AUTISM GROWS UP: Pennsylvania's Innovations to Support Adults With Autism

Pia Newman, Former Manager, Adult Autism Waiver
Stacy Nonnemacher, PhD, Office of Developmental Programs, Bureau of Autism Services
Lindsay Shea, MS, DrPH, Office of Developmental Programs, Bureau of Autism Services
Kaitlin Koffer Miller, MPH, ASERT Collaborative

August 29th, 2018
Agenda

Innovations to Support Adults With Autism in PA

Adult Autism Waiver

Goal Attainment Scale

Periodic Risk Evaluation (PRE)

ASERT Collaborative

www.dhs.pa.gov
Pia Newman

ADULT AUTISM WAIVER
The Need that Gave Rise to the Waiver: ASD Prevalence

Number of Adults with ASD Receiving Services in Pennsylvania (2015-2030 Projected)

- From 6.7 in 1,000 in 2000 to 16.8 in 1,000 in 2014 (CDC, ADDM Network)
- From “tsunami anxiety” to Pennsylvania Autism Census (www.dhs.pa.gov)
250 Stakeholders

12 Subcommittees

5 Primary Recommendations

Develop an autism-specific Medicaid Waiver to allow for greater flexibility & creativity in providing services for this population.

Starting at age 21 and without age limit | Priority for those not already receiving long term services | IQ not a consideration for eligibility (ICF/ORC and ICF/IID) | Administered directly by the state Medicaid agency (not counties, as the ID waivers are administered)
Goldilocks Conditions

“Big History uses this concept to describe when the right conditions occur at precisely the right time to trigger a form of fundamental change.” - www.BigHistoryProject.com

Right Governor, Right Secretary of Medicaid Agency, Right Consultants
- Ed Rendell, Governor
- Estelle Richman, Secretary of Public Welfare
- Ernest McKenney and Steve Eiken, Consultants (Medstat then; IBM Watson now)

Engagement of the Autism Community
- Pushing the system to change

“MR” changing to “ID”
- The Bureau of Autism Services was born, 2007

www.dhs.pa.gov
Adult Autism Waiver: Principles and Philosophy

- IQ should not be an eligibility criterion
- Build on what we know: lessons from the kids’ systems
- Evidence-based practices as foundation
- Design for the entire spectrum
- Promote learning through the lifespan: Neuroplasticity applies to ASD, too
- Providers must be partners in this new venture
- Technical assistance for providers is a priority
- High quality services require high quality training, training, training
Sometimes it’s better not to know what you’re getting into…

- This was probably one of our greatest strengths!
- How hard could a Medicaid waiver be?
- “How should things work?” not “How do things work?”
- Evidence-based practices
- Needs-based service planning
- Data-driven program evaluation and improvement

Stakeholder Waiver Advisory Committee

- Included Task Force members
- Representation from around the state
- Fresh eyes and novel ideas
- Buy-in and credibility
What We Knew

➢ Distinctive features of ASD that should inform supports
  – Limitations in Communication, Social Relatedness, Executive Functioning, Decision making, Theory of Mind, maladaptive behaviors impact quality of life
  – Scattered skills
  – Broadest spectrum of any developmental disability

➢ Adults with ASD are adults
  – Increasing independence is a program goal
  – Most participants will be living with their families; they need support, too

➢ Applied Behavior Analysis/Positive Behavior Supports is a strong foundation
  – Objective, observable evidence of effectiveness should drive program design and improvement
What We Knew (cont.)

We needed an in-house team of behaviorally-trained staff with direct experience supporting individuals with ASD to:

- Participate in program and service definition design, including provider qualifications
- Design collection and analysis of program data on program effectiveness at the individual as well as the program levels
- Provide direct technical assistance to individual providers and ISP teams when participants and teams are struggling
- Be available to consult with other BAS staff
- Act as interlocutors with mental health providers
- Identify needs and participate in the design of training resources for providers
- Do training, training, training
What We Knew (cont.)

➢ Find what you need, make your own for the rest
  – Try not to reinvent the wheel
  – If you can’t find what you need, don’t wait for someone else to design it. Make or adapt your own: PA Census, Needs Assessment, annual PA Autism Training Conference, web-based trainings, webinars, infographics, focus groups, annual ASD Seminar “tour,” Goal Attainment Scale, Periodic Risk Evaluation, ASERT (more on those later in the presentation)…

➢ Training and standards for providers
  – Can’t assume direct support professionals or their supervisors are familiar with ASD
  – Staff training needs to cover a broad range of topics

➢ Dearth of research on ASD in adulthood (see first bullet)
What We **Thought We Knew**

**ABA:** Effective learning technique for children, probably would be effective for adults as well. (This is true.)

**ASD isn’t a variant of Intellectual Disability** (This is true)

**Employment:** getting the job is not as difficult as keeping the job (True)

**What to expect of providers:** PA had lots of Behavioral Specialist Consultants working in the kids’ system – that should provide lots of qualified providers! (Not so much)

**We would be flooded with calls as soon as we opened our doors** (Not)
What we didn’t know, but learned

- Needs of Adults
  - Dearth of Research wouldn’t get better soon
  - Other states didn’t also start to focus on ASD in adulthood
  - Comorbid serious MH & PH conditions are not uncommon, but co-occurring ASD is unfamiliar to mental health professionals
  - Sexuality
    - Sexual identity (Like in the general population)
    - Illegal sexual behavior (child pornography, public masturbation, et al.)
    - And lots more…

- No rest for the wicked
  - Quality improvement never ends
  - Never enough hands/never enough time
  - Always learning what we don’t know
What we didn’t know, but learned

➢ A waiver can’t do everything
  – Housing
  – Medical/Clinical services; diagnostic capacity
  – Streamlining system navigation (OVR, SSI, Education, Transition age)

➢ Things take longer than anyone can predict, justify or explain…
  – Government Years make dog years look short
  – We thought we were moving S-L-O-W-L-Y, but not by bureaucratic standards!

➢ Politics (unfortunately) continue to matter
  – Moving the system forward
  – Supporting funding
  – Setting priorities

➢ Now what??
If you’d like to focus on adults with ASD…

Think outside the box.

Learn from other DD programs and benefit from their experience, but don’t be limited by them.

Direct technical assistance and fostering a cooperative culture with providers is one key element to success: It’s a partnership.

Find ways to keep the ASD community engaged and supportive: they can advocate in the ways you can’t.
Stacy Nonnemacher

GOAL ATTAINMENT SCALE (GAS)
Goal Attainment Scale

Need to prioritize, monitor, and report on progress

The GAS is an individualized, criterion referenced measure that is useful in measuring and reporting on:

- individual goals
- aggregate goals to determine programmatic outcomes
Encourages Providers

To create more meaningful, functional and attainable goals and objectives

To make better informed data-based instructional decisions

To report participant progress more efficiently
Are there sufficient data to inform supports and progress reporting?

No: No QSR
No: Inconclusive
Yes: Informative Data

36.19%
25.37%
38.43%
No Model - Distribution of Objectives Across Categories

- ADLs: 48.84%
- Behavior: 25.58%
- Employment: 13.95%
- Social/Communication: 11.63%
## Goal Attainment Scaling Chart

<table>
<thead>
<tr>
<th>Level of Attainment</th>
<th>Quarter 1</th>
<th>Quarter 2</th>
<th>Quarter 3</th>
<th>Quarter 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dates:</td>
<td>Dates:</td>
<td>Dates:</td>
<td>Dates:</td>
</tr>
<tr>
<td>Much less than expected -2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat less than expected -1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expected level of outcome 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat more than expected +1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Much more than expected +2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of Attainment per quarter</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructional Decision</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of Attainment</td>
<td>Quarter 1 Dates: 2/1/16-4/30/16</td>
<td>Quarter 2 Dates: 5/1/16-7/31/16</td>
<td>Quarter 3 Dates: 8/1/16-10/31/16</td>
<td>Quarter 4 Dates: 11/1/16-1/31/17</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>---------------------------------</td>
<td>---------------------------------</td>
<td>---------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>Much less than expected -2</td>
<td>0/11 steps completed independently (all steps need no more than model prompts)</td>
<td>2/11 steps completed independently (rest of steps need no more than direct verbal prompts)</td>
<td>4/11 steps completed independently (rest of steps need no more than indirect verbal prompts)</td>
<td>6/11 steps completed independently (rest of steps need no more than gesture prompts)</td>
</tr>
<tr>
<td>Somewhat less than expected -1</td>
<td>1/11 steps completed independently (rest of steps need no more than model prompts)</td>
<td>3/11 steps completed independently (rest of steps need no more than direct verbal prompts)</td>
<td>5/11 steps completed independently (rest of steps need no more than indirect verbal prompts)</td>
<td>7/11 steps completed independently (rest of steps need no more than gesture prompts)</td>
</tr>
<tr>
<td>Expected level of outcome 0</td>
<td>2/11 steps completed independently (rest of steps need no more than model prompts)</td>
<td>4/11 steps completed independently (rest of steps need no more than direct verbal prompts)</td>
<td>6/11 steps completed independently (rest of steps need no more than indirect verbal prompts)</td>
<td>8/11 steps completed independently (rest of steps need no more than gesture prompts) for one quarter</td>
</tr>
<tr>
<td>Somewhat more than expected +1</td>
<td>2/11 steps completed independently (rest of steps need no more than direct verbal prompts)</td>
<td>4/11 steps completed independently (rest of steps need no more than indirect verbal prompts)</td>
<td>6/11 steps completed independently (rest of steps need no more than gesture prompts)</td>
<td>9/11 steps completed independently (rest of steps need no more than gesture prompts)</td>
</tr>
<tr>
<td>Much more than expected +2</td>
<td>3/11 steps completed independently (rest of steps need no more than direct verbal prompts)</td>
<td>5/11 steps completed independently (rest of steps need no more than indirect verbal prompts)</td>
<td>7/11 steps completed independently (rest of steps need no more than gesture prompts)</td>
<td>10/11 steps completed independently (rest of steps need no more than gesture prompts)</td>
</tr>
</tbody>
</table>

| Level of Attainment per quarter      | -2                                                                 | -2                                                                 | -2                                                                 | -2                                                                 |
| Comments                             | Services did not begin until April 14th, so there is no data to report during this quarter. | Shawn consistently completed 3 steps independently following the TA, but still requires model prompts for the remaining steps. Although this is an improvement from baseline, he did not meet her expected outcome for this month. | | |
| Instructional Decision               | Continue                                                           | Continue                                                           | Continue                                                           | Continue                                                           |
Are there sufficient data to inform supports and progress reporting?

- No: No QSR
- No: Inconclusive
- Yes: Informative Data
Preliminary Outcome Data

Percentage of Goals Reported on by Goal Category

- ADL: 44%
- Social/Communication: 25%
- Employment/Education: 25%
- Behavior: 6%

www.dhs.pa.gov
Preliminary Outcome Data

Distribution of Participant Progress Across Level of Attainment: Social Communication

![Bar chart showing distribution of participant progress across levels of attainment. The levels are labeled as -2, -1, 0, +1, and +2, with percentages indicating the distribution. The data shows a higher percentage of participants at level +2.]
Preliminary Outcome Data

Percentage of Goals Across Performance Criteria

- Performing Below Criteria: 37%
- Met Criteria: 19%
- Exceeding Criteria: 44%

www.dhs.pa.gov
We feel we are on the right track with skill building, but how can we address risk and behavior more proactively in this model?
Lindsay Shea

PERIODIC RISK EVALUATION
Periodic Risk Evaluation: Why?

Need to systematically identify risk and need for additional services and supports

- Informs planning and operational processes

Shortage of available tools

- Few options predict risk
- Fewer options for adults with autism
Peer-reviewed research conceptualizes autism risk in a different way…
SIS and its use for people with Autism Spectrum Disorders

The Supports Intensity Scale may be a useful tool for planning teams interested in identifying support needs of people with Autism Spectrum Disorders (ASD). The same support needs assessment and planning process outlined in the SIS User’s Manual, that is, using the SIS in conjunction with person-centered planning, is recommended. It is important to understand that the norm-referenced SIS Support Needs Index (i.e., the overall score) is based on a population of people with intellectual disabilities and related developmental disabilities. This population overlaps, but does not consume the population of persons with ASD. Please note that there are no separate norms for people with ASD. Also, for those people with autism whose intellectual functioning is higher and therefore whose social communication abilities are higher, SIS would not be as appropriate a tool to determine support needs.
PRE Creation

Clinician-identified domains

1. Law enforcement
2. Risk of harm to self and others
3. Stressful life events
4. Unstable living environment
5. Natural supports
6. Substance abuse
7. Co-occurring mental health diagnoses
8. Chronic medical conditions
PRE Creation (cont.)

Structural Priorities

Maximize mutual exclusivity to optimize analytics

- Chronic medical conditions does not include mental health conditions
- Risk of harm to self or others not related or leading to law enforcement contact

Validate and qualify elected responses for analysis and service planning

- Type of law enforcement contact (police called, arrested, probation/parole)
- Specific mental health/physical diagnoses (ADHD, diabetes)
## PRE Creation (cont.)

### History/Frequency
- No history
- Remote history (2 or more years)
- Recent lower intensity (2 or fewer incidents in the last 2 years)
- Recent high intensity (3 or more incidents in the last 2 years)

### Ongoing
- Yes
- No

### Concern/Impact
- No concern
- Mild concern
- Moderate concern
- Severe concern

### Severity
- Mild intermittent
- Mild persistent
- Moderate persistent
- Severe persistent

### Maintenance
- Receiving consistent treatment or therapy as recommended
- Inconsistent treatment or therapy
- No treatment or therapy despite provider recommendations

---

Medical and mental health conditions domains only
PRE Creation: Scoring/Weighting

Clinician-identified domains

1. Law enforcement
2. Risk of harm to self and others
3. Stressful life events
4. Unstable living environment
5. Natural supports
6. Substance abuse
7. Co-occurring mental health diagnoses
8. Chronic medical conditions
PRE Testing

- BAS programs with ~850 enrollees
- PRE administered at intake, quarterly, and at change of risk

**Step 1.**
BAS Clinical Expert blind rates individuals based on 'complex' status at regular intervals

**Step 2.**
Establish testing groups

**Step 3.**
Identify scoring cut point for implementation

**Group A:**
80% of sample
- Establish scoring optimization

**Group B:**
20% of sample
- Test scoring optimization
### Initial Results

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity</td>
<td>64%</td>
</tr>
<tr>
<td>Specificity</td>
<td>91%</td>
</tr>
<tr>
<td>Positive Predictive Value</td>
<td>72%</td>
</tr>
<tr>
<td>Negative Predictive Value</td>
<td>88%</td>
</tr>
</tbody>
</table>
PERIODIC RISK EVALUATION (PRE):
INDIVIDUAL SUPPORT PLAN (ISP)

The PRE is designed to inform the ISP. This can be done in two sections of the ISP. Note the different domains.

<table>
<thead>
<tr>
<th>RISK DOMAIN</th>
<th>ISP SECTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Law Enforcement</td>
<td>General Health</td>
</tr>
<tr>
<td>Risk of Harm to Self or Others</td>
<td>General Health</td>
</tr>
<tr>
<td>Unstable Living Environment</td>
<td>Crisis Support F</td>
</tr>
<tr>
<td>Natural Supports</td>
<td>General Health</td>
</tr>
<tr>
<td>Substance Use</td>
<td>General Health</td>
</tr>
<tr>
<td>Chronic Medical Conditions</td>
<td>Physical Assess</td>
</tr>
<tr>
<td>Stressful Life Events</td>
<td>General Health</td>
</tr>
</tbody>
</table>

PERIODIC RISK EVALUATION (PRE):
FULL RISK MITIGATION CYCLE

Recognize:
The PRE is one of several components used to recognize risk. It is used in conjunction with ISP assessments, SC monitoring, Incident Report Analysis and participant/family member and provider information.

Evaluate:
Evaluate the effectiveness of the risk mitigation plan and continue to monitor either during quarterly team meetings or more frequently at provider team meetings. The PRE can be completed again if a new risk is present and again annually at the

Assess:
The PRE informs assessment based on whether concerns were identified as mild, moderate or severe in the different domains. Risk factors are verified as present and severity of risk is determined.
PRE Refinement

Opportunities for item reduction

Scoring modifications

Continued development of resources

New groups for adaptation

Bayesian Additive Regression Tree (BART)
THE ASERT COLLABORATIVE: AN INNOVATIVE PUBLIC-PRIVATE PARTNERSHIP MODEL

Kaitlin Koffer Miller
PA AUTISM TASK FORCE RECOMMENDATION

Situate Regional Autism Centers across the state that provide high quality services to individuals with autism, train professionals in the area to assess & evaluate the needs of people living with autism, provide education & supports to families, & create opportunities for research to continually improve treatment & supports.
WHAT IS ASERT?

Autism Services Education Resources & Training

- Funded by the Bureau of Autism Services, Pennsylvania Department of Human Services.

- A unique partnership of public and private academic centers

- A key component of the BAS strategy for supporting individuals with autism and their families throughout Pennsylvania.

ASERT PAautism.org
ROLE AND PURPOSE OF ASERT

- Leverage academic expertise
- Bring together local, regional, and statewide resources
- Support (not replace) existing community efforts and activities
- Develop innovative projects based on data, community need, and commonwealth priorities
What does ASERT do?

- **Support**
  The Autism Community Throughout Pennsylvania

- **Educate**
  Individuals with Autism and their Families, Professionals, and Community Members

- **Measure**
  Data, Needs, and Change

- **Build**
  Resources, Programs, and Innovative Projects

- **Connect**
  Local, Regional, and Statewide Resources
**How Does ASERT Support BAS?**

- **Training and Resources**
  - Justice Professionals
  - ASD 101
  - Infographics
  - Resource Center

- **Clinical Support**
  - PRE
  - PCAMS
  - Social Skills Groups

- **Data**
  - PA Autism Census
  - PA Autism Needs Assessment

- **Policy Support**
  - Policy Briefs
  - Focus Groups

ASERT: Bringing Autism Resources Together

PAautism.org
Pennsylvania Autism Census

Captures number of people with autism receiving services

Where are people with autism being served? Where they are located geographically?
How is the PA Autism Census Used?

1. Identifying individuals with autism who are receiving services is important for program planning for the commonwealth.

2. Planning for ASERT and BAS priorities, programs, and projects.

3. Linking across systems.
What Have We Learned?

- Autism is increasing: There was a 181% increase in the number of individuals with autism receiving services.
- Adults are growing fastest: A 334% increase in adults 21+ makes adults the fastest growing group.
- The majority of individuals with autism are receiving services through Education and Human Services.
- The highest numbers of individuals with autism are in Philadelphia and Allegheny (where Pittsburgh is located) counties.
- Many people with autism are receiving services from multiple systems.
The PA Autism Needs Assessment is the largest and most comprehensive survey of individuals with autism and their caregivers to date in the nation.
HOW IS THE PA AUTISM NEEDS ASSESSMENT USED?

1. Identifying emerging issues in the autism population
2. Planning for ASERT and BAS priorities, programs, and projects
3. Determining needs of individuals with autism and their families.
People with autism and their families struggle to find the services they need, and are often dissatisfied with the services provided.

As individuals with autism age, the need for services increases but services are harder to access.

The lack of interventions for challenging behaviors and co-occurring mental health diagnoses leads to crisis situations.

Families need services to meet their needs, in addition to their family member with autism.

Most adults with autism are unemployed or underemployed.
Connection to autism core deficits and community needs

2014 PA Autism Census
Increasing number of individuals with autism involved with the Justice System

Social and communication impairments could lead to increased risk for negative outcomes with law enforcement
JUSTICE PROJECTS

Survey
• Statewide survey of justice system professionals to determine training needs and priorities
• 350+ respondents

Trainings
3500+ professionals trained
Judges, CYS, Adult and Juvenile Probation and Parole, Sheriffs, Corrections, Detention, RTF workers and Police Officers
Certified by MPOETC

Resources
• www.paautism.org/justice
• Bench Book for Judges
• Key Signs of Autism for Justice System Professionals
• Social Stories
What Have We Learned?

There is a substantial training need across the justice system

Media coverage has pushed for more attention to the interaction between individuals with autism and the justice system

More training and resources are needed for individuals with autism to prepare for law enforcement interaction (self-advocacy)
ASERT Resource Center

- Call Center (English and Spanish)
- Email (English and Spanish)
- Website

ASERT Statewide Resource Center
ASERT Resource Center Features

- Contact a live person
- Resources available by region & statewide
- Access a broad array of information
- Online resource database
- Strict vetting criteria
- Continually updated with news, events, and trainings
- Create a personal account

ASERT: Bringing autism resources together.

PAautism.org
LGBTQI Resource Page

Are you looking for resources and information about the LGBTQI community for participants or families?

paautism.org/LGBTQI
Are you trying to prepare for election day?

paautism.org/vote
Website: www.PAautism.org
Email: info@PAautism.org

ASERT is funded by the Bureau of Autism Services: Office of Developmental Programs,
PA Department of Human Services
QUESTIONS?

Pia Newman: pnewman@pa.gov
Stacy Nonnemacher: c-snonnema@pa.gov
Lindsay Shea: c-lishea@pa.gov
Kaitlin Koffer Miller: kk629@drexel.edu

August 29th, 2018