolving life circumstances of community members. These ongoing assessments ensure diverse perspectives are heard and meaningfully integrated into decision-making.

**Conclusion**

To facilitate a citywide autism initiative, community-academic partnerships were utilized, with implementation through the lens of an ecological framework. The outcomes of this initiative have led to interventions at an individual level through to environmental and policy levels. Embedding voices of lived experience throughout development and implementation of this citywide autism initiative has provided valuable lessons learned. This model serves as a replicable approach for similar efforts.

**Acknowledgements**

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# 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:**

**Self Determination:** Meaningful participation and choice regarding in all aspects of life for individuals with ASD and their families.

**Independence/Fullest Potential:** Independence and the ability for individuals with an ASD to achieve their fullest potential in accordance with their hopes and dreams.

**Safety:** The safety and well-being of individuals with an ASD is the responsibility of the entire community.

**Inclusion, Access & Full Participation in Community:** Individuals with ASD are supported to the extent necessary to live, learn, work, and socialize in their communities of choice.

**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.

**Early Intervention:** Early identification of an ASD and early intervention services are key for positive outcomes for young children with an ASD.

**Family Support & Involvement:** Family members of individuals with an ASD receive the information and supports they need.

**Inclusive, Collaborative Service/Support Teams & Services:** Providers, educators, and systems work collaboratively and in partnership with the individual and his/her family.

**Best Practices & Innovative Approaches:** Evidence-based practices and innovative approaches are utilized.

**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.

**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.

# Community Advisory Board

## PURPOSE

- Provide feedback on initiatives for the Philadelphia Autism Project to focus on in the coming year, 5 years, 10 years
- Ensure that the voice of individuals with lived experience is involved in initiative development and implementation

- Provide guidance when receiving community feedback
  – Ex. Person First versus Identity First language
  – Ex. Developing a payment structure for individuals and consultants on the Spectrum
- Facilitate champions to share the work of the Philadelphia Autism Project and expand engagement of stakeholders

## MEMBERSHIP

- The initial Community Advisory Board will comprise of no more than 4 – 6 members
- At least two individuals on the Spectrum with direct, lived experience
- One parent or Caregiver: This individual may have indirect experience and can provide feedback from a caregiver's perspective in considering family support needs
- One individual who has been involved over a long period of time

- One member to provide program related expertise (Provider, educator, non-profit leader)
- Temporary members with specialized general expertise (subject matter experts to fill gaps in knowledge) on an as-needed basis
- Once Board is established and consistent, members will elect someone to serve as the Chairperson.

## RESPONSIBILITIES

- Bring community concerns and feedback for discussion.
- Monitor our effectiveness in achieving goals
  – Ex. These are the 3-4 programs we have, are we reaching our goals?
- Share Philadelphia Autism Project initiatives and accomplishments

- Attract new members to the Board
  – New skills and new ideas to meet gaps in knowledge or expertise
- Establish policies and general procedures pertaining to operations
  – Ex. Publicizing of fundraisers and research studies or not

## LOGISTICS AND FUNCTIONING

- Board will meet two - four times a year via in-person and/or web-based platform
- Smaller meetings with members who are interested in particular projects can be facilitated by the Philadelphia Autism Project
- Members will abide by term limits - to be determined

- Members who may not be able to contribute or participate regularly may be asked to vacate their seat for someone who can participate on a regular basis
- The Philadelphia Autism Project will provide compensation by providing snacks/meals, travel expense and/or a small stipend.

**If you are interested, please complete an Advisory Board Application HERE.**

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**Philadelphia Autism Collaborative Workgroup: Systems and Community Updates [Template]**

Goal: A forum to provide systems and community updates, brainstorm ideas and seek feedback on initiatives/projects/opportunities.

Time Investment
- Meetings will be held 3 times a year for 1 hour. The dates below avoid summer months, September when school starts, and holidays at the end of the year.
  - February | 10 – 11 am
  - May | 10 – 11 am
  - October | 10 – 11 am

Meeting Structure/Agenda
- Introductions: Please state your name and affiliation. (10 minutes)
- Highlight of a program, opportunity, etc. (15 minutes)
  - Examples: New policies, programs, research opportunities, brainstorming or troubleshooting challenges.
- Brief Updates (30 minutes, approximately 5 minutes for each system)
  - City Council Updates
  - State-level Updates: Waivers, state technical assistance, etc.
  - Managed Care Organization (Ex. Family Navigator and CAPS)
  - Autism Treatment Provider
  - School District
  - General PhillyAP
  - Autism-related Policy Implementation
  - Physical Health
- Questions/Open Comment (5 minutes)

Representation
- Feedback sought from group who indicated a smaller, targeted workgroup is more helpful in troubleshooting and getting systems updates. Will not expand this to public outreach.
- Providers
- Policymakers
- County entities
- School district professionals
- Researchers
- Community partners
- Individuals and family members

*Enter Update Version*