



**AUTISM WORK GROUP:  
MEDICAID ADVISORY COMMITTEE  
SECOND REPORT:  
JUNE 30, 2025**



**HFS**

Illinois Department of  
Healthcare and Family Services

## **The Authority and Purpose of the Autism Work Group of the Medicaid Advisory Committee**

[House Resolution 818](#), from the 103<sup>rd</sup> General Assembly, urges the Medicaid Advisory Committee (MAC) to examine, make recommendations, and develop a strategic plan through specific stakeholder input around the medical and dental services for individuals with intellectual and developmental disabilities (I/DD), and specifically those with autism spectrum disorders, receiving Medicaid services. The progress reports and strategic plan must be submitted to the Governor and the Illinois General Assembly.

### **Work Group Mandates For the Medicaid Advisory Committee (from House Resolution 818):**

- **“Make recommendations** that will expand the network of Medicaid enrolled specialty providers for persons with autism and is urged to assess the following, consulting with relevant stakeholders with lived experience and provider experts:
  - (1) Strategies to improve access for adult Medicaid customers experiencing autism to specialty providers, including, but not limited to, dentists, anesthesiologists, phlebotomists, and occupational therapists;
  - (2) Ways to improve provider services under the Adults with Developmental Disabilities Waiver”
- **Written Report:** The Work Group of the MAC will provide progress reports to the Governor and Illinois General Assembly by December 31, 2024, and June 30, 2025.
- **Final Report:** The Work Group of the MAC will provide a final report and strategic plan with measurable objectives to the Governor and General Assembly by December 31, 2025.

### **Stakeholder Recruitment**

- (1) One representative of the Department of Healthcare and Family Services;
- (2) One representative of the Department of Human Services;
- (3) One representative of the Department of Insurance;
- (4) One representative of the Children's Behavioral Health Transformation Initiative;
- (5) One representative from the Illinois Council on Developmental Disabilities;
- (6) One representative of the Illinois State Board of Education and/or an educator who specializes in working with children with autism;
- (7) Two parent advocates of persons with disabilities;

(8) At least one representative of each of the following provider groups:

- (a) Dental care;
- (b) Primary care;
- (c) Behavioral Health; and
- (d) Occupation, Speech, and Physical Therapy;

(9) At least four representatives of non-profit entities representing people with disabilities, including at least two representatives of rural areas and two representatives of Cook and collar counties;

(10) One representative of an advocacy organization focused on residents of Illinois State-Operated Developmental Centers (SODCs) or Intermediate Care Facilities for Individuals with Developmental Disabilities (ICFs/DD); and

(11) One current employee of a Community Integrated Living Arrangement (CILA).

### **2024-2025 Progress To Date and Work Group Goals**

- **First Meeting: November 22, 2024**

The Autism Work Group of the MAC met to introduce new members of the Work Group, review the purpose of House Resolution 818, and provide an overview of mandatory and optional medical and dental services funded via the State's Medicaid, CHIP, and certain All Kids programs.

Members shared practical recommendations based on pressing challenges faced by families:

- Improve access to dental care for people with autism, particularly for procedures requiring sedation.
- Address challenges in performing blood draws for individuals with sensory or behavioral difficulties.
- Close gaps in specialized care, including aging-related services such as cardiac and psychiatric care.
- Increase provider training and support to reduce reluctance to accept Medicaid patients.
- Develop strategies to better support the transition from pediatric to adult healthcare services.

- **Second Meeting: April 14, 2025**

The Autism Work Group of the MAC met to discuss barriers faced by providers in dentistry and gain insight into Medicaid provider enrollment. **Stakeholder and Expert Presentation:**

“Discussion on the Barriers Faced by Providers: Dentistry” was provided by Dr. James D. Benz, DDS, Chair of the Department of Dentistry and Program Director at Advocate Illinois Masonic Medical Center.

Work group members recommended the following:

- Invite Managed Care Organization (MCO) representatives to a future work group meeting to gain a deeper understanding of how these organizations deliver care to children and adults with I/DD.
- The Autism Work Group should proactively monitor changes in state and federal legislation, and such legislative updates should be provided in future meetings.
- Explore additional training strategies for medical professionals and trainees in techniques for stabilizing and desensitizing individuals to medical restraints, while being mindful of their controversial nature.
- Assess and address wait times for routine dental care, particularly for individuals with I/DD or complex needs.
- Enhance access to specialized dental training and services by identifying barriers and expanding teaching efforts to better meet demand.
- Research and share comparable programs and training strategies across different regions in Illinois to identify best practices, techniques and potential models for replication, and best practices for stabilizing and desensitizing individuals to medical restraints, while being mindful of their controversial nature.
- Encourage providers to contact the Department of Insurance directly to be connected with the Dental Society and help create a closed-loop system for dental referrals.

- **Third Meeting: June 17, 2025**

The Autism Work Group of the MAC met to nominate a Work Group Chair and discuss a new children’s behavioral health pilot program recently launched in Illinois. **Stakeholder and Expert Presentation:** “In-Home Behavioral Health Aides for Youth with Autism” was provided by Dr. Dana Weiner, Chief Officer for Children’s Behavioral Health Transformation.

Work group members recommended the following:

- Further discussion of Medicaid in-home services for:
  - Children with autism and developmental delays in the Prioritization of Urgency for Need of Services (PUNS) database, but not receiving services under a Developmental Disability Waiver.
  - Children with autism without developmental delays (not eligible for PUNS).
  - Medicaid-eligible families seeking services through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program.
  - Explore service options for high-need children who fall outside current waiver coverage.
- Further discussion on workforce challenges, specifically Direct Support Professional (DSP) recruitment and hiring one-on-one DSPs for adults with high support needs.
  - Consideration of other workforce development and training initiatives like exploring non-traditional behavioral health roles and credentialing pathways and aligning those efforts with DSP-related needs where appropriate.
  - Streamlining access to sedation dentistry for individuals with I/DD or complex needs and eliminating the current multi-step process that contributes to referral rejections and long delays, which can lead to medical emergencies.
- Further discussion of possible expansion of outpatient therapy services.
  - Dressing Medicaid coverage gaps for psychotherapy and social skills groups and nontraditional therapies (e.g., animal therapy, art therapy).
- Further discussion of evaluating the potential expansion of the In-Home Behavioral Health Aides for Youth with Autism pilot program (as presented by Dr. Dana Weiner of the Illinois Children’s Behavioral Health Transformation Initiative (CBHTI) and included in CBHTI’s Blueprint for Transformation) to provide short-term, in-home support services for children with autism or behavioral health needs who do not qualify for Illinois’ Home and Community-Based Services (HCBS) Medicaid waivers or Medicaid programming.

The pilot is intended for children with high support needs but whose IQs are too high for eligibility under the Department of Human Services Division of Developmental Disabilities HCBS Medicaid Waivers, as well as families with private or no insurance and individuals transitioning from hospitalization who need stabilization support. The recommendation is to monitor outcomes to inform future efforts to make these services billable under Medicaid and more broadly available.

### **Autism Work Group Members**

- **Dana Weiner** – Children’s Behavioral Health Transformation Initiative
  - **Mathew Pickett** – Department of Insurance
  - **Jennifer Gentile** – Department of Human Services
  - **Sarah Myerscough-Mueller** – Department of Healthcare and Family Services
  - **Kimberly Mercer-Schleider** – Illinois Council on Developmental Disabilities
  - **Rebecca Doran** – Illinois State Board of Education
  - **Mike Baker** – Parent Advocate
  - **Stephanie Brown** – Parent Advocate
  - **Samantha Alloway** – (Arc of Illinois) – Non-Profit Entity
  - **Lore Baker** – (AID) – Non-Profit Entity
  - **Charlene Bennett** – (IAG) – Non-Profit Entity
  - **Caroline (Carrie) Chapman** – (Legal Council for Health Justice) – Non-Profit Entity
  - **Kristen Huffman Gottschling** (PACTT) – Non-Profit Entity
- Provider Groups
- **Dr. Robert Rada:** Dental Care- Provider Group
  - **Lauren Hintzman:** Occupational, Speech, and Physical Therapy – Provider Group
  - **Dr. Alexandria Saulsberry:** Primary Care, Behavioral Health – Provider Group
  - **John Haley (ILADD)** - ICF/SODC Advocacy Organization

For printed copies, additional information, or to submit comments and questions about this report, please contact:



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## Illinois Department of Healthcare and Family Services

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