

PHILADELPHIA AUTISM PROJECT LISTENING SESSIONS: YOUR CITY, YOUR VOICE

YOUR CITY, YOUR VOICE

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2022 - 2024 REPORT



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EXECUTIVE SUMMARY

INTRODUCTION

Since its inception in 2014, the Philadelphia Autism Project (PhillyAP) has worked closely with the community to identify priorities and guide its initiatives. During the development process, stakeholders participated in shaping a report that outlined over 100 initiatives to improve the lives of autistic individuals and their families in Philadelphia. With significant changes in the autism landscape including the impact of the COVID-19 pandemic, increasing autism prevalence, and evolving community needs, it was time to engage in a renewed effort to define our priorities and guide our work. Are the same challenges in autism support and services persisting in Philadelphia? Have new concerns emerged? The *PhillyAP Listening Sessions: Your City, Your Voice* were designed to answer these questions and to gather insights, experiences, and concerns from the individuals and families we serve. The feedback collected will directly shape new PhillyAP initiatives and may lead to adjustments in existing programs.

SESSIONS

To gather meaningful and diverse community feedback, we conducted a total of 10 between 2022 and 2024. These sessions were held in a combination of formats, with majority conducted virtually via Zoom to ensure accessibility and participation from a broad range of stakeholders. To accommodate individuals who were unable to attend the listening sessions, we offered additional options for participation, including a Qualtrics survey and the ability to leave a voice message directly on our website.

NEXT STEPS AND ACTION PLAN

The findings suggest that PhillyAP should prioritize the following actions based on community feedback:

1. Improve Comprehensive Resource Guides
2. Enhance Employment Programs
3. Promote Inclusive Policies
4. Strengthen Family Support Systems
5. Expand Mental Health Services
6. Support Transition Programs
7. Provider Education and Cross-Care Coordination
8. Address Criminal Justice System Challenges
9. Engage Marginalized Groups
10. Increase Community Outreach and Awareness

METHODS AND PARTICIPATION

METHODS

To ensure a wide range of perspectives, we hosted a variety of sessions, including broad, open-format discussions where participants could speak freely on any topic, as well as sessions focused on specific communities, such as the Black or African American and LGBTQ+ communities. Each session was facilitated by PhillyAP staff and followed a general format:











- **Introduction:** PhillyAP staff introduced the organization, provided an overview of the purpose behind the listening sessions, and outlined the goals of gathering community feedback.
- **Questions:** Participants were asked to share their perspectives on:
 - What is going well regarding autism services and support in Philadelphia?
 - What needs improvement regarding autism services and support in Philadelphia?
 - What should PhillyAP work on over the next five years?
- **Discussion Topics:** The conversation was guided by participants' experiences, with a list of suggested topics provided to add structure and encourage deeper discussion.

<ul style="list-style-type: none"> – Access to education on sexuality, body development, and relationships. – Access to mental health services. – Access to trauma-informed care. – Child welfare system and foster care involvement. – Clinical treatment and access to services. – Criminal justice interactions. – Educational system and school-based services. – Employment opportunities and supports. – Finding and maintaining housing. 	<ul style="list-style-type: none"> – Inclusion in community life and activities in Philadelphia. – Opportunities following high school graduation. – Supporting caregivers and family members. – Addressing the needs of under-resourced communities. – Supporting older adults on the autism spectrum. – Exploring funding options for programs or services (e.g., grants, waivers, county funds). – Workforce challenges, including staffing shortages in programs or services.
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The data collected from the listening sessions were analyzed using a qualitative approach to identify key themes and insights. All sessions were transcribed and coded using NVivo, a qualitative data analysis software, to systematically group responses into recurring themes. This thematic analysis helped highlight common concerns, challenges, and recommendations shared by participants. In addition to the session transcripts, feedback from Qualtrics survey data is incorporated into this report. The survey included the same discussion topics as the listening sessions, allowing respondents to identify the top three strengths in supporting autistic individuals and their families in Philadelphia, as well as the top three areas needing improvement. Respondents also had the option to provide open-ended responses to elaborate on their selections.

OVERVIEW OF LISTENING SESSIONS

The table below provides an overview of the listening sessions, detailing the date, format, focus area, and number of participants. The first session, held during our 7th annual conference on October 14, 2022, had the highest attendance, with 43 participants, demonstrating strong engagement in a broad, open-format discussion. In contrast, participation was lower in sessions focused on specific communities, such as the Black/African American community (9 participants) and the LGBTQ+ community (5 participants), suggesting potential barriers to participation that warrant further exploration. The final sessions on March 21, 2024, were initially planned to focus on Employment and Mental Health. However, to encourage broader participation, we adjusted them to open discussions. The evening session also featured a presentation from Philadelphia Family Voices (PFV), a community organization where family peer support specialists assist other parents of autistic children in navigating autism service systems. We believe that incorporating this presentation helped foster engagement by providing valuable resources and creating a more interactive and informative discussion.

DATE	SESSION FORMAT	TOPIC/FOCUS AREA	NUMBER OF PARTICIPANTS
10/14/2022	 Virtual (Zoom)	Open	43
05/02/2023	 Virtual (Zoom)	Teens/Young Adults	7
05/04/2023	 Virtual (Zoom)	Adults	7
05/17/2023 (Afternoon)	 Virtual (Zoom)	Open	9
05/17/2023 (Evening)	 Virtual (Zoom)	Open	9
10/11/2023	 In-Person	Criminal Justice	35
02/15/2024	 Virtual (Zoom)	Black/African American Community	9
02/22/2024	 Virtual (Zoom)	LGBTQ+	5
03/21/2024 (Afternoon)	 Virtual (Zoom)	Open	19
03/21/2024 (Evening)	 Virtual (Zoom)	Open (PFV presentation)	19

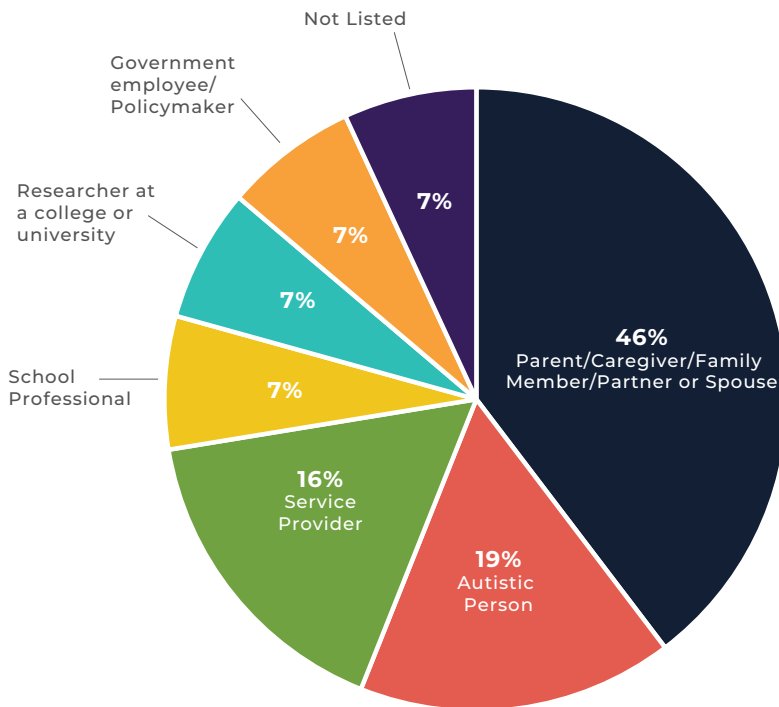
Note: We did not count the number of participants for the in-person session on 10/11/2023. This is an estimate based on the room capacity and conference registration.

DEMOGRAPHICS OF PARTICIPANTS

In each Zoom session, participants were presented with a poll asking them to indicate their role, racial identity, and whether they identify as Hispanic or Non-Hispanic. The percentages for role and racial identity may exceed 100% since participants could select multiple roles and identities that apply to them.

Zoom Participants

Role of attendees (percentages):

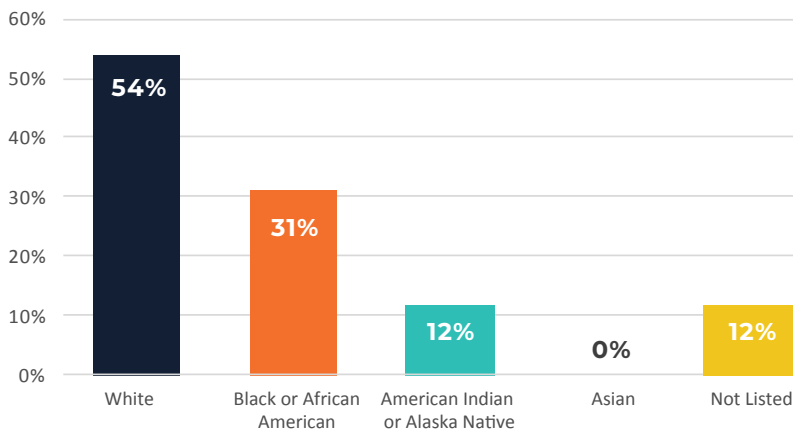


Hispanic or Non-Hispanic

12% Hispanic

88% Non-Hispanic

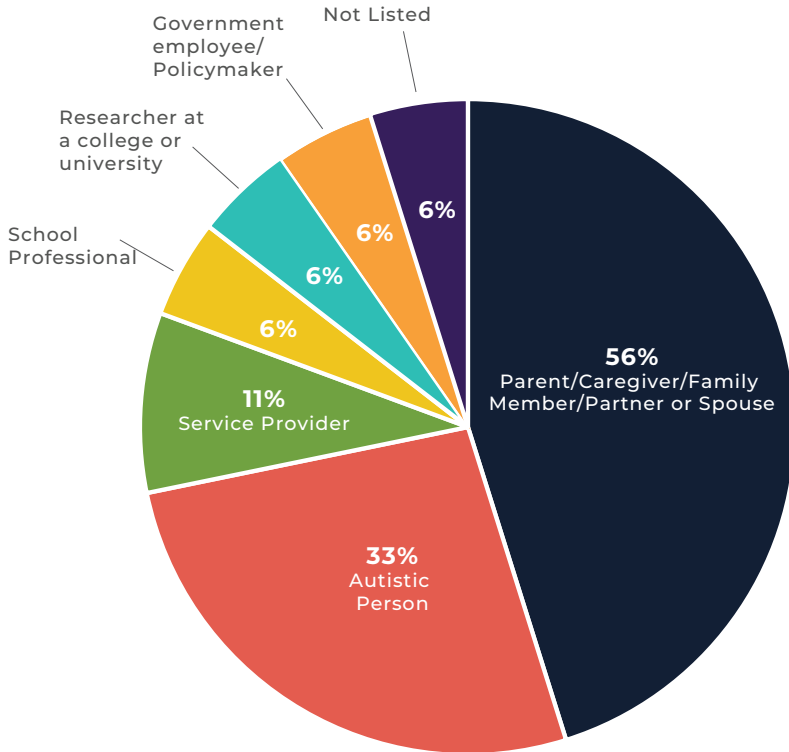
Race/ethnicity



The Qualtrics survey included the same questions about role and racial identity, along with a question about zip code to identify where in Philadelphia participants were coming from. As in the Zoom poll, participants could select multiple roles and racial identities, so the percentages for these categories may exceed 100%.

 **Qualtrics Survey**

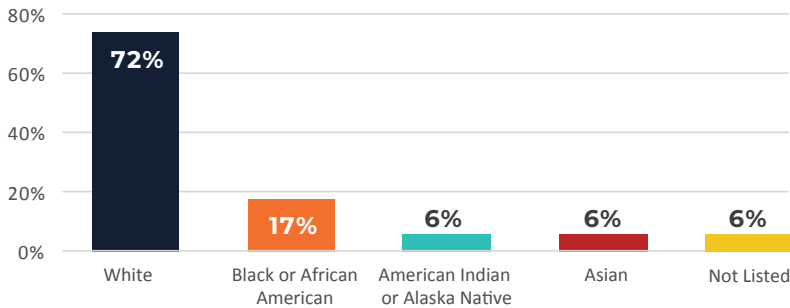
Role of attendees (percentages):



Hispanic or Non-Hispanic



Race/ethnicity



Zip code

- | | | |
|----------|----------|-------|
| 19104 | 19143 | 19095 |
| 19014 | 19027 | 19125 |
| 19425 | 19124 x2 | 19118 |
| 19145 x2 | 19114 | 19139 |
| 19119 x2 | 19138 | 19026 |

KEY THEMES AND FINDINGS

WHAT IS GOING WELL IN PHILADELPHIA:

1. Access to Educational and Community Programs:

Families and individuals highlighted the growing number of educational programs, events, and fairs, such as the Autism Day at the Zoo and various CHOP-affiliated programs.



“I guess I could say some things I noticed in the city that are going well, because I really do try to be involved and look out for things we can do, I noticed there are things going on here and there, different organizations where they’re trying to do fun things....But I know the one was affiliated with CHOP and there were some other ones. I know we went to the zoo day where they did the autism day at the zoo.”



2. Community Support and Peer Networks:

The GRASP support group and CAPS Program were noted as effective and helpful resources for individuals and families.



“I think the GRASP support group is very helpful.”
“I think the CAPS program has been a good step in trying to provide more of a support system for autistic adults, as well as employment. I hope it can continue to grow.”



3. Autism Awareness and Involvement:

There was a recognition of increased awareness and community participation in autism-related events.



“The general feeling I think is that there is more acceptance and understanding of folks on the spectrum as well as opportunities for employment.”

“So I believe when you’re saying inclusion means to include everyone regardless of where they live, where they come from. So everyone matters no matter where they’re from. So everyone is entitled or has the right to receive the proper human services. And I think Philadelphia is definitely very, very inclusive, is very diverse, and there’s a connection within the communities, I believe is that definition, city of brotherly love is definitely so true because I see it on an everyday basis.”



MAJOR THEMES IDENTIFIED FOR IMPROVEMENT

1. Resources

A significant emphasis on the need for comprehensive resources and information related to autism support, indicating a desire for accessible, consolidated information on services, programs, and funding options. This theme was the most mentioned across sessions.



Survey Feedback

Streamline and simplify the processes to qualify for services, it shouldn't be a full-time job just to figure out what is what.



Listening Session

- “I’m the parent of a 21-year-old who was diagnosed when she was just about to turn four. And I have to say that I feel as though everything that I have learned about in terms of resources and programs and support for her have always just been things that I have stumbled upon, or someone has said, ‘Oh, did you know about this?’ Once she was diagnosed and I followed the path for treatment and going to therapy and things like that, but I couldn’t find, there wasn’t one place that I could go to that said, ‘Now that you have a child with this diagnosis, these are all the things you should investigate, all the resources, all the waivers, different sources of funding’.”

2. Employment

The importance of job placement, career development, and the need for supportive employment programs for autistic individuals was highlighted, with a focus on improving access to meaningful employment opportunities.



Listening Session

- “... my daughter had her first job and she realizes that that job doesn’t have an interpreter. And in order to understand on how to navigate the job functions, that is an example of I don’t have the tools I need to be included..”
- “my son is 24. He successfully graduated high school a couple of years ago. I don’t know if the other families feel the same way, but I know that the things that his school was getting him prepared for, they didn’t feel [like] jobs to be proud of, so to speak, or that had a high enough income associated with them. I feel like I don’t know if it’s out there, so I feel like it has to be created. Myself or some other parents or whatever, we’re going to have to create these types of honorable positions or maybe established companies for our children and then create a space where they can have success and have trained in a skill. I don’t know, I think a lot of times, like I said, they have things for younger children, but the adults they time out.”

3. Inclusion

The desire for greater inclusion in various settings (community, education, and employment) was frequently discussed, underscoring the need for environments that are welcoming and accommodating.



Survey Feedback

- Most major cities are more educated and liberal in their thinking process. With that said, Philly is still behind on inclusion. The black community and the gay community are still fighting for the same thing. Our tribe is in its infancy, when it comes to having acceptance and inclusion.
- Only a few schools with autism support and it's little support. Would love to see more public places be aware of non verbal communicators and provide communication alternatives for these folks. Training on how communication devices work and are used so they communicate with this population.



Listening Session

- “Hi. I think inclusion to me is just, I guess, in the literal sense, having autistic people be included in this conversation. I think a lot of people say, “Oh, I don’t see you for your autism. I recognize you outside of your disability.” But it’s also important to that disability can affect a lot of aspects of people’s lives, and there are legitimate challenges that come with it. And just trying to listen to autistic people and accommodate their very specific set of support needs.”

4. Community Engagement

Participants expressed the need for enhanced community involvement and advocacy efforts, emphasizing the importance of connecting autistic individuals and their families with local resources and support networks, while also highlighting concerns about workforce shortages and the lack of staff to support local resources and programs.



Survey Feedback

- My son is and has been on waiting lists for everything. We need staff in ALL areas. We obviously must not be compensating well enough for these positions.
- As a provider helping Philadelphia families connect with resources, I know it is next to impossible to find requested resources such as Medication, Management, Family Based, IBHS, ABA, etc. Every place I call is not accepting new consumers or had a 6-8 month waiting list.



Listening Session

- “It’s just a lot of turnover, and I can get into a whole thing on that in terms of availability of therapists. So I don’t know if that is included with inclusion, but I have not experienced the whole. He’s going to go to kindergarten soon. And that’s going to be a whole different change for me, and I’m really nervous about that. I have no idea what to expect with schools in terms of that. And then with community, no, I don’t feel that at all. But I know it sounds negative.”

5. Family Support

Family members highlighted the need for greater support for caregivers and families, focusing on education and resources that empower them to advocate effectively for their loved ones.



Survey Feedback

- School Districts need to be doing more to provide our kids what they need, Behavioral support, 1:1 when needed, what about after care? parents need to work and after care in schools ends usually in elementary. We have no one to help, no one to be a caregiver to our older children that cannot be left without 1:1 care.



Listening Session

- “I bring in a biracial son who has autism. He’s non-verbal. [inaudible 01:10:23] four months and then again at three years because he doesn’t want to eat anything. So he’s on a PediaSure-only diet. And so they see he’s underweight. Immediately, the agencies jumped the gun. And I say the agencies in a broad sense. I’m not going to name them...It’s just been difficult because when I need to be my son’s best advocate and I don’t present well, especially when I’m nervous or stressed out or worried about him, I bring him into the ER. There’s just been situations where apologies don’t cut it from DHS after he’s already been taken from me wrongly, abruptly, because they misunderstood me as a person with the way I present because of my brain injury...I don’t even know where they put him. There was lack of staff. So with that said, the trauma is substantial. He changed. He Hasn’t been the same kid. He wasn’t the same kid, child. He was only three. Now, he’s four and a half. So when it happened, he was doing all kinds of new types of things, flapping. I was a lot of physical types of different things. He lost trust in me because he was literally taken right from the hospital.”

6. Mental Health

Concerns regarding mental health support for autistic individuals were prevalent, indicating a need for accessible psychological services and support networks.



Listening Session

- “I think resources and services are important and I do think that the mental health focus is really important as well. I remember having a conversation, I think it was in school that we were talking about mental health and how bad mental health has been normalized and how a lot of people are just accepting that they have mental health issues instead of coping with it and working on it...I know something that I struggle with is sensory issues and I think working with that and learning to cope with that is something that just improves general quality of life. So I think that behavioral and mental health are definitely things to focus on.”

7. Transition to Adulthood

There was a focus on the challenges faced by youth transitioning to adulthood, with discussions around the need for services that support this demographic in navigating life changes.



Survey Feedback

- I am concerned about my brothers and sister, who could benefit from education and it starts with school. The resources are poor for autistic people after graduation. Older adults can not afford to be diagnosed and have no support.



Listening Session

- “And I think our hardest struggle was transition, and you guys did an excellent series on that, but in the school I was with, and it wasn’t their fault. They just didn’t have all the resources maybe to give us, but I think that was our hardest thing. But I would definitely say to the parents out there, try to get involved in the Arc chat and choose or parent groups because that’s such a positive thing and will leave you with a wealth of knowledge and information of where to go outside of the schools...”

8. Barriers to Access

Several participants noted various barriers to accessing services and resources, pointing out systemic challenges that hinder the support available to autistic individuals and their families.

THEMES ACROSS MADE-MARGINALIZED GROUPS

We recognize that the findings from these listening sessions may not fully represent the experiences of the broader community, especially groups that have been made marginalized due to systemic barriers, policies, and social structures that limit their access to resources and opportunities. While lower participation in sessions focused on these populations may limit the generalizability of the results, we believe it is still important to highlight the themes and perspectives shared. These insights provide valuable context and can help inform future efforts to engage a more diverse range of voices.

- **Black and African American Communities:** Feedback from the evening session indicated that Black and African American families are concerned about access to services, especially around housing and mental health resources. One of the suggestions was to increase outreach to under-resourced communities to improve accessibility.
- **Foster and Adoptive Families:** Foster and adoptive parents shared challenges about not knowing where to find appropriate housing and resources for children with autism. There were calls for more centralization and guidance on accessing services. There is a recognized need for increased support and resources specifically tailored to foster and adoptive parents of autistic children, emphasizing the importance of their engagement in the autism community.



Listening Session

- “ something to consider in the future is to have a session specifically for foster, adoptive and kinship populations so that those agencies that serve them and DHS and et cetera could hopefully get the word out...So if you all could maybe connect to all of the foster, adoptive and kinship agencies in Philly, as well as DHS to say, listen, we’re having a specific session for foster parents, what I call the FAKs, foster, adoptive, and kinship families. Then that can help them to get on board and get more informed of the resources that are available to them because they’re mostly left in the dark..”
- “There’s a lot of considerations as we think of this population, like the types of traumatic experiences that they may have gone through as they’re in the foster care or kinship care. Part of what we’re doing at the Office of Children and Families is thinking of different types of feedback mechanisms to see how we can better improve our services in those areas.”

ADDITIONAL THEMES:

9. Criminal Justice and Policing

Concerns about the interactions between autistic individuals and the criminal justice system were noted, highlighting issues related to policing, intervention practices, and the experiences of autistic individuals within legal contexts.



Listening Session

- “it’s really just about how the whole system’s set up realistically, where it’s like police need to protect themselves, but their lack of understanding of when something is defiance for the sake of defiance versus an active meltdown or breakdown that happens when you’re just scared or things are new and you don’t know how to interact with the process. I think that that’s consistently an issue.”
- “I don’t know if that really ties with LGBTQ at the same time, but I have to imagine that exacerbates it where it’s like already, if they view you as other, especially for trans folks and stuff, all of the behavior is not viewed through the possibility of, “Oh, they might be dealing with a mental health situation in this moment,” or “We might be exacerbating it.” So yeah, just training on being able to identify when something is like stimming, being able to recognize things like stimming as necessarily nervous behavior, but a self-soothing behavior, instead of treating it like a threat.”

10. Culturally Humble Care and Intersectionality

The need for cultural humility was recognized, highlighting the importance of understanding and addressing the diverse backgrounds of autistic individuals and their families.



Listening Session

- “cultural differences, immigrant population’s harder to understand and access services and criminal justice as well.”
- “cultural differences with religion...religion does impact a lot of people’s beliefs and the way they might do different things. “
- “I almost envision a buddy system. If it was me personally, I would seek out someone who I have some relationship with, whether it’s on a personal or professional level, and invite them so it doesn’t feel overwhelming for that individual and I’m supporting that person along the process because it can be a little intimidating...When you’re in the room with the doctor and just say I went to this conference and just speak about it. If you’ve already attended one before and you know there’s another one coming the following year, share the information.”

11. Reaching Younger Families

A recurring theme in the feedback from newer parents (like those who discovered their child's diagnosis in the past year) emphasized the importance of outreach to younger families, with suggestions to create clearer navigation tools or services that could help new families avoid feeling lost or unsupported.



Listening Session

- “I can add that I think what’s working well at least is the idea and the funding and the energy and the initiative to reach out to younger families. I think that is a great initiative. Now, I don’t believe that they’re reaching them, but I surely appreciate that the attempt is there.”
- “Well, I think as I mentioned that initiative, which is wonderful to reach out to younger people raising younger children. But the challenge that I’m seeing is that it’s not effective. Somehow, they’re not understanding, they’re not buying in and to me they’re not taking advantage of it. So when someone doesn’t take advantage of something that is important and that is meaningful, that is helpful, I always wonder what’s missing? What are the gaps? So I’m not sure about the marketing...We have such a huge prevalence in Philly, but yet so few families, people raising younger families I’m talking about, are really engaged and involved.”

STEPS FOR MOVING FORWARD

The findings suggest that the Philadelphia Autism Project should prioritize the following actions based on community feedback:

1. **Improve Comprehensive Resource Guides:**

Improve comprehensive resource guides, ensuring that they are user-friendly and clearly outline available services, funding opportunities, and support networks for autistic individuals and their families. Regularly update content to reflect evolving community needs and disseminate resources through community organizations, schools, healthcare providers, and online platforms to maximize reach and accessibility. Enhance outreach efforts to ensure these guides reach those who need them most and include information on how to navigate services and find resources, particularly for new families who may not know where to start.

2. **Enhance Employment Programs:**

Implement job training and placement initiatives customized to the unique skills and interests of autistic individuals. Launch educational campaigns for employers highlighting the advantages of hiring autistic individuals, including the provision of training on how to create supportive and inclusive work environments. Additionally, work on increasing employment retention by addressing workplace challenges and providing ongoing support for employees and employers.

3. Promote Inclusive Policies: Advocate for the implementation of inclusive policies in educational institutions, workplaces, and community organizations. Ensure that environments are adaptable and accessible to autistic individuals. Conduct workshops and training sessions for educators, community leaders, and employers on best practices for fostering acceptance, understanding, and participation of autistic individuals. Ensure

that policies reflect the diverse needs of marginalized groups, such as Black and African American families or foster and adoptive parents.

4. **Strengthen Family Support Systems:**

Develop training programs and workshops for families, particularly those newer to the autistic community, that focus on navigating available services, understanding their rights, and effectively advocating for their loved ones. Establish peer support groups to facilitate connection and sharing of experiences among families, and provide resources that address common challenges faced by caregivers. Expand these programs to address the specific needs of marginalized families, including foster and adoptive families and younger parents.

5. Expand Mental Health Services: Increase access to mental health services specifically designed for the needs of autistic individuals. This includes advocating for organizations to hire mental health professionals trained in autism spectrum disorders and to provide therapy options that accommodate sensory sensitivities and communication differences. Expand trauma-informed care and mental health support across systems, particularly for those involved in child welfare or criminal justice settings.

6. Support Transition Programs: Create structured transition programs for autistic youth that focus on building life skills, such as financial literacy, job readiness, and self-advocacy. Partner with schools, community organizations, and employers to provide workshops and resources that assist youth in navigating the transition to adulthood.

Focus on guiding youth in accessing higher education, vocational training, and career opportunities, with specific programs for marginalized groups such as youth in foster care.

7. Provider Education and Cross-Care

Coordination: Implement ongoing training programs for healthcare providers, educators, and service providers to enhance their understanding of autism and the specific needs of autistic individuals. Promote cross-care coordination among service providers, schools, and community organizations to ensure a holistic approach to support that addresses the multifaceted needs of autistic individuals and their families. Ensure that providers are trained in culturally competent and inclusive practices to better serve diverse communities, particularly those that are underrepresented or underserved.

8. Address Criminal Justice System

Challenges: Advocate for increased training for law enforcement and criminal justice personnel on how to interact with autistic individuals. Develop programs that support autistic individuals who may be involved in the criminal justice system, ensuring that they receive appropriate accommodations and avoid unnecessary interactions that could escalate due to misunderstandings. Promote legal reforms that create more autism-friendly protocols within the justice system.

9. Engage Marginalized Groups: Focus on increasing outreach and providing resources for marginalized groups, including Black and African American families, foster and adoptive parents, and younger families. Develop programs that address the specific challenges faced by these groups, such as navigating housing, mental health services, and educational systems. Ensure that initiatives are inclusive and provide culturally humble care tailored to the needs of these diverse communities.

10. Increase Community Outreach and

Awareness: Strengthen community engagement by hosting more accessible events, fairs, and workshops that provide information on services and resources for autistic individuals and their families. Partner with local organizations, such as schools, community centers, and cultural institutions, to reach underserved populations. Raise awareness about available resources, including Medicaid waivers, mental health support, and legal assistance, ensuring that families know where to turn for help.

CONCLUSION

The Philadelphia Autism Project Listening Sessions: Your City, Your Voice provided valuable insights into the experiences, needs, and concerns of the autism community in Philadelphia. By gathering direct input from autistic individuals, families, caregivers, and other stakeholders, we were able to identify key themes that highlight both ongoing challenges and opportunities for improvement in autism support and services. However, we know that some voices, especially from marginalized groups, were not fully represented. Because of this, we are committed to reaching more people to make sure everyone has a chance to be heard.

Based on what we learned, we will focus on making it easier for families to find resources, connecting them with important services, and improving support in key areas like jobs, mental health, and transitioning into adulthood. We also plan to hold listening sessions regularly, so we can continue to hear directly from the community.

By keeping the voices of autistic individuals and their families at the center of our work, PhillyAP will continue to improve and better meet their needs.



PHILADELPHIA
AUTISM PROJECT
Guided by the Autism Community

JOIN OUR COMMUNITY! [f](#) [@](#) [in](#)

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