

Individual Rights Document - Update

Revisions:

- Be respected for who you are, for what you look like, for what you believe in, **for how you communicate**, and for who you love.
- Express concerns **complaints** about services you receive.
- Separated 6100 rights and 6400 rights

Next Steps:

- Work with self-advocates to include an image with each right
- Multiple languages
- Audio version
- Announce to all people, not just individuals and families

Recommendation #1

Assure Effective Communication

ISAC
August 2025



Pennsylvania
Department of Human Services

➤ Performance Measure Proposed Revisions 1

Current	Revision	Reason
1. For people who do not communicate effectively using words, the percent of people with a communication system in place, overall and by race, age, and living situation i.e., a written plan in place that describes and documents a communication system, e.g., sign language, a picture board/system such as Picture Exchange Communication System (PECS), a voice-output communication device, or a combination of methods. A communication profile in the ISP is not sufficient in and of itself. (IM4Q)	For people who do not use speech to be understood, the percent of people who use a device or tools such as a picture board, an object board, or a speech-generating device for communication, overall and by race, age, and living situation. (IM4Q)	Revised 'communication system' language to be more clear.



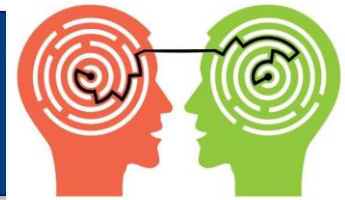
➤ Performance Measure Proposed Revisions 2

Current	Replacement	Reason
2. For people with communication systems in place, the percent of systems that are in working order and being used. (IM4Q)	For people who use technology or equipment to support communication, such as but not limited to glasses, hearing aids, or a vocal output device, the percent of people who have technology or equipment in good repair. (IM4Q)	Expanded this question to include other technology or equipment that is important to communication access.

➤ Performance Measure Proposed Revisions 3

Current	Revision	Reason
3. For people with communication systems in place, the percent of individuals and self-advocates, overall and by race, who report using them across all settings (i.e., you use the system at home, at work, at school, and in your community). (IM4Q)	For people who use aided Augmentative and Alternative Communication (AAC), such as a picture board, an object board, or a speech-generating device, the percent of people who have access to it all the time. (IM4Q)	Revised to use more concrete terms. It appears that we got a variety of responses based on what people thought a “communication system” was.

Use data better to identify people in service that have communication access needs.

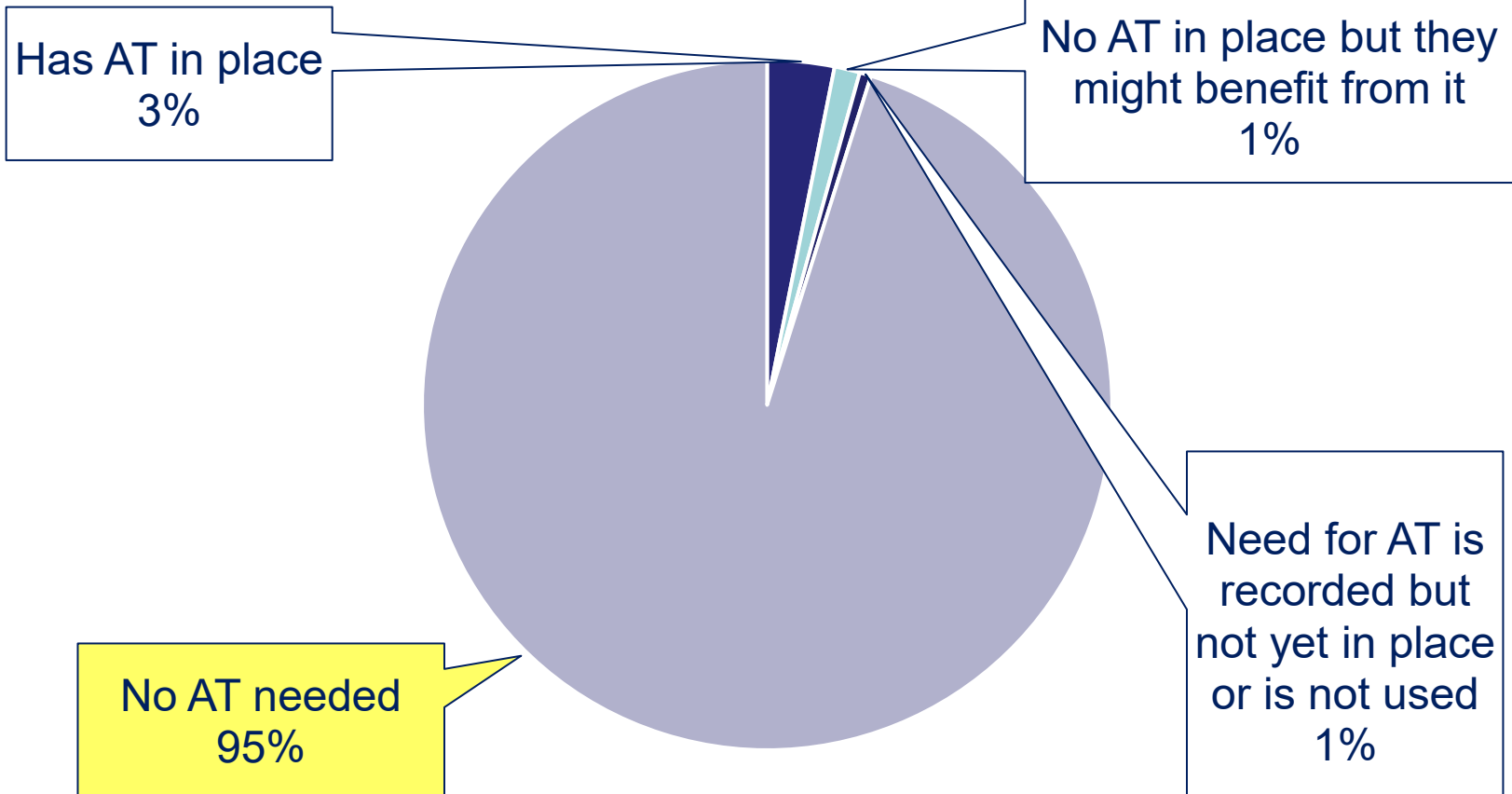


- Supports Intensity Scale, PA Supplement 2024 results
 - About 8,000 individuals
- How much support does the person need with regard to vision?
 - 51% require corrective lenses or surgery
 - 7% require large print, other modifications, or personal support even with corrective lenses
- Plan to increase training and resources related to vision

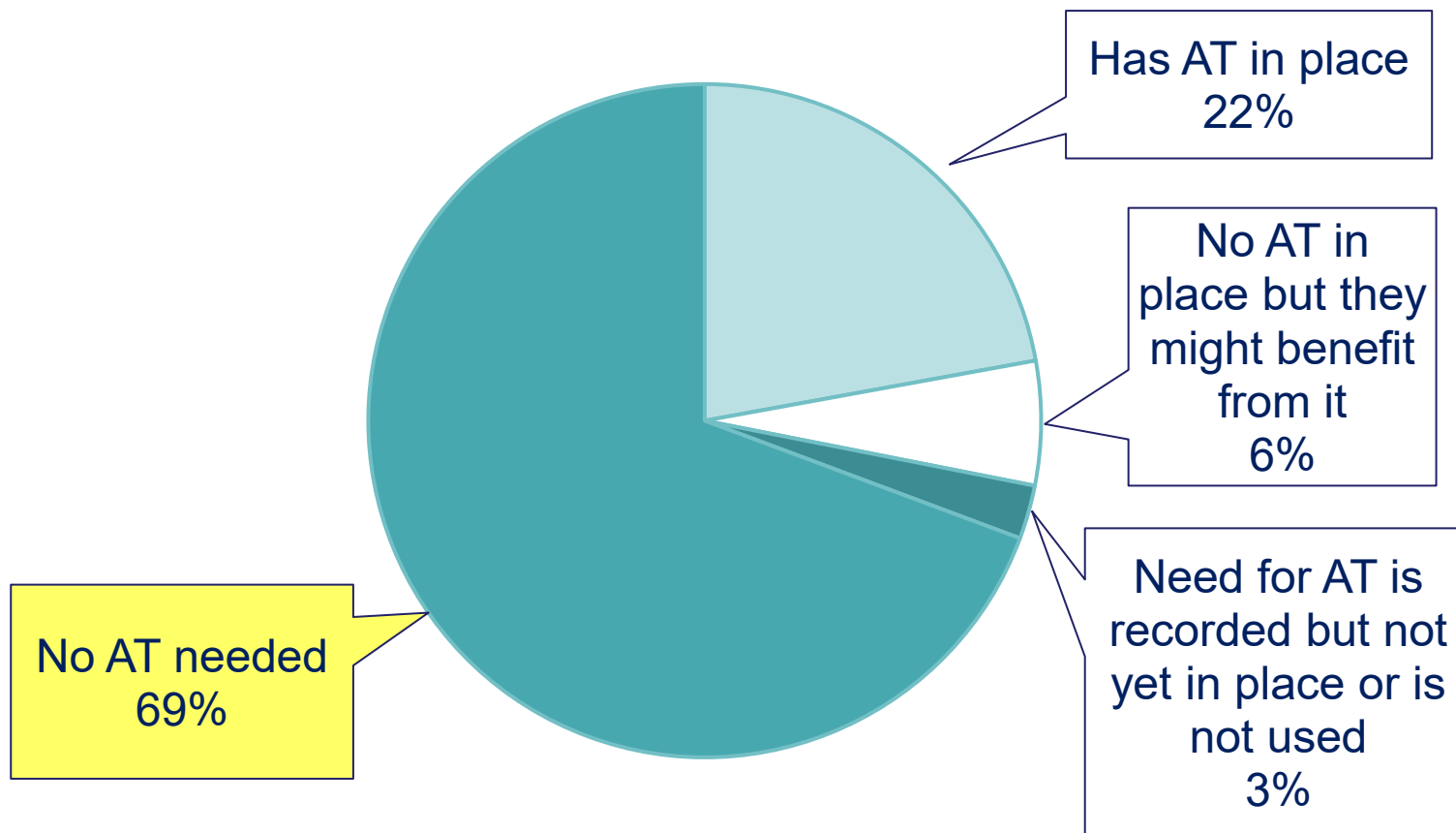
SIS, PA Supplement 2024 results continued

- How much support does the person need to communicate effectively with a variety of people in a variety of settings?
 - 1% None
 - 5% Requires extra time
 - 59% Requires some assistance from familiar people or assistive technology
 - 35% Requires familiar persons or technology at all times
- Does the person have Assistive Technology (AT) in place for communication?
 - 10% Yes
 - 3% No, but they might benefit
 - 1% Need for AT is documented but not yet in place or not used
 - 86% None needed

Of the individuals who require some assistance from familiar persons or AT to communicate (59%)



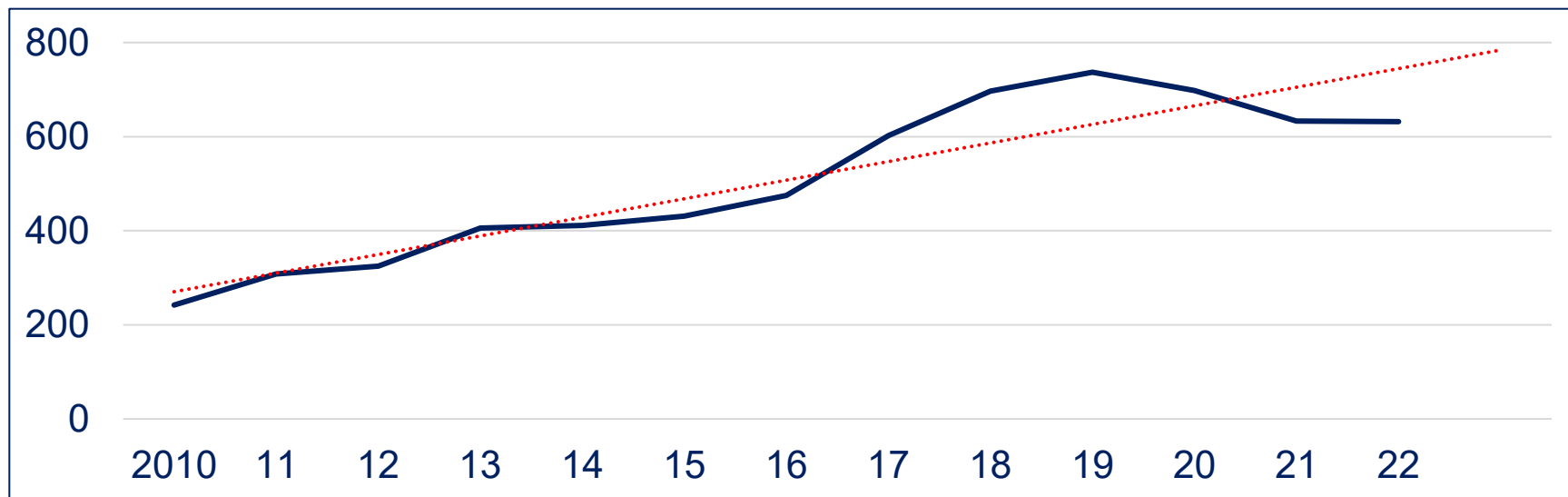
Of the individuals who require familiar persons or AT
to communicate at all times (35%)



Increase the number of professionals with expertise in communication to work with individuals with intellectual disabilities or autism across the lifespan.

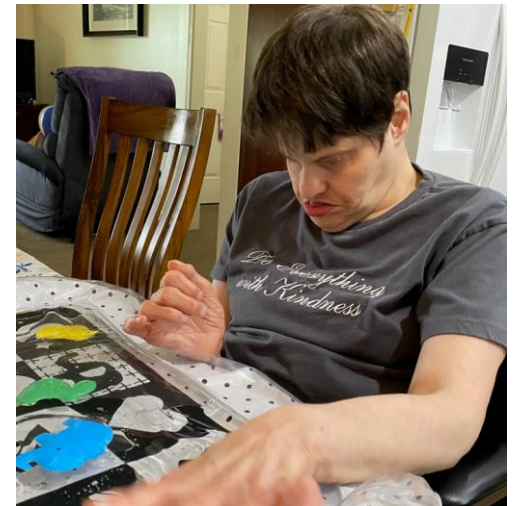
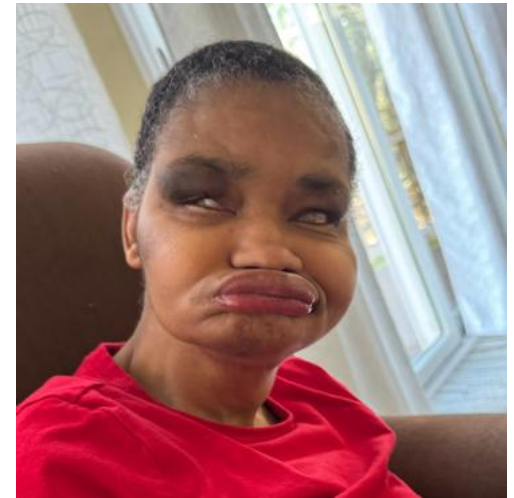


- Receiving more requests for support for individuals who are deafblind
 - 27% of Harry M class members are DeafBlind
 - Claims data for individuals registered with ODP in 2018-2020 with two or more ICD-10 diagnosis codes from the Risk List for Combined Vision and Hearing Loss codes from National Center on Deaf-Blindness = over 500 people
- Pennsylvania DeafBlind Child Count 2010-2022
 - PA is the 4th highest count in the nation



DeafBlind Immersion Experiences with Helen Keller National Center

- For individuals who are DeafBlind with intellectual disabilities and their team to gain insights into effective DeafBlind strategies
 - Family, Providers, Supports Coordinator, County, etc.
- HKNC staff, Tammie Christian, goes to the individual's home, day program, community, etc. for 4 days
- Tailored training day for team with a simulation experience on day 5
- A debrief with a report, and additional follow up meetings
- An ongoing, individual portal with training information
- We did 6 experiences in FY 2024-2025



Challenges and Outcomes so far

Challenges and Themes

- Undressing in public and/or inappropriate areas
- Understanding of vision and hearing diagnosis
- Behavior support plans
- Regression in communication
- Lack of environmental access and intellectual stimulation
- Beliefs the individual can't learn something new
- Teams doing things for the individual, not with

Outcomes so far

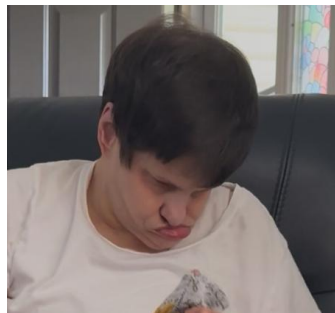
- Partnerships with Special Populations Unit
- Staff expressed they developed empathy instead of sympathy
- All teams added training for staff specific to deafblindness
- All teams are already seeing a positive change in their relationships with the individual
- Teams not only doing things for the person, but with the individual



▶ Thank you!

Any Questions?

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Department of Human Services