ASDAC Legislative Priorities

Autism Spectrum Disorder Advisory Council 2025

Agenda

- Introduction to the Council
 - Purpose
 - Membership

- Legislative Priorities
 - Have Voice
 - Evaluate Needs
 - Expand Access

Purpose

Major Responsibility:

Advise the Secretary of the Office of Policy and Management concerning policies and programs for persons with autism spectrum disorder (ASD) and recommendations to improve coordination and address gaps in autism services.

Main Goals:

- Enhance support services for individuals with ASD and their families.
- Address key gaps identified in autism services.

<u>Autism Spectrum Disorder Advisory Council</u>

Membership Structure

- Core Members: Commissioners (or designees) from key state agencies: Social Services, Children and Families, Education, Mental Health and Addiction Services, Public Health, Aging and Disability Services, Developmental Services, and Early Childhood.
- Community Representatives: Persons with ASD, parents/guardians, advocates, licensed professionals, service providers, and representatives from higher education institutions.
- Chairpersons: Three members, with specific roles for persons with ASD and guardians.

Legislative Priorities

Call upon Us. We want to be involved.

Our membership represents the stakeholders and your constituents.

We understand the impact.

We have the expertise.

We can advise on policies, recommendations, and strategic planning related to ASD services.

We want to be at the table for any conversations about changes in definitions and eligibility.

Recent Study: "Evaluation of Statutory Definitions and Regulations: Intellectual Disability and Related Programs"

- In collaboration with state agency work groups per legislation, OPM commissioned a study conducted by the Altarum Institute.
- There were two key areas for evaluation:
 - Potential new definitions for intellectual disability; and,
 - Reviewing the level-of-need assessment tool used for service planning.

LINK TO REPORT for PA 23-137 Sec 4 on Statutory Definition for ID and DD

Altarum Institute: Final Report

The report ...

- Outlined potential recommendations to change statutory definitions, eligibility, enrollment workflows, the Level of Need (LON) assessment, etc.
- Cautioned:
 - "... full adoption of any proposed changes could impact existing waiver program eligibility ... and the number of eligible program participants;"
 - "...must begin with an understanding of, and appropriate planning for, any potential impacts;" and,
 - "... recommendationswill require strategic thinking, analysis, and development **before** implementation ..."
- Emphasized the need for additional information & analysis as the first step.

Fund a needs assessment. Are needs being met?

This will identify unmet needs & gaps.

Data will help create transparency.

CT can replicate an assessment done in Pennsylvania by the ASERT

PA Autism Needs Assessment

The estimated cost would be \$150,000, and it would take 15 – 27 months to complete. This information will inform next steps.

This aligns with the Altarum Report's recommendation for an impact study.

Remove age limitations for insurance. We must expand access to services.

Applied Behavior Analytic (ABA) services are <u>only</u> mandated through age 21 per CT statute.

Expanding services through private medical insurance allows for alternative options beyond Medicaid.

Ensuring services other than through Medicaid increases opportunities along a continuum of support.

Removing Age Limits from Medical Insurance

- The Affordable Care Act (2010), the Mental Health Parity Act (2008), and Connecticut 2014 bulletins (HC-96 & HC-99) request removing age caps; however, the statutory age limit (21 years) remains.
- note: Behavior therapy is the only autism service with an age cap.
- 19 states removed age caps, according to <u>Autism Speaks</u>.

- If ABA supports are covered by private insurance and on the exchange, adults with autism would have access to continued coverage after they turn 21.
- This could reduce the number of people on the waitlist for waiver services and be more equitable.
- Working adults with autism would have access to evidence-based support specific to their needs and would not have to apply for Medicaid to access services.

Next Steps

- Support for legislative priorities
 - Funding the needs assessment
 - Changes to age limits (caps) within medical insurance for services
- A seat at the table
 - Active participation in the impact study and strategic planning with potential statutory definition changes for intellectual disability and development delay

Questions and Discussion

Thank you!