



JB Pritzker, Governor

Dulce M. Quintero, Secretary Designate

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DATE: 12/23/2024

MEMORANDUM

TO: The Honorable John F. Curran, Senate Minority Leader
The Honorable Don Harmon, Senate President
The Honorable Tony McCombie, House Minority Leader
The Honorable Emanuel "Chris" Welch, Speaker of the House

FROM: Dulce Quintero
Secretary Designate *Dulce Quintero*
Illinois Department of Human Services *by [signature]*

SUBJECT: 2024 Illinois Autism Progress Report

The Illinois Department of Human Services respectfully submits the 2024 Illinois Autism Progress Report on behalf of the Office of the Secretary of the Department of Human Services in order to fulfill the requirements set forth in Public Act 093-0773.

If you have any questions or comments, please contact Christine Hammond, Project Manager PSA, at Christine.hammond@illinois.gov.

cc: The Honorable JB Pritzker, Governor
John W. Hollman, Clerk of the House
Tim Anderson, Secretary of the Illinois Senate
Legislative Research Unit
State Government Report Center

STATE OF ILLINOIS

DEPARTMENT OF
HUMAN SERVICES



ANNUAL PROGRESS REPORT

*State Efforts to Improve Services
for Persons with Autism Spectrum Disorder*

As required by PA93-773

Overview

On July 21, 2004, Public Act 093-0773, "An Act in Relations to Persons with Disabilities", was signed into law. PA 093-0773 directed IDHS to convene a special task force, to "study and assess the service needs of persons with ASD".

This report, as required by Public Act 93-773, focuses on this year's progress relative to four specific areas:

1. Addressing Early Intervention services for children with autism.
2. Enhancing family support mechanisms to enable persons with autism to remain in their homes and communities.
3. Transition services from public school services; and
4. The Section 1915c waiver for persons with autism

THE ILLINOIS AUTISM TASK FORCE

The Illinois Autism Task Force (IATF) members include parents of children and adults challenged by ASD, people with lived expertise, healthcare professionals, academic professionals, and community-based operators. The co-chairs of the Illinois Autism Task Force are Patti Boheme M.S., LCPC, Director of Autism Services, SamaraCare, and Kiya Olson M.A., M.S., BCBA, LCPC Autism Consultant/Owner, ASPB Therapy Pathways.

The members of the task force demonstrate determination to improve the availability of services and assistance for individuals with autism spectrum disorder (ASD) and their families in Illinois.

The full task force met 4 times this year. There are four workgroups of the task force to address the 4 specific areas required of Public Act 93-773:

Act Early Workgroup
Transition Workgroup
Adult Services Workgroup
Insurance Workgroup

According to the Centers for Disease Control and Prevention (CDC) the Autism incidence in 2004 was 1 in 125. In 2020 that incidence rose to 1 in 36. This steep rise in data highlights that many more children need access to support.

PROGRESS IN ADDRESSING FOUR AREAS REQUIRED BY PA93-773

1. Early Intervention Services for Children with Autism

a. The Act Early Workgroup:

Act Early Goals:

- Improve robustness of service provision 0-5 (both Early Intervention (EI) and school-based services) with education and advocacy to Illinois Department of Human Services (IDHS).
- Support children on waitlists for EI services, diagnostic and therapeutic services.
- Work with Illinois Individuals with Disabilities Education Act (IDEA) Part C (Early Intervention) on how services for our autistic children can be best integrated into the new Department of Early Childhood.
- 2024 Work: Drafting of Educational Statement to IDHS for improved service provision for children with autism in Illinois.

Purpose:

- The incidence of autism has risen steeply over the last 2 decades. Early identification and diagnosis of children with indications of autism is essential as the brain is most neuroplastic before the age of 3, and early intervention therapies before this age has exponential positive life-long impacts on the child’s developmental trajectory.
- The Act Early Workgroup seeks to provide education to and advocacy for the Illinois Department of Human Services to provide more comprehensive early intervention services for the children of Illinois to improve the early identification, diagnosis, and provision of support services, including appropriate therapies.
- Families face multiple barriers to identification, diagnosis, therapeutic care, and comprehensive supports from birth to 5 years of age. Waitlists are years long for diagnostic and therapeutic services, especially for children using Medicaid insurance plans.

Plan:

- Describe the lack of access and barriers to appropriate care for Illinois families and provide some potential recommendations to help IDHS provide improved and comprehensive care to these families and become a model state in the nation for service provision for our children.

2. Enhancing Family Support Mechanisms to Enable Persons with Autism to Remain in Home-based or Community Environment.

- a. Updates on the Support Service Teams (SST’s) and related information can be found on the DHS website [IDHS: Support Services Teams \(SSTs\) \(state.il.us\)](https://www.idhs.state.il.us) or <http://www.dhs.state.il.us> under the Division of Developmental Disabilities' (DDD) link.
 - IDHS DDD has implemented movement from the Prioritization for Urgency of Need for Services (PUNS) list into a Developmental Disability (DD) Waiver service at a “Reasonable Pace”. This means that Adults in the Seeking Services category will be selected from the PUNS list annually, as appropriations allow. Adult selections will be based on a person's cumulative length of time in the Seeking Services category after their 18th birthday (i.e., those with the most months accumulated are selected first).
 - In Fiscal Years FY20 the DDD agreed to serve an average minimum of 600 individuals from the PUNS list for the years. In FY21 through FY25, the DDD agreed to serve a minimum of 630 individuals from the PUNS list each year. This multi-year plan has an end goal such that by FY25, the maximum wait time for the PUNS list will be 60 months or 5 years. Independent Service

Coordination Agencies (ISCs) will continue to submit funding requests for eligible individuals who are determined to be in crisis (homeless, abused or neglected), these individuals will not wait for PUNS selection.

3. Adequate Transition Services for People with Autism from Public School Programs to Adult Services.

a. The Autism Task Force Transition Workgroup

Purpose:

- Transition Planning is a required and important process that is a part of every student's Individual Education Plan (IEP) starting at age at age 14½. The format and information that is provided to parents and students regarding transition varies greatly across the state. Parents and professionals who attend IATF meetings have voiced concerns that the information and services provided to parents and students across the state is inconsistent and/or transition planning is not occurring at all. Therefore, parents and students are not getting all the information needed to plan. They may be missing opportunities for advocacy that affects success in future post-secondary educational settings, employment, training, and community/independent living that otherwise would be available to them if they were better informed.

The autism transition workgroup set out to answer the following questions:

- What and at what point do parents know about the transition process and the tools available to them to get through the process with positive outcomes?
- How and when do parents receive guidance to walk them through the transition process and life after high school?
- How and when are parents informed on services provided by Developmental Disabilities (DD)/Prioritization of Urgency of need for Services (PUNS), Independent Service Coordination Agencies (ISCs), Division of Rehabilitation Services (DRS), Division of Mental Health (DMH)/Screening Assessment Support Services (SASS), Division of Specialized Care for Children (DSCC), Supplemental Security Income (SSI), Supplemental Nutrition Program for Women, Infants, and Children (WIC), Department of Healthcare and Family Services (HFS), Achieving a Better Life Experience (ABLE) accounts, Medicare/Medicaid.
- Who is responsible for the messaging of important information parents need and at what point in the transition process should this occur?
- How and when can step by step guidance be available for families statewide?

Plan Design:

- The Autism Task Force Transition workgroup developed a survey tool to assess parent/family knowledge when it comes to understanding services available for the autism population during their high school transition years.
 - The survey received 395 responses.

Transition Workgroup Goals 2025:

- Analyze the survey, share the results of the survey and recommendations with the Secretary of IDHS

- Develop a baseline understanding of the survey results and make recommendations to the IATF, autism-based services entities and schools who will receive survey results information.
- Results obtained from the survey will inform agencies (i.e., Illinois Department of Human Services (IDHS), Illinois State Board of Education (ISBE), Illinois Board of Higher Education (IBHE), Illinois Community College Board (ICCB) where there is a gap in knowledge and understanding in parent/guardian (s) in respect to the transition process, services, and resources.
- The expectation is that agencies will utilize this information implement methods to improve their process of informing parents about transition in order to maximize outcomes for their children post high school.
- The expectation is that agencies will make commitments to IATF to improve these processes identified where there are gaps.

b. Employment First

- The Co-chairs of the IATF Transition workgroup remain active members of the Employment and Economic Opportunity for People with Disabilities (EEOPD) Transition Workgroup.

c. Adult Services Workgroup

Purpose:

- Enhance family support mechanisms to enable persons with autism to remain in their homes and communities. Recognize the diversity of need among individuals with ASD and provide the wide array of supports they need and give people the ability to use funding that matches each person's unique needs.

The Adult Services workgroup set out to answer the following questions:

- What does it mean to meet varied needs?
- Define Community Services.
- Define what the ideal system looks like?
- What are we doing right in Illinois?
- What are the barriers that prevent us from meeting people's needs?
- Where does the funding come from?
- How is the distribution of funding determined?
- Who are the entities that make funding determination?
- What is missing in this determination?
- What innovative practices/programs/policy can we adopt to allow the system to do a better job?
- What are the tools to get us there?

Plan Design:

- At present, in providing and receiving person- centered services there is a disparity between what is needed for the individual served and the infrastructure/support ability providers have in order to meet those person- centered plans. The Adult Services workgroup is in the process of developing a short three component survey tool to get a better understanding of the underlying reality of providing person centered services.
- Component 1: Survey the Individual/Guardian/Family on whether they are a recipient receiving actual person- centered planning services from their providers.

- Component 2: Survey the Providers to understand what their true needs are in order to better support real person- centered planning.
- Component 3: Survey the Individual Service Coordinator Agencies on the barriers they observe that hinder the ability of providers to meet the needs of the individuals to receive person – centered planning.

Adult Services Workgroup Goals 2025:

- Structure the survey and publish on the IDHS Website.
- Market the survey to enhance response rate.
- Collect and interpret survey results.

d. Insurance Workgroup

Purpose:

- Illinois has an average of a 9 month to 2- year wait list across the entire state for diagnostic services including initial diagnosis and re-evaluations. Wait length varies by geographic location in the state. Additionally, there is limited access to evaluation sites across the state especially outside the Chicago area. Without a diagnosis treatment is very limited, children are less likely to get an autism educational diagnosis in school. Children not treated early risk not meeting their full potential, and parents and individuals with ASD suffer because people don't understand how to help them. The Insurance workgroup has engaged to increase access and reduce wait times for diagnostic services, including initial and re-evaluations.

The autism insurance workgroup set out to answer the following questions in Illinois:

- Who is accepted to make a diagnosis under Medicaid plan?
- Who can do the required testing?
- Who determines the diagnostic/testing tools to be used?
- What is the Medicaid re-imburement costs for diagnosis?
- Reevaluations are a bottleneck to the system; evaluate what purpose they serve?
- What services are children missing by not being able to get a diagnosis, despite early warning signs?
- Is there a bridge to begin services while a child is waiting for the diagnosis process.
- Is there a coordinator/case manager to navigate systems for families.
- Is there a centralized place to guide families for kids past the EI referral stage to assist them in navigating the complex systems.

Plan Design:

- The Autism Insurance workgroup is still in the plan design stage. The work group reviewed other states and their process surrounding achieving early diagnosis.

Insurance workgroup goals 2025:

- Develop a priority plan for implementation in coordination with DHS for 2025 with the goal of reducing diagnostic wait times in the state for children and adults.

4. Feasibility of obtaining federal financial participation and obtaining a Section 1915c waiver for persons with autism.

The Division of Developmental Disabilities continues to operate and receive federal financial participation on three 1915c Medicaid Home and Community-Based Services (HCBS) Waivers for children and young adults with developmental disabilities (including children with autism). The Children’s Support Waiver was approved on January 1, 2023, the Children’s Residential Waiver on July 1, 2024, and the DD Adult Waiver on January 1, 2024. The most recent Waivers are available at <https://hfs.illinois.gov/medicalclients/hcbs.html>

In addition to the specific service options outlined below, each individual in a DD Waiver program receives case management from an Independent Service Coordination (ISC) Agency. ISC agencies serve as the front line for information and assistance to help individuals and families navigate the DD system and to ensure individual's health, safety, welfare, well-being, and satisfaction with services funded by DDD.

a. Children’s Support Waiver

The Children’s Support Waiver serves children and young adults (age 3 through 21) with developmental disabilities (including children with autism) who live at home with their families. Families are given a monthly allotment to purchase needed services.

Available service options:

- Personal Support
- Self-Direction Assistance (assist the family in arranging for, directing, and managing services)
- Temporary Assistance
- Behavior Intervention and Treatment
- Training and Counseling for Unpaid Caregivers
- Home/Vehicle Modifications

The maximum unduplicated number of participants for the Children’s Support Waiver was 1,080 at the end of FY24. New enrollees will be selected from the PUNS database when there are appropriations in the state budget or enter service as a crisis (homeless, abuse or neglected).

The Children’s Support Waiver is designed to be similar to the adult Home-Based Support Services (HBS) in the DD Adult waiver. This facilitates a seamless transition to adult Home-Based Supports, should these services be needed for young adults between the ages of 18 and 21. Services are specified in each individual’s Personal Plan and HBS Service Agreement. Services are limited each month to not exceed the monthly allotment which is two hundred percent (200%) of the monthly federal Supplemental Security Income (SSI) rate. The Waiver cost limit is adjusted annually at the start of each calendar year based on cost-of-living changes in the federal SSI payment levels.

b. Children’s Residential Waiver

The Children’s Residential Waiver provides residential habilitation in a licensed child group home for children and young adults (ages 3 through 21) with developmental disabilities (including children with autism) that require this service. Child Group Homes are licensed by the Illinois Dept. of Children & Family Services (DCFS).

Covered Services include:

- Residential habilitation
- Behavior Intervention and Treatment

The maximum unduplicated number of individuals served in the Children's Residential Waiver was – 131, FY24.

Services are designed to be similar to residential services in the DD Adult waiver to facilitate a seamless transition to adult waiver services for individuals between the ages of 18 and 21, should these services be needed.

c. Overview of 2024 Waiver Activities

Annually, IDHS reviews a variety of waiver quality assurance performance measures. Results are shared with the Healthcare and Family Services (HFS) and the federal Centers for Medicare & Medicaid Services (CMS). The compliance results are posted on the Division's website at: [IDHS: Developmental Disabilities Reports \(state.il.us\)](https://www.idhs.gov/developmental-disabilities-reports) (see Medicaid Waiver Reports).

Partner Accomplishments- Calendar Year 2024

In 2024, The Autism Program of Illinois (TAP), produced the following deliverables:

- Twenty-eight (28) expert-led trainings were conducted with a total of 449 participants.
 - Four virtual ADOS-2 trainings were conducted with a total of 164 professionals being trained.
 - Autism Symposium: The fourth annual Autism Symposium consisted of four days of virtual presentations. Two days were dedicated to professional training topics and two days were dedicated to caregiver topics. One hundred ninety-two (192) professionals and community members were in attendance.
 - Advocating for Supports to Improve Service Transitions (ASSIST) Training: A 12-session, expert-led, research-supported training program for parents of transition aged youth with the goal to improve parent's ability to advocate for services. Topics included models of decision-making, benefits, such as social security and health insurance, and transitioning to post-secondary education and employment, post-secondary education opportunities, housing and technology options, services available through IDHS-DRS, and special needs trusts and ABLE accounts. Sessions were offered monthly via Zoom.
- TAP provided 458 training programs serving 6,431 professionals, pre-professionals, parents, family, and community members. Training topics included: first responder crisis intervention training, trauma informed classrooms, classroom strategies for teaching individuals with autism, autism and co-occurring mental health disorders, social justice and autism, understanding autism, new diagnosis training, considerations for autism and the IEP, tips for home, and transitioning to adulthood.
- TAP completed 809 ASD-specific screenings, with 680 screenings resulting in referrals for comprehensive diagnostic evaluations and 122 screenings resulting in referrals to numerous services that address the child's (and family's) individual needs.

- TAP completed 516 ASD-specific diagnostic evaluations, with 332 evaluations resulting in a formal diagnosis of autism spectrum disorder.
- TAP served 6,158 Illinoisans through the Family and Community Resource Rooms (FCRR) with 3,633 individuals served as first-time visitors. In addition, FCRR staff completed 1,090 projects for parents, service providers, and teachers.
- TAP provided 3,492 hours of consultation services to 2,046 individuals across the state, with 982 people receiving unique (first-time) consultative services.
- TAP network partners received 2,075 requests for autism services through the TAP referral database and spent 1,405 hours following up with families regarding their needs.
 - Autism screenings and diagnostic evaluations were the top requested service needs across all quarters in 2024.
- TAP partners conducted 1,023 group treatment sessions serving 2,428 individuals across the state, with 740 individuals being unique (first-time) group participants. Groups were provided for individuals preschool age through 21 years old and some groups were conducted in Spanish serving the autistic Latinx community.
- TAP provided evidence-based ASD interventions totaling 22,820 hours of service for 679 individuals, with 121 individuals being unique (first-time) clients. Individual treatment services included ABA therapy, counseling, speech and language therapy, assistive technology support and job skills training.
- The TAP network participated in 233 collaborations with state and national level agencies and organizations.
 - National collaborations included the National Human Trafficking and Disability Working Group, the Association for Behavior Analysis International, and the American Speech-Language-Hearing Association.
 - Statewide collaborations included work with the Midwest Autism Consortium, AARTS Center, All our Kids Network, and the Coalition Against Sexual Abuse of Children with Disabilities.
 - Regional and local collaborations included county health departments, medical and behavioral health providers, local school districts, and Early Intervention providers.
 - TAP Central Office staff participated in ECHO Autism Primary Care, as well as the Illinois Autism Task Force which included participation in the Autism Insurance workgroup and ACT Early workgroup.
- In 2024, families who received TAP funded intervention services, autism screening, and/or autism diagnostic assessment reported a 98.7% satisfaction rate.

ILLINOIS AUTISM TASK FORCE MEMBERSHIP

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*Ms. Patti Boheme, SamaraCare Counseling - Co-Chair of the IATF, and Co-Chair of the Transition Workgroup**

Ms. Sasha Boheme, Hinsdale Township High School

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Ms. Sherry Brueck-Ladislav, Parent, Trinity Services

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Ms. Theresa Forthofer, Easter Seals-DuPage, Fox Valley

Dr. Karen Fried, Sonia Shankman Orthogenic School

The Honorable Sara Feigenholtz, State Senator- 6th District

Dr. Ramiro Gumuccio, Parent

The Honorable Don Harmon, State Senator – 39th District

*Ms. Sherry Healey, Parent- Chair of the Adult Services Workgroup**

Mr. Terry Herbstritt, Parent, PACTT Foundation

*Ms. Kiya Olson, ASPB Therapy Pathways Co-Chair of the IATF, and Co-Chair of the Insurance Workgroup**

*Ms. Zoubida Pasha, Parent, Family Resource Center on Disabilities- Co-Chair of the Transition Workgroup **

*Ms. Cari Roestel, Act Early Ambassador- Chair of the Act Early Workgroup**

Ms. Colleen Shinn, Autism Speaks

Ms. Ruth Ann Sikora, Parent, Comprehensive Services Committee

**Co-chairs of the Task Force and Workgroups*

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