

# ***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*

January 1, 2009

Dear Honorable Governor Rod Blagojevich and Honorable Members of the General Assembly:

Consistent with PA 93-773, I am pleased to submit to you the third annual progress report on efforts to improve services for persons with Autism Spectrum Disorder (ASD) and their families.

The Autism Task Force (ATF) and its working committees have continued to work this year on behalf of persons with ASD and their families, providing valuable input and guidance to the Departments of Human Services (DHS), Healthcare and Family Services (HFS), and the Illinois State Board of Education (ISBE).

This report details progress made in several areas:

- Addressing Early Intervention services for children with autism;
- Enhancing family support mechanisms to enable persons with autism to remain in their homes and communities;
- Transition services from public school services; and
- Feasibility of obtaining federal financial participation and obtaining a Section 1915c waiver for persons with autism.

By supporting the work of this Task Force, supporting the Children's Waivers and the use of federal reimbursement for the growth of services, and supporting crucial legislative changes, you have demonstrated your interest in and continued support of this important work. We look forward to continuing to partner with you and the ATF in the future.

Sincerely,



Carol L. Adams, Ph.D.  
Secretary

## **I. ILLINOIS AUTISM TASK FORCE MEMBERSHIP**

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*Ms. Ellen Adcock, FASST*  
*The Honorable Suzie Bassi, State Representative – 54<sup>th</sup> District*  
*Ms. Kathy Baumann, Family Counseling Center*  
*The Honorable Patti Bellock, State Representative – 47<sup>th</sup> District*  
*Ms. Patti Boheme, Little Friends – Chair of Transition Training Committee\**  
*The Honorable Jim Brosnanhan, State Representative – 36<sup>th</sup> District*  
*Ms. Sherry Brueck-Ladislav, Parent*  
*Ms. Gina Buck, Parent*  
*Ms. Laura Cellini, Parent\**  
*The Honorable James Clayborne, State Senator – 57<sup>th</sup> District*  
*Dr. Edwin Cook, University of Illinois at Chicago*  
*The Honorable Dan Cronin, State Senator – 21<sup>st</sup> District*  
*The Honorable Maggie Crotty, State Senator – 19<sup>th</sup> District*  
*Dr. Ann Cutler, University of Illinois at Chicago*  
*The Honorable Willie Delgado, State Representative – 3<sup>rd</sup> District*  
*Dr. Mina Dulcan, Children’s Memorial Hospital*  
*The Honorable Sara Feigenholtz, State Representative – 12<sup>th</sup> District*  
*The Honorable Deborah Graham, State Representative – 78<sup>th</sup> District*  
*The Honorable Don Harmon, State Senator – 39<sup>th</sup> District*  
*Mr. Terry Herbstritt, PACTT Foundation, Parent\**  
*Ms. Georgia Hillyer, FASST*  
*Dr. Nancy Keck, St. Alexis Medical Center*  
*Mr. Chris Kennedy, Kennedy Pierson & Strachan\**  
*Mr. Carl LaMell, Clearbrook\**  
*Dr. Bennett Leventhal, University of Illinois at Chicago—Co-Chair of the ATF\**  
*Dr. Earl Loschen, Psychiatric Consultant*  
*The Honorable David Luechtefeld, State Senator – 58<sup>th</sup> District*  
*Ms. Renee Lumpkin, Community Services Options, Inc.*  
*Ms. Kimberly Maddox, Autism Society for Illinois*  
*Dr. Elina Manghi, University of Illinois at Chicago*  
*Dr. Joseph Nyre, The Hope Institute*  
*Ms. Elaine Romas Rackos, Parent*  
*Mr. Brian Rubin, Parent – Co-Chair of the ATF\**  
*Mr. Scott Rudin, Parent*  
*The Honorable Skip Saviano, State Representative – 77<sup>th</sup> District*  
*Ms. Ruth Ann Sikora, Comprehensive Services Committee\**  
*The Honorable Ron Stephens, State Representative 102<sup>nd</sup> District*  
*Dr. John Sweeney, University of Illinois at Chicago*  
*Ms. Susan Szekely, Illinois Center for Autism*  
*Dr. Marie Weissbourd, Developmental Evaluation Clinic*  
*Ms. Christine Thornton Wiener, Giant Steps*  
*Ms. Georgia Winson, The Autism Project*

\*Chair or co-chair of a committee

## **II. STATE AGENCY PARTNERS**

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*Tanya Anderson, Department of Human Services – Division of Mental Health\**

*Eileen Deroze, Department of Human Services – Early Intervention*

*Barb Ginder, Department of Healthcare and Family Services*

*Caronina Grimble, Department of Human Services -- Office of the Assistant Secretary*

*Janet Gully, Department of Human Services – Early Intervention*

*Seth Harkins, Department of Human Services – Division of Mental Health\**

*Robert Holladay, Department of Human Services – Division of Developmental Disabilities*

*Reta Hoskin, Department of Human Services – Division of Developmental Disabilities*

*Grace Hou, Assistant Secretary, Department of Human Services*

*Barbara Sims, Illinois State Board of Education*

*Jeff Standerfer, Department of Human Services – Office of Rehabilitation Services*

*Lilia Teninty, Department of Human Services – Division of Developmental Disabilities*

### III. BACKGROUND ON REPORT

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In April 2004, a multi-agency Autism Task Force (ATF) was launched by the Department of Human Services as a means of addressing issues presented by the growing number of children and adults being diagnosed with Autism Spectrum Disorders (ASD).

The Task Force was comprised of parents of children and adults challenged by ASD, representatives of state agencies serving persons with ASD and their families, healthcare professionals, service providers, academicians and members of the legislature.

Co-chairs for the Task Force were Bennett Leventhal, M.D., a leading medical expert in ASD and Brian Rubin, Esquire, an attorney and parent of an adult child with ASD.

The Task Force met a number of times during 2004 to explore how the state might better serve individuals with ASD and their families, across the life span. Five working committees were established: *Transitions*; *Medicaid Waiver*; *Information Clearinghouse*; *Research*; *Workforce Development*; and *Insurance*.

The momentum of the ATF was further advanced by legislative action. On July 21, 2004, Governor Rod Blagojevich signed Public Act 93-773, an ACT in relation to persons with disabilities, into law. The law required DHS to convene a special task force to study and assess the needs of persons with ASD. The existing ATF fit the role.

The new law also required the Secretary of DHS to submit a full report of the Task Force findings and recommendations to the Governor and General Assembly by September 1, 2005, followed by annual reports by January 1 in subsequent years.

The Task Force and its working committees continue to work toward addressing the needs of persons with ASD, providing substantive input and guidance to the Departments of Human Services, Health and Family Services and the Illinois State Board of Education.

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

- Addressing Early Intervention services for children with autism;
- Enhancing family support mechanisms to enable persons with autism to remain in their homes and communities;
- Transition services from public school services; and
- Feasibility of obtaining federal financial participation and obtaining a Section 1915c waiver for persons with autism.

## **IV. OVERVIEW OF KEY ACCOMPLISHMENTS**

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The full ATF met three times during 2008 – on April 22, August 12, November 18 – utilizing videoconferencing sites in Chicago and Springfield to maximize participation. Key accomplishments this year include:

- Effective July 1, 2007, two Children’s Medicaid Home and Community-Based Services (HCBS)Waivers were approved by the federal Centers for Medicare and Medicaid Services (CMS). Authorized for three years, the waivers cover residential supports in licensed child group homes and home-based supports for children who reside with their families. The current status of the waivers is described in this report.
- In 2008, IDHS and The Autism Program of Illinois collaborated to write and obtain rule changes to include Board Certified Behavior Analysts (BCBAs) as credentialed/enrolled providers for the Early Intervention system. Seven BCBAs have become credentialed. These professionals work with children, parents, and other service providers to improve social, daily living, self care, recreation, leisure, and other developmentally appropriate and functional behaviors.
- The Autism Information Clearinghouse is nearing completion. A mock website has been developed, and is in the final stages of review by the Autism Task Force and IDHS.
- Funding for research and awareness has been made available through the Autism Check-Off Fund and the Autism Awareness Fund.

Other accomplishments:

- PA 95-1005 provides insurance coverage for all individuals under age 21 for the diagnosis and treatment of Autism Spectrum Disorders (ASDs), up to \$36,000 per year. Also known as “Brianna’s Law”, this legislation received overwhelming support from the legislature.
- PA 95-0897 allows for the testimony of a criminal sexual abuse victims affected by a developmental disability, including autism, to be taken outside the courtroom and shown in the courtroom by means of a closed-circuit television.
- PA 95-0226 established the Autism Awareness Fund, supported through issuance and renewal of Autism Awareness license plates. A portion of each original issuance and each renewal fee shall be deposited into the fund. Subject to appropriation by the General Assembly and approval by the Secretary of State, all monies in the Autism Awareness Fund shall be paid to IDHS for the purpose of providing grants for research, education, and awareness regarding autism and autism spectrum disorders.
- PA 95-106 amends the Mental Health and Developmental Disabilities Administrative Act, requiring the Department of Human Services, or independent consultants, to research possible funding for the development and implementation of services for adults with autism spectrum

disorders without mental retardation. A subcommittee of the Task Force is addressing this legislation; their progress is outlined in greater detail later in this report.

- PA 94-442, passed in 2007, established the Autism Research Fund to provide resources for research that will advance the understanding, techniques, and modalities effective in the detection, prevention, screening, and treatment of autism and may include clinical trials. The fund received contributions through an Income Tax check-off program for the taxable year ending December 31, 2005. Due to a limited response, the check-off program was discontinued, but netted \$56,000 total contributions. Implementation of this act requires an administrative rule, which has been drafted and will be submitted to the Joint Committee on Administrative Rules in early 2009. As of December 2008, the amount in the fund has grown to \$62,000 due to accrued interest.

## **V. PROGRESS IN ADDRESSING FOUR AREAS REQUIRED BY PA93-773**

### **A. Early Intervention Services for children with autism and their parents.**

#### **Board Certified Behavior Analysts**

In response to a request from the Illinois Autism Task Force, the Early Intervention program has included Board Certified Behavior Analysts (BCBAs) as credentialed/enrolled providers in the system. Revisions to the Early Intervention Program rule (89 ILL. Adm. Code 500) went into affect on January 23, 2008. BCBAs are now being credentialed and enrolled in the system under the service category Clinical Assessment, Counseling and Other Therapeutic Services.

#### **Transition from Early Intervention to Early Childhood**

A number of recommendations from the Early Intervention to Early Childhood section have involved improving the transition process. Several efforts are ongoing in this area, directed toward ensuring that no child falls through the cracks and that all families receive the necessary supports.

- A family transition workbook, “*When I’m 3, where will I be?*” became available in January 2008. This family transition workbook is a product of the Illinois Birth-5 Transition Guidance Committee in collaboration with the Illinois State Board of Education (ISBE) and the Illinois Department of Human Services (DHS). Parent liaisons and service coordinators from Child and Family Connections (CFC) offices, parent representatives, school district personnel and many others contributed to this workbook. The workbook is given to families in the Early Intervention Program as a resource and planner for their transition from Early Intervention into school district and community programs.
- A statewide transition system, including a data sharing agreement between the ISBE and the DHS, is fully operational. Personally identifiable information and contact information regarding Part C Early Intervention clients are shared for the purpose of transition and Child Find as required by law. A geocoding function has been added to identify a child’s school district based upon his/her home address.
- CFC Offices and LEAs/School Districts continue to use the *Early Intervention to Early Childhood Tracking Form* as part of the transition process to determine eligibility for preschool services. With parent permission, the tracking form is sent to the LEA/School District as part of the referral packet or is given to the LEA/School District representative at the transition meeting. The LEA/School District completes the form and returns it to the CFC within 20 calendar days after the child’s third birthday. The information received from the LEA/School District documents the initiation of Early Childhood services and is entered into the child’s record in the Cornerstone system.
- STARnet and the Early Intervention Training Program continue to provide statewide training regarding the transition of children from early intervention services into early childhood special education services. This is a five-hour training by a panel that includes trainers from STARnet

and the Early Intervention Training Program, someone from the local school district, and a parent liaison.

## **Autism Training**

The Early Intervention Training Program has coordinated several autism-specific training activities including the following:

- On September 16, 2008, 211 Early Intervention professionals and others attended a one-day conference in Fairview Heights, *Trends in Autism and Early Intervention*, sponsored by the Early Intervention Training Program.
- An on-line basic-level autism training (54 hours), developed by Illinois State University/Illinois Autism/PDD Training and Technical Assistance Project, has been converted to the Early Intervention Training Program's on-line platform and made available to CFC staff, Early Intervention providers, and other interested families and professionals. This course includes information on the history of autism spectrum disorder, how it is identified, its current prevalence, and an overview of educational strategies based on areas of concern. There are currently 886 individuals enrolled in the on-line course. Two hundred nineteen individuals have completed the course and received Early Intervention continuing education credit hours. Of those who have completed the course, 23% are identified as administrative, teaching, and/or paraprofessional fields of education; 15% as developmental therapists; 15% as service coordinators; 15% as other professionals in nursing/medical, social work/psychology; 3% as occupation therapists; 3% as physical therapists, 22% as unknown professions, and < 1% as parents.

## **B. Enhancing family support mechanisms to enable persons with autism to remain in home-based or community environment.**

### **Transition of Department of Children and Family Services (DCFS) young people aging out of children's services into DHS Community Integrated Living Arrangements (CILA's)**

DHS continues to work with the Department of Children and Family Services (DCFS) to aid in the transition of state wards, 18 years or older, who have developmental disabilities (including some wards who have autism) and who wish to move from their current children's residential settings into adult developmental disability (DD) residential services.

Consistent with available appropriations, many wards are choosing to move to adult DD CILA's, which provide community-based services in homes for eight or fewer individuals.

## **Autism Information Clearinghouse**

The Clearinghouse Committee has continued to meet and to develop the online Information Clearinghouse. The Autism Clearinghouse Committee worked diligently throughout the year, and was confronted by concerns about the posting of content and the need to provide information suitable for a state-sponsored website. The Autism Task Force has agreed to the design and initial content for the site. The Information Clearinghouse is expected to launch in January, 2009.

The site will be internally hosted by DHS and launch is pending the development of a policy on the posting of new content. The Committee is committed to using the highest standards in evaluating research and proposed content for the site.

## **Adult Services**

The Adult Services Committee of the Autism Task Force has developed the Post Secondary Education to Employment Autism Spectrum Disorder Services Subcommittee (PSEEASDS) to address the needs of the population of adults with autism who do not have mental retardation and who are not supported in postsecondary vocational, educational and employment services. The Subcommittee has met to gather necessary background information on the legislation, and has determined a formal course of action.

This committee has also worked on an agreement with ISBE for ISBE to provide PUNS database information to families.

### **C. Adequate transition services for people with autism from public school programs to adult services.**

#### **Transition Coordinator**

ISBE currently has staff whose focus is placed on easing the transition process for their young people, and IDHS is in the process of hiring a second Transition Coordinator.

As a direct result of a recommendation from the Task Force, IDHS hired a Transition Coordinator to help facilitate the transition from Early Intervention with IDHS to Early Childhood services with ISBE and from Special Education services with ISBE to adult services with IDHS. The Transition Coordinator established a number of important linkages between service providers, the Early Intervention Child and Family Connection centers, and representatives from school districts across the state. The Transition Coordinator also laid the foundation for the development of a resource for families with children transitioning from Special Education services with ISBE to adult services with IDHS. This guide will be designed to assist families in navigating the transition process for their older children.

IDHS is currently in the process of recruiting a new Transition Coordinator. This position will focus on the transition from Early Intervention with DHS to Early Childhood Services at ISBE and from Special Education Services with ISBE to adult services at DHS.

This position will be a high level policy-making position, requiring the coordination and oversight of staff efforts with and between staff from four DHS program divisions: Community Health and Prevention, Developmental Disabilities, Mental Health, and Rehabilitation Services.

Primary duties of the Transition Coordinator are as follows:

- Monitoring the transition processes from EI to school, and assisting in establishing an effective transition process for adults from school to adult services;

- Coordination of the development, implementation, and evaluation of an Intergovernmental Agreement, outlining and defining the roles and responsibilities for educational and non-educational services to children with disabilities; and
- Working with DHS and ISBE staff to outline and/or streamline how all the different agencies work together.

A position description was drafted and circulated to the Autism Task Force for input. The position was posted twice to solicit candidates. The Autism Task Force was asked to pass the posting on to prospective candidates.

DHS expects the Transition Coordinator to start in 2009. The new Transition Coordinator will report to Assistant Secretary Grace Hou.

### **Transition Training**

The Task Force created an ad hoc working committee to develop an orientation and training for the DHS Transition Coordinator and the ISBE transition staff specific to autism.

The committee developed three categories of orientation and training: 1) needs of children and adults with autism spectrum disorders, 2) array of services available, and 3) access to services.

The resultant document outlines core training on Autism Spectrum Disorders and the visitation opportunities that will be made available with agencies serving children and adults with autism in early intervention, high school and adult services across the state.

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

Effective July 1, 2007, two Children's Medicaid Home and Community-Based Services (HCBS) Waivers for children and young adults with developmental disabilities (including children with autism) were approved by the federal Centers for Medicare and Medicaid Services (CMS).

The waivers are authorized for an initial period of three years and cover residential supports in licensed child group homes and home-based supports for children who reside with their families. The waivers were outlined in greater detail in last years report. Key elements of the waivers are outlined below.

### **Children's Support Waiver**

The Children's Support Waiver covers children and young adults (age's three through twenty-one) with developmental disabilities (including children with autism) who live at home with their families.

In 2008 the approved waiver capacity was increased from 600 to 1100 participants. One-hundred percent (100%) of the federal matching funds generated by this program are deposited in a special dedicated fund that is appropriated to the Department to provide funding to serve additional families. New enrollees are selected from the Prioritization of Urgency of Need for Services (PUNS) database.

The Waiver is designed to be similar to Home-Based Support Services in the adult DD waiver to facilitate a seamless transition to adult services between the age of 18 and 21. Services are limited each month by the individual service plan up to the maximum allocation. The current calendar year 2008 maximum allocation is \$1,274 per month.

For participants who choose to self-direct, the Waiver includes a Fiscal/Employer Agent (FEA) to conduct required background checks and issue payroll for domestic employees, such as individual Personal Support workers, hired by the participant, guardian or representative.

Covered Services include:

- Service Facilitation/case management
- Personal Support (includes in-home respite in definition)
- Behavior Intervention and Treatment
- Training and Counseling for Unpaid Caregivers
- Home/Vehicle Modifications, Adaptive Equipment and Assistive Technology
- Individual Service and Support Advocacy (ISSA) for each participant

### **Children’s Residential Waiver**

The Children’s Residential Waiver provides residential habilitation in a licensed child group home for children and young adults (age’s three through twenty-one) with developmental disabilities (including children with autism) who require this service.

The approved waiver capacity is 175 participants. No expansion of this waiver is planned at this time. However, as attrition occurs, funding will become available for new applicants for this service.

Services are designed to be very similar to the current adult DD waiver to facilitate a seamless transition to adult services between the age of 18 and 21.

Covered Services include:

- Child Group Homes (licensed by the Illinois Dept. of Children & Family Services (DCFS))
- Adaptive Equipment and Assistive Technology
- Behavior Intervention and Treatment
- Individual Service and Support Advocacy (ISSA) for each participant

### **Overview of 2008 Waiver Activities**

During 2008 the Children’s Support Waiver (CSW) was expanded to serve additional children and their families using one-time Hospital Tax funds and federal matching funds deposited in the dedicated fund. Of the almost 1,000 children receiving services in 2008, over half (51%) are children with a reported diagnosis of autism or an autism spectrum disorder. In addition to the number currently receiving services, in late 2008, 180 letters were issued to families of children seeking services and registered on the PUNS database inviting them to apply for the CSW. Depending on available total funding and the number of children determined eligible, the waiver capacity may be increased in 2009.

Of the approximate 175 children receiving residential supports in licensed child group homes during 2008, approximately 49% are children with a reported diagnosis of autism or an autism spectrum disorder.

## VI. PARTNER ACCOMPLISHMENTS

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The Illinois Department of Human Services collaborates with 350 partners throughout the state who serve individuals and families affected by autism every day. Included here are some of their accomplishments.

- In FY 2008, The Autism Program Service network, through a competitive bid process, increased services to families and community providers through development of:
  - Seven new Service Centers (Easter Seals Rockford, Easter Seals Metro Chicago, Trinity Services, Kreider Services, Easter Seals Peoria-Bloomington, Easter Seals Southwestern Illinois, Charleston Transitional Facility);
  - Two new Outreach Centers and Collaborative Funding to Easter Seals LaSalle-Bureau County, and Illinois Center for Autism;
  - Nine new Centers to work in collaboration with The Autism Program's existing training centers (University of Illinois-Institute for Juvenile Research; University of Illinois-Urbana Champaign; Illinois State University; Hope Institute for Children and Families; Southern Illinois University-Carbondale
- In FY 2008, The Autism Program of Illinois provided 8,207 clinical contacts and 13,120 resource and referral supports, trained 4,852 parents and providers, distributed 18,108 free learning aids, and raised awareness through 10,268 community contacts.
- The Puentes Project is a program operated through Illinois Masonic Hospital in Chicago which provides Early Intervention services and training to families affected by autism. These services support and sustain positive outcomes for individuals with Autism Spectrum Disorders.
- The Illinois Center for Autism provides a variety of services for individuals with autism. Of particular note is the Illinois Center for Autism's Pasta Fare Program. The Pasta Fare Program is a supportive employment grant-funded program that employs 23 individuals with autism. Pasta Fare operates a store that sells pasta, as well as a restaurant. Persons with autism work in both the restaurant and storefront operations.
- PACTT Learning Center continues to provide services to children and adults with autism through a children's group home, a Community Integrated Living Arrangement (CILA), and Supported Employment.

## **VII. ADDITIONAL WORK TO BE DONE / NEXT STEPS**

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As this report describes, much progress has been made on the ATF priorities. Yet, much work remains in order to accomplish the spirit and intent of the ATF recommendations and better meet the needs of persons with ASD and their families.

In January 2009, the **Autism web presence** is scheduled to be available to families.

A new IDHS **Transition Coordinator** will begin, with the first steps being training and developing an Interagency Agreement with ISBE.

Medicaid claiming will continue for the **two children's waivers**, bringing new federal funding into Illinois for expansion of services.

The **Adult Services** committee will continue to refine recommendations for individuals transitioning from Special Education services to adult services. The Post Secondary Education to Employment Autism Spectrum Disorder Services Subcommittee (PSEEADSDS) of the ATF will assist DHS in the research of possible funding for the development and implementation of services for adults with autism spectrum disorders without mental retardation.

A rule will be submitted to JCAR to release the funds in the **Autism Research Fund Tax Check-off fund**. IDHS will utilize the \$62,000 in the fund, and IDHS will explore the impact of recent legislation (PA 95-0226, the **Autism Awareness Fund**) and leverage the funds to maximize the impact on autism research and awareness in Illinois.