

**REPORT OF THE AUTISM TASK FORCE:
FINDINGS AND RECOMMENDATIONS**

**Bennett Leventhal, M.D., Co-chair
Brian Rubin, J.D., Co-chair**

Illinois Department of Human Services

**Carol L. Adams, Ph.D.,
Secretary**

ILLINOIS AUTISM TASK FORCE MEMBERSHIP

Ms. Ellen Adcock, Foundation for Autism Services Today and Tomorrow (FASST)/Parent
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Ms. Kathy Baumann, Family Counseling Center/Parent
The Honorable Patricia R. Bellock, State Representative 47th District
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Mr. Christopher M. Kennedy, Parent/Autism Society of Illinois*
Dr. Bennett Leventhal, University of Illinois Chicago*
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Dr. Marie Weissbourd, Developmental Evaluation Clinic
Ms. Christine Thornton Wiener, Giant Steps
Ms. Georgia Winson, The Autism Program

* *Chair or co-chair of a committee.*

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Ms. Barb Ginder, Department of Healthcare and Family Services
Dr. Mark Holzberg, Department of Children and Family Services
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I. Introduction

Autism Spectrum Disorder (ASD) is widely recognized as an urgent national healthcare crisis. According to the Center for Disease Control, the prevalence rate is 0.6%, or one in every 166 children born today. This represents a drastic change from past prevalence rates. According to the Center for Disease Control, classic Autism consistent with the Diagnostic Statistical Manual IV diagnosis occurs at a rate of one in 1000 individuals. When individuals within the Autism Spectrum are considered, including pervasive developmental disorders (PDD), one in 500 is diagnosed. When Asperger's Disorder is considered, one in 166 individuals is diagnosed. In Illinois, as recently as the 1996-97 school year, only 1,980 students age 3-21 were served by the public school system under the special education category of Autism. During the 2002-03 school year, 6,125 children were receiving special education services under the Autism category. However, by 2004, 8,076 students were listed, a 32% increase in only one year. The dramatic increases experienced in Illinois are consistent with increased prevalence nationally.

Illinois has undertaken several initiatives in the last eight years to address the impact of ASD. The Illinois General Assembly commissioned The Autism Program (TAP) which addresses the needs of ASD-challenged children in the areas of screening, identification, diagnosis, programs and services, workforce development, and research. Equally important has been the Illinois State Board of Education's (ISBE) sponsorship of the Illinois Autism Technical Assistance and Training program, which provides professional development and training to local school districts and special education cooperatives. ISBE has also sponsored Giant Steps, a school with a professional best practices curriculum for ASD challenged children. Additionally, DHS has sponsored the Early Intervention Program (EI), which provides services to children birth to three years of age.

Given the impact of ASD on families across the state, the Illinois Department of Human Services (DHS) led the development of a multi-agency Autism Task Force on April 27, 2004. DHS recruited parents of children and adults challenged by ASD, representatives of State agencies, healthcare professionals, service providers, academic professionals, and members of the legislature to serve on this task force. Bennett Leventhal, M.D., a leading medical expert in ASD, and Brian Rubin, a parent of a child with ASD, were selected to co-chair the Task Force.

DHS Secretary Carol L. Adams designated Assistant Secretary Grace Hou to facilitate the group, which met for the first time on April 27, 2004. The charge to the Committee included five goals:

1. to provide initiatives to promote best practice standards for diagnosis and treatment within existing systems of care;
2. to provide educational opportunities throughout the State on diagnosis and treatment;
3. to support existing systems of care for persons with ASD across the life span
4. to work with universities and providers to identify untapped resources and unmet needs;
5. to encourage and support research efforts on services to persons with ASD across the life span.

Since its inception, the Autism Task Force has met numerous times to discuss its visions and recommendations for how the State of Illinois might better serve families and individuals across

the life span impacted by ASD. The Autism Task Force established the following committees to assess and study: a Transitions Committee with subcommittees for Early Intervention to Early Childhood, High School to Adult Life, and Seniors with ASD; Medicaid Waiver; Information Clearinghouse; Research/Training/Workforce Development; and Insurance.

The momentum and energy of the Autism Task Force dovetailed into complementary action by the Illinois legislature. On July 21, 2004 Governor Rod Blagojevich signed Public Act 093-0773, An Act in Relations to Persons with Disabilities, into law. PA 093-0773 directed DHS to convene a special task force, such as that described above, to study and assess the service needs of persons with ASD. The Act further required that the Secretary of DHS submit a report of the Autism Task Forces's findings and recommendations to the Governor and General Assembly by September 1, 2005. The Autism Task Force is on schedule to deliver the report. The State agencies will continue to consult with the Autism Task Force as they develop priorities and develop an implementation plan to reflect that report.

II. Preliminary Plan

A. Vision Statement: *In Illinois, people with Autism and autistic spectrum disorders and their family members will be able to readily access an array of effective services that meet their functional and clinical needs across the life span.*

B. Mission Statement

The Autism Task Force convenes family members, service providers, educators, legislators, departmental staff, other professionals, and researchers to study and assess the needs of people with Autism and ASD across the lifespan. The Autism Task Force will report on the status of home-based and institutional care; access, availability and responsiveness of services; state of the workforce; financial options for potential expansion of services, recent research and epidemiology; and any other factor that emerges as a challenge or opportunity for advancement of an array of effective services. The Autism Task Force will recommend short and long term strategies for consideration by the General Assembly that achieve the vision of a public system where Illinois citizens with ASD and their families may readily access an array of effective services to meet their functional and clinical needs across the lifespan.

C. Preliminary Plan

This Preliminary Plan is divided into two sections. The first section describes a set of guidelines and principles that can serve as a "Road Map" toward implementation of an effective and efficient system of services for individuals and families impacted by ASD. The section is organized into five areas of focus, which includes Policy, Funding, Workforce Development, Research, and Information. The second section outlines immediate steps that can be taken to lay the foundation for building a system that is appropriate and responsive to the needs of Illinois' citizens.

D. Road Map

1. An effective and efficient system of services for individuals with ASD crossing the entire lifespan must be supported by sound policy.

The following Principles for System Effectiveness should be included in any and all policy decisions:

- Consumers/Stakeholders driven;
 - Outcome focused;
 - Data-driven decision-making;
 - Address entire autistic spectrum;
 - Address needs across the lifespan;
 - Family focused;
 - Community based and least restrictive;
 - Responsibilities and accountability specified;
 - Cultural inclusion/sensitivity;
 - Individualized treatment based on need and preference;
 - Coordinated and collaborative care;
 - Preservation of confidentiality.
- a) Administrative Policy must be driven by consumer needs, be responsive twenty-four hours a day and seven days a week, be available within a reasonable distance, have the capacity to respond immediately if necessary, have multiple portals of entry and define default accountability.
 - b) The system must encourage reliance on sound evidence-based and evidence supported practices.
 - c) There must be a commitment to maintenance and advancement of measurable quality standards.
 - d) The system must be able to bridge inevitable gaps in service and force accountability in coordination of efforts – it must not be defined by exclusionary interpretations or other artificial references that serve to limit or obfuscate accountability and responsibility.
 - e) The system must recognize the importance of transitional phases of treatment based on changing clinical need and personal or chronological development and establish policies that support a continuum of services tailored to meet individual needs.
 - f) Rules/Codes/Legislation must clarify accountability within government, allow for “right sizing” of capacity based on prevalence data, mandate that school districts provide access to appropriate educational services, support appropriate information technology, and support efforts to inform and educate the public.
 - g) Effective policy must require a commitment to field test programs and develops supportive administrative structures and supports. Experience dictates that there are dependable components to the successful implementation of service programs:
 - Research supported;
 - Entry upon diagnosis;
 - Intensive Instructional Program 5-7 days a week year round;
 - Repeated teaching opportunities of short intervals;
 - Inclusion and support of parents and caregivers;
 - Low student: teacher and person: staff ratios;
 - Commitment to outcomes and evaluation.

2. **Any and all funding sources must be accessed in order to adequately finance a system of services for individuals with ASD across the lifespan.**
 - a) Establish presumptive eligibility for Medicaid as an important potential funding source for individuals that would support a fee-for-service approach to financing, as many individuals are determined ineligible for disability despite high likelihood of unemployment and limited or no access to private insurance.
 - b) Develop and submit a waiver for children with ASD.
 - c) Revise adult DD waiver in regards to service availability and rates.
 - d) Review the procedure for “disability determination” to assure consistent application of criteria that optimizes inclusion of individuals with ASD
 - e) Review current Early Prevention Screening Detection and Treatment (EPSDT) implementation: it is essential that primary care clinicians be reimbursed in a manner that encourages screening and assessment of social and emotional functioning in children.
 - f) Design funding to promote evidence-based and evidence-supported services.
 - g) Include within the array of covered services appropriate assessment strategies and use of field-tested diagnostic instruments, speech and language evaluation, and applied behavioral analysis.
 - h) Arrange the financing of the system in order to recruit, secure, and maintain an appropriately skilled workforce that is culturally and linguistically diverse.
 - i) Design the financing system so as to propel broad availability of home-based services.
 - j) Mandate insurance coverage for ASD. Currently this diagnosis results in declinations for some applicants, while even covered individuals face exclusions and limitations. Many proven treatments are capped below necessary levels or excluded entirely. When available, many professionals and parents are forced to use diagnosis codes for related or comorbid conditions.

3. **The State must be committed to recruiting and maintaining a workforce of clinicians and practitioners with the right skills to assist individuals and families with ASD across the lifespan.**
 - a) Provide training and education in multidisciplinary settings: EI, DD, MH, School, Rehab, and Primary Health Care in assessment and treatment across the lifespan
 - b) Provide skills training to front line support staff, family members and caretakers, teachers, and others to assist with development of practical skills to address day to day occurrences.
 - c) Involve higher education – a workforce must be developed with the skills necessary to assist individuals with ASD in educational and vocational efforts in all developmental stages.
 - d) Create positions in the workforce, such as a “Transition Specialist,” with age specific and transition specific competencies to address the unique challenges of cohorts who find themselves in transitional stages: e.g. early childhood, adolescence, young adulthood, middle age, and seniors.
 - e) Ensure that the use of standardized assessment instruments is appropriate.
 - f) Develop a workforce with interest to understand the impact of behaviors/aggression on subjective measures such as quality of relationships and community integration.
 - g) Train for care taking across the lifespan – group home industry, nursing homes and/or natural supports.

- h) Establish a commitment to retraining - keeping core competencies up to date with new evidence based approaches.
 - i) Recruit a culturally and linguistically competent workforce, which reflects the diversity of the individuals being served.
- 4. An important function of the State is to promulgate scientifically supported standards of care and to advance the body of knowledge in the area of autistic spectrum disorders.**
- a) Families must be able to choose from an array of scientifically supported options and need information to make informed decisions.
 - b) Establishment of the Cross-Disabilities Database (including the developmental disabilities PUNS or Prioritization of Urgency of Need for Services database) and the Autism Registry and Reporting Act within the Department of Public Health (DPH) should lead to data for research into both services and public health aspects of ASD in Illinois.
 - c) Parent and family partnership in clinical service systems research should facilitate the development and implementation of programs that support individuals with ASD.
 - d) Despite much advancement in understanding the basic science of Autism, it remains a mystery and the State should support this research, which will one day reduce the financial burden to taxpayers.
 - e) The State should promote the establishment of centers of excellence for ASD.
 - f) The State should incorporate advances in biomedical, behavioral, and psychosocial interventions into programs and practices for persons with ASD.
 - g) Scientific studies should take into consideration what parents report anecdotally as being effective for their children.
- 5. The State must provide information about ASD and the availability of services.**
- a) A public campaign should disseminate information on developmental disorders and Autism
 - b) Autism services should have their own web link in the DHS web site to direct and inform stakeholders and families.
 - c) A newsletter should be published with up-to-date information including news from the research front, treatment success stories, and coordination efforts across multiple domains and agencies.
 - d) Outreach efforts should provide accessible referral sources.
 - e) Primary care physicians, pediatrics, internists, and family practitioners should be engaged in outreach and education efforts.
 - f) Focus should concentrate on family linkages and supports to establish networks for crisis response.
 - g) Linkages should be developed for direct consumer resources that support independent living and practical problem solving strategies.

III. Transition Committee

Committee Members: Terry Herbstritt – Chairperson, Elizabeth Abraham, Ellen Adcock, Patti Boheme, Kim Cooper, Ann Cutler, Mary Anne Dzik, Bill Ferguson, Seth Harkins, Georgia

Hillyer, Steve Hoffman, Renee Lumpkin, Elina Manghi, Brendan McCormick, Barbara Murphy, Bob Okazaki, Lori Orr, Aimee Pfister, Consuelo Puente, Brian Rubin, Kathy Schrock, Ruth Ann Sikora, Jenny Simone, Phil Vitkus, Cheryl Walton, Nadine Woodle.

A. Early Intervention to Early Childhood

1. Findings: What's Working

- a) There is a definitive transition process. Child and Family Connections (CFC) agencies follow the transition process, except when school districts alter that process.
- b) Through various efforts, more professionals (e.g. pediatricians) are being made aware of the early signs of Autism so more young children enter public school with ASD diagnosis.
- c) Parents are more prepared to transition their child because of the support they receive from EI services.
- d) Many parents are using medical diagnostics for ASD through the EI system so some children with ASD have a diagnosis when they enter public school.
- e) Some children with ASD are more prepared to enter early childhood education programs because EI programs are preparing them to enter structured settings.
- f) There are some center-based EI programs and demonstration programs that specifically specialize in ASD and offer structured groups, which in turn help the children to transition to early childhood group settings.
- g) Good working relationships between the schools and CFCs help the child and the family more easily makes the transition.

2. Findings: Challenges

- a) Programs and Services
 - 1) Differences in mandated models of intervention between IDEIA and Early intervention create conflict and confusion for families of children with ASD in transition.
 - 2) More uniformity in the schools' transition process is needed. Most schools vary in how they implement the transition process. The CFCs have to alter their transition process for each different school district. CFC representatives stated they have different procedures for transition for most of their school districts.
 - 3) There is a need for schools to serve children immediately when they turn three years old. Some school districts wait several months before providing services.
 - 4) School programs need to review early intervention discharge reports in order to prepare them to best work with a child.
 - 5) Gaps in services occur in the summer. When children turn 3 years old in the summer, school districts provide minimal to no services. Families can go from having speech, occupational therapy, and developmental therapy provided to their children once a week, to no services for several weeks. Some districts will pay for a child to continue in EI through the summer, but that is rare. Having school districts pay EI to continue services could help deal with this problem.
 - 6) Children with ASD need to be in an early intervention program that provides them with the right type of structured experience that will enable them to transition successfully into an early childhood structured group setting. An early intervention model can be developed that enables providers to offer

children with ASD an environment that lets them experience and get accustomed to a structured group setting to prepare them for the transition to early childhood education services. There needs to be a continuum of least restrictive services for children with ASD.

- 7) Children with ASD need to have their mode of communication transition with them, even if it is different from what the school district uses. The school district often transitions the child to a new communication system, losing continuity.
 - 8) There is a lack of normed standards and reliable qualitative indicators for programs serving children with ASD.
- b) Legal Issues and Conflict Resolution
- 1) Some school districts interpret the law in a way that enables them to delay services to the child. There is a need for clarification of the education laws that regulate transition from early childhood. The interpretation of law that regulates transition from EI to EC varies significantly with each school district.
 - 2) There is a need for an early intervention representative at the Individualized Education Program (IEP) meetings, if a parent requests one. Parents need support when going through the transition process. Parent mentors or parent liaisons are very helpful.
 - 3) Parents lack information and access to legal advocacy.

3. Recommendations

a) Programs and Services

- 1) ISBE and DHS should require all parties involved – ECEs and EIs and parents – to follow the already well-defined transition process presented in the DHS Early Intervention Procedure Manual
- 2) DHS should examine the feasibility of extending EI programs to age 5 at parent option, pursuant to Section 635c of IDEIA.
- 3) Individual Family Service Plans (IFSPs) should include outcomes to enable children to successfully enter into early childhood structured group settings. EI service programs should provide children with ASD a structured group setting (play groups, day care centers, preschool programs, etc.) prior to transition to an ECE program. Professional best practices should guide and direct this process.
- 4) Children with ASD should be able to use the mode of communication they are accustomed to as they enter the school system, then, as appropriate, train the children in modes of communication equal to or better than the ones they used upon entering ECE.
- 5) ISBE and DHS should make all efforts to enhance the promotion of functional verbal speech as the primary means of communication for all children with ASD to the fullest extent possible for each individual.
- 6) DHS and ISBE should define the array of services and appropriate conditions for choosing each service within the continuum and establish quality indicators or program standards.
- 7) DHS should require EI service providers to encourage parents to sign releases of information to send EI records, including initial reports, to facilitate a smooth transition to ECE services. Parents should be encouraged to sign consent for the case study evaluation at 30 months to ensure a decision

regarding eligibility is made by age three. EI providers must continue to provide summative (discharge) reports not later than age 3.

- 8) The State should establish advocacy programs to allow for increased access to legal services for parents of children with ASD.
- 9) DHS and ISBE should establish minimum standards and/or program quality indicators, in order to promote higher quality programs and consistency between EI and ECE.

b) Legal Issues and Conflict Resolution

- 1) ISBE should educate parents on their FAPE (free appropriate public education) rights and procedures and the process to follow when services are delayed or not provided. Families should understand that, if their early childhood education services do not begin at age 3, they are entitled to pursue a due process hearing.
- 2) DHS and ISBE should conduct an educational campaign to educate EI personnel and ECE administrators and special education staff regarding special education regulations and case law about EI to ECE transition.
- 3) For children who do not enter EI services until age 30 months, EI and ECE providers should collaborate to ensure the case study evaluation is completed in time for the child to begin ECE services upon the child's third birthday (and with no delay).
- 4) ISBE should direct local school districts to follow the Individuals with Disabilities in Education Improvement Act (IDEIA) rules to consider Individualized Family Services Plans (ISFPs) when developing the Individualized Education Program (IEP).
- 5) ISBE should modify special education regulations to require school districts to either provide ECE services or to provide funding for EI services for children who turn age 3 during the summer months when school is not in session.
- 6) DHS and ISBE should collaborate to ensure that an early intervention representative is present at the transition meeting from EI or ECE meeting, regardless of whether that transition meeting occurs before or after the third birthday. An appropriation to facilitate EI representation at ECE IEP meetings after age 3 is necessary.

c) Training and Professional Development

- 1) DHS and ISBE should inform parents about the differences in EI and ECE services and train parents to cope with their changing role as their children move from EI to ECE services.
- 2) DHS and ISBE should conduct workshops to define a single, seamless model of transition from EI to ECE services.
- 3) DHS and ISBE should train local EI and ECE service providers in collaboration.
- 4) DHS and ISBE should establish certification programs for providers and teachers to specialize in ASD.

d) Dissemination of Information

- 1) DHS should direct EI service providers to provide information about the ECE services and to connect parents to information (e.g. online), advocacy, and support services (e.g. parent groups) for transition.
- 2) DHS should conduct an educational campaign to educate pediatricians/physicians to refer parents to CFCs that can refer the parents for medical diagnostics.

- e) Monitoring and Accountability
 - 1) ISBE should increase monitoring and accountability for ECE programs to begin services at the proper, legally defined time.
 - 2) ISBE should direct and hold accountable ECE service providers to start the case study evaluation at 30 months for children with Autism or ASD, so they enter school at age 3 with an appropriate ASD diagnosis.
 - 3) ISBE should enforce Illinois rules and regulations for IDEIA 2004, ensuring that highly qualified teachers and related services providers (Occupational Therapists, Physical Therapists, Psychologists, Social Workers, etc.) credentials include training in ASD characteristics and educational and intervention methodologies.

B. High School to Adult Life

1. Findings: What's Working

- a) Some secondary school programs include transition-focused education (e.g. Secondary Transition Experience Program [STEP], Vocational Alliance Autism Project, and Business Approach to Social Integration and Communication [B.A.S.I.C]) that have demonstrably supported successful transitions from secondary to post-secondary settings.
- b) Some high schools and community colleges are collaborating to provide programs for 19-21 year old students with ASD, who are high functioning or dually diagnosed (mentally ill and developmentally disabled).
- c) Vocational Alliance Autism Project and B.A.S.I.C. are programs focused on vocational skills and thus prepare students with disabilities for competitive employment, supportive employment, vocational education, life skills education, or other post secondary educational settings.
- d) The Illinois State Board of Education's Transition Outreach for Training for Adult Living (TOTAL) ensures that training and technical assistance to position transition planning at the beginning of the high school Individualized Education Program (IEP) development process
- e) State-funded agencies (for example, Department of Human Services/Developmental Disabilities, Illinois Board of Higher Education, and Illinois State Board of Education) provide assessment, individual planning, advocacy, and referral services for individuals with ASD.
- f) Public Act 093-0773 and the creation of The Autism Task Force is a sign by the Illinois Legislature and DHS of commitment to meeting the transition needs of children with ASD.
- g) DHS Division of Developmental Disabilities has created a cross-disability database (PUNS – prioritization of urgency of need for services) so that individuals with disabilities, including individuals with ASD, can be identified, categorized, and prioritized.
- h) The 1990, 1997, and 2004 reauthorization of the Individuals with Disabilities in Education Improvement Act (IDEIA) includes the requirement for objective, measurable, post secondary transition goals and objectives. This includes the need for developing functional living skills.
- i) Legislators, state agencies, and the public are becoming increasingly aware of the needs of individuals with ASD, especially students and young adults and their need for transition planning and services.

- j) There are pockets of successful collaborations (school, family, agencies) that can guide other groups involved in the transition planning and services to individuals with ASD.
- k) There are pockets of successful family and/or business collaborations that can guide families in alternative approaches to employment for individuals with ASD.
- l) Proactive planning and advocacy by consumers (individuals with ASD and their families) are increasing.
- m) Public Act 093-0773 and the creation of the Autism Task Force demonstrate an investment in transition planning and services.

2. Findings: Challenges

- a) State Culture and the Overall System
 - 1) There is cultural resistance to changing the system in regard to funding and implementation of community-based programs and an array of individualized services and supports for the unique needs of individuals with ASD.
 - 2) The problems are systemic and affect post-high school education, vocational training, life skills, housing, transportation, recreation and leisure, and community integration.
 - 3) There are insufficient statewide technical support and training systems for interacting and educating individuals with ASD for the educational systems, and no support and training system for young adult service providers.
 - 4) There is a lack of coordinated, integrated services. There is a lack of mutual ownership of responsibilities and interagency cooperation.
 - 5) No one at the state level “owns” the transition process; consequently there is no one at the highest levels of Illinois agencies that can educate others, champion the process, and elevate this essential process among DHS, ISBE, and other agencies.
- b) Funding
 - 1) State educational and post secondary school services systems provide insufficient support funding and implementation of community-based individualized services and support in the areas of post-high school education, vocational training, life skills, and housing, recreation and leisure.
 - 2) There is insufficient funding for individualized and appropriate least restrictive services. Insufficient funding or illogical funding formulae exist for providing individualized and appropriate services in the least restrictive environments for many individuals with ASD.
 - 3) There is a gap in funding an array of community-based services. IDEIA is an underfunded mandate.
- c) Programs and Services
 - 1) There is a lack of “extended school day services” (i.e., providing services and supports to enable continued educational services beyond the typical school day – for example, between 3:00 p.m. and 6:00 p.m.
 - 2) There is a lack of ownership of “extended school year” services (beyond the typical 9-month school year).
 - 3) There are extremely few post-high school services and fewer that are effective. Few community-based agencies exist to provide services to students with ASD while students are in high school and after they exit the high school setting.
 - 4) Some schools fail to provide functional skill training for students with ASD, as required by federal law. There are few community-based life skill programs

available to students. School is primarily focused on “academics” with insufficient focus on individualized, functional living skills to ready students with ASD for targeted post-secondary programs.

- 5) Transition planning is on a low priority list. Technical assistance in this area is largely unavailable for schools. The transition plan does not drive the IEP process in high school. Consequently, there is a lack of focus on transition results. Schools do not adhere to best practices in transition planning, where the transition plan drives the development of the IEP (i.e., determining courses of study and training throughout the high school years). Many schools do not develop appropriate IEPs. There is often a lack of alignment between the desired post-secondary transitional goals and objectives.
 - 6) School staff who work with transition-aged youth are very often not aware of how ASD presents in individuals – some school staff misinterpret some behavior of individuals with ASD as disciplinary problems. School staff sometimes do not respond with an educational approach that matches the learning styles of individuals with ASD; they consequently “teach” but with little or no results.
 - 7) Post-high school agencies do not provide continuing training programs that promote continued performance of skills learned while in high school by individuals with ASD. Consequently, individuals with ASD do not maintain skills because they do not continue to use the skills learned during the high school years.
- d) Legal Issues and Conflict Resolution
- 1) There is often a barrier in communication among schools, families, and non-educational agencies. Consequently, there is often conflict between schools, families, and non-educational agencies.
 - 2) Information is not disseminated to parents of children with ASD regarding rights, laws, procedures (i.e., how to “navigate” the system) and their children’s entitlements while they are in school and beyond. Consequently, many parents do not understand the laws and the rights and entitlements they and their children have while their children are in high school, and how that differs from when their children exit high school.
 - 3) Some parents do not accept the disability and do not recognize the implications that ASD has on future education, employment, and living options.
- e) Dissemination of Information
- 1) Parents, school personnel, and agency staff often do not know how to perform results-driven planning or how to provide effective transition services.
 - 2) There is a lack of continuity in student skill training between schools and non-educational service providers.
 - 3) There is a lack of centralized dissemination of transition data and services.
 - 4) Some school “transition teams” are not knowledgeable, and some do not assume responsibility for communicating government programs and services available to families and individuals with ASD.
 - 5) There is a lack of education and training of students in self-advocacy.
 - 6) High school vocational/technical opportunities are lacking for children with ASD.
- f) Professional and Workforce Development

- 1) There are very limited professional development and training in the area of transition for post-secondary service providers. Community-based, non-educational agency staff does not understand the area of transition or the needs of individuals with ASD. Nor do they provide services that effectively facilitate the movement of individuals with ASD to post-secondary settings, including employment, housing, recreation and leisure, and community participation.
 - 2) Teacher education graduate programs do not always include field-tested best practices for transition planning and services for individuals with ASD.
 - 3) There are insufficient qualified personnel and multiple, confusing job descriptions. The transition specialist labor pool is limited and there are few transition specialists, who by the nature of their position facilitate transition.
 - 4) Transition planning technology is underutilized. Most schools and families are unaware of technology that enables individuals with ASD and their families to do effective transition planning and create digitized individualized transition plans that link to local community providers.
- g) Community Integration
- 1) There are few opportunities for community experiences and involvement – for example, employment, volunteering, or recreation and leisure – for individuals with ASD.
 - 2) There are limited wage earning employment opportunities available to young adults challenged with ASD.
 - 3) There is limited appropriate housing and limited funding to support independent or supported living.
 - 4) There is a lack of involvement, on a community-wide basis, for inclusive living. Community governments, as a whole, do not support inclusive living for individuals with ASD.
 - 5) Transportation is a significant barrier to successful transition from adolescence to young adulthood. There is insufficient public transportation that would otherwise permit individuals with ASD to participate in a wide range of community-based employment, living, and recreational and leisure opportunities.

3. Recommendations

- a) State Culture and Overall System
 - 1) DHS and ISBE should create an Interagency Coordinator and an Interagency Agreement. The Interagency Coordinator should coordinate the development, implementation, and evaluation of an Interagency Agreement, which should define the roles and responsibilities for educational and non-educational services to children with ASD. The Interagency Coordinator should be a transition specialist who champions the cause of transition within and among agencies. The Interagency Coordinator should report to the Secretary of the Department of Human Services and Illinois State Superintendent and work in collaboration with the Interagency Coordinating Council. The Interagency Coordinator should ensure that an Interagency Agreement would provide statewide technical support and training and dissemination of information on transition through an entity like StarNet for early intervention. The Interagency

- Agreement should require a coordinated implementation of high quality community-based services and supports for individuals with ASD.
- 2) DHS and ISBE should create a memorandum of understanding that defines the roles and responsibilities among the schools and non-school agencies, creates an integrated transition plan document that works across education and human services, delineates roles and responsibilities for transition planning from secondary school to post-secondary adult services, and promotes appropriate outcomes and facilitates the seamless provision of services.
- b) Funding
- 1) Additional funding must be appropriated to DHS and ISBE to fund the development, implementation, and evaluation of models of appropriate arrays of services that facilitate the community integration of individuals with ASD.
 - 2) DHS and ISBE should create funding incentives for adult service providers to develop, implement, and evaluate model transition programs for individuals with ASD.
 - 3) DHS and ISBE should create an integrated transition plan document that can function across agencies.
 - 4) ISBE should receive an appropriation sufficient to implement an improved system of monitoring and enforcing appropriate individualized student transition plans that are in compliance with federal law. This accountability process should ensure timely interactions between family members and school services providers; include the student in the planning process; and promote transition plans that reflect the students' strengths, preferences, and interests; promote measurable appropriate post-secondary goals; develop or identify age appropriate transition assessments; and ensure the provision of a full array of transition services.
 - 5) ISBE should be appropriated sufficient funding and resources to create transition services at the local school district level that include vocational/technical opportunities for students with ASD. The capacity of S.T.E.P. should be expanded.
 - 6) Funds should be appropriated for ISBE to promote field-based research and best practices for facilitating effective transitions for high school students with ASD.
 - 7) DHS and ISBE should fund community outreach coordinators who can educate communities on the benefits and approaches to including individuals with ASD within community activities.
 - 8) Funds should be appropriated to DHS and ISBE so that regional models of community integration programs can be created that address employment, housing, recreation and leisure, transportation, and community support for youth with ASD.
 - 9) ISBE should be sufficiently funded to provide incentives to local education agencies to increase community-based life skills training programs for students with ASD. There needs to be a balance of academic and community-based learning time.
 - 10) Funding to DHS should be increased to develop young adult services for community integration, including vocational/technical education, employment training, housing, transportation, and recreation and leisure.

- c) Programs and Services
 - 1) DHS and ISBE should purchase, implement, and evaluate statewide transition planning software for school district personnel, students, family, and adult providers for: transition planning, transition assessment, linkage to community resources, end of high school summary, and post-high school tracking.
 - 2) ISBE should take advantage of federal grants, which identify field-tested advocacy curriculum models. Training should be conducted in self-advocacy for school personnel and parents, and local education agencies should promote self-advocacy training in transition plans for students with ASD, when appropriate.
- d) Legal Issues and Conflict Resolution
 - 1) DHS and ISBE should amend regulations to mandate inclusion of adult service providers in the transition-focused IEP meetings; and to make available adult service provider staff for the meeting. An appropriation sufficient to support this is necessary.
 - 2) DHS and ISBE should adopt, implement, and evaluate a mediation model to diminish conflicts between families, schools, and agencies, and to promote interagency cooperation and seamless transition. An appropriation is necessary to fund this new service.
 - 3) ISBE should revise the Illinois Special Education Regulations to require schools to collaborate with adult service providers while students are still in school and no later than the school year the student turns 16 and to articulate the student's transition plan to community service providers (no later than the beginning of the last year of high school).
 - 4) DHS and ISBE should provide school-family-agency communication training regarding families of children with ASD in the following areas: family dynamics; divergent expectations of students with ASD between families, schools, and agencies; collaboration; and mutual challenges.
- e) Dissemination of Information
 - 1) DHS and ISBE should create a central clearinghouse for information about ASD so that there is a single point of entry of information services about ASD.
 - 2) DHS and ISBE should widely disseminate information about ASD to parents and communities through the centralized clearinghouse referenced above.
- f) Professional and Workforce Development
 - 1) DHS and ISBE should develop and support a statewide technical support and training entity and disseminate information on transition through an entity like StarNet.
 - 2) DHS and ISBE should conduct statewide training campaigns to educate parents regarding the rights, laws, and procedures that they and their children are entitled to receive as part of transition services.
 - 3) ISBE should initiate an education and training campaign for school districts, special education cooperatives, and parents regarding transition-focused and best practices IEPs. As part of this, ISBE should provide model IEPs and transition plans for students with ASD. Teachers should be trained to the level of quality represented by the model IEPs and transition plans.

- 4) ISBE should initiate an educational campaign for all district special education personnel working with transition-aged youth in the manifestations of ASD and in behavioral and educational strategies matched to the manifestations and learning styles of students with ASD.
- 5) DHS and ISBE should adopt, implement, and evaluate an activity-based, measurable results-oriented -technical assistance and professional training model like StarNet to increase professional staff understanding and professional practice.
- 6) DHS, ISBE, and IBHE should promote and expand the pool of licensed and certified transition specialists for school and non-school adult service providers. These agencies should collaborate with Illinois colleges and universities to establish professional standards and licensure for transition specialists.
- 7) DHS should require Qualified Mental Retardation Professional (QMRP) certification to include ASD training in manifestations and behavioral approaches.
- 8) DHS and ISBE should educate school district personnel and adult service providers in the possibilities and availability of assistive technology.
- g) Community Integration
 - 1) A young adult service system should be developed to address the needs of ASD persons in the areas of vocation/technical education, employment training, supported employment, housing, recreation and leisure, and transportation.
 - 2) See funding recommendations

C. Transition of Seniors with ASD from Adult Day Programs or Employment to Senior Programs and Services

1. Findings: What's Working

- a) Some agencies are addressing transition to senior services by offering creative programming geared to individuals with ASD who are no longer able or interested in continuing developmental training or supported employment.
- b) Legislators, agencies, and the public are becoming aware of the need to plan for the transition of older individuals with ASD into programs that are geared to their interest and needs.

2. Findings: Challenges

- a) There are many triggers to senior transition, including age, choice, employment capabilities, and behavior changes.
- b) It no longer makes sense to send a senior to developmental training.
- c) There are no criteria for what active treatment for seniors is to include.
- d) Agencies are serving adults with ASD but can't publicize these services such as recreation, leisure, etc., because: the state agencies are concerned about charges of Medicaid fraud; the perception that publicity might not be seen as a legitimate use of taxpayer dollars; there is little recognition by the state for specialized services tailored to senior needs.

3. Recommendations

- a) DHS should provide benchmarks for senior transition needed for Individual Service Plan teams.
- b) DHS should obtain guidance from the Federal level on appropriate services.
- c) DHS should determine what senior services qualify for state funding. DHS should communicate to agencies that senior services are legitimate.
- d) DHS should explore coverage in a fully funded Medicaid waiver.

IV. Autism Waiver Committee

Committee Members: Laura Cellini – Chairperson, Dave Adden, Barb Ginder, Seth Harkins, Robert Holladay, Chris Kennedy, Carolyn Kopel, Patricia Reedy, Susan Szekely.

A. Findings: What's Working

1. The Department of Human Services (DHS) Early Intervention program for children ages 0 through 3 generally provides an adequate level of appropriate services and supports to children with ASD and their families.
2. The DHS Division of Developmental Disabilities (DDD) provides the following in-home and related services to children and their families, including children with ASD:
 - 72D Family Assistance and Support –Child. This provides in-home supports and habilitation for children whose behavioral difficulties have caused the families to request residential services.
 - 160 Client/Family Support. This provides in-home consultation and planning services for children and adults. This service is not available in every area of the State.
 - 87D In-home respite, 880 Group Respite, and 89D Residential Respite. This provides respite services for a few hours a week or a few days. Some services may not be available in some parts of the State.
 - A Family Assistance Program for children 0-18. This program provides a financial stipend to families of children identified through a computerized random selection process.
 - 500 Independent Service Coordination. This is provided on a limited-time basis for children and families during times of critical need.
 - 18D Children's Group Home and 9D Residential Schools. This provides funding for residential services when in-home services are not appropriate or have been tried and are unsuccessful. These programs require co-funding of educational costs by the school system.
3. Special education services for children and young adults with ASD age 3 through 21 are available throughout the State. These services are generally limited to school time hours.

B. Findings: Challenges

1. Autism is the most expensive disability category within IDEIA (Government Accountability Office report – January 14, 2005), exceeding regular education by 300% and other special education categories by 150%.
2. Special education services are under-funded on the State and Federal level.
3. Programs have insufficient funds to meet the existing needs; those that are available to families with Autism are insufficient and are not tailored to meet the needs of many individuals with Autism.
4. Early Intervention demonstrates a wide geographic variability in services with some sites resistant provision of intensive behavioral interventions, some having too few professionals truly qualified in Autism, and some failing to focus on the core deficit of functional verbal speech.
5. Special education services range in quality in different parts of the State and are available only during school hours with a limited focus on educational goals.
6. There is an unmet need for services to children with ASD and their families during non-school hours.
7. The apparent increased incidence of children with ASD is not being addressed.
8. Intervention programs are needed that can maintain and increase the gains made by those transitioning out of the 0-3 Early Intervention program and that can serve other children with ASD who have not participated in that program.
9. Parents statewide report inadequate services and conflicts, leading to litigation.
10. Affordable and effective advocacy services for individuals with ASD and their families are limited.
11. Eligibility criteria as applied by DD Pre-Admission Screening agencies appear to determine that many adult individuals with ASD are not eligible for services.
12. Reimbursement rates currently provided through the DD adult services waiver appear to be inadequate to support many adult persons with ASD who have minute-to-minute needs for intervention and/or support to enable them to function adequately, even within a highly structured environment.
13. There are more adult persons with DD (including persons with ASD) seeking Services than there are capacities to serve them. Provider agencies tend to offer services to those eligible persons who may be less challenging, leaving more persons with ASD underserved.
14. Adult persons with ASD require providers with specialized knowledge regarding their condition. Traditional providers of DD services do not have this specialized knowledge; in addition, providers of generic services (medical services, dental services, etc.) also lack this knowledge.
15. For a comparatively small percentage of adult persons with ASD, highly specialized transportation services, beyond the level of specialized transportation traditionally provided for persons with developmental disabilities, are a critical need. For some individuals, even their family members cannot safely provide transportation.

C. Recommendations

1. Children's Services, Including Establishment of an Autism Waiver for Children.

- a) The establishment of a children's Autism Waiver program in Illinois is a feasible and desirable goal. The Governor and State Legislature should give it the highest priority. A children's Waiver will provide Federal Match to the State through reimbursement by the Federal government for waiver services.
- b) With the support of the Governor and the Legislature, the Department of Healthcare and Family Services (HFS) and DHS should prepare and submit as soon as possible to the Federal Centers for Medicare and Medicaid Services an application for an Illinois Children's ASD Waiver. Department staff should consult the Task Force at key decision points and report to the Task Force on progress. The first priority for the waiver should be to provide services for children with ASD ages 3 through 18.
- c) DHS is the appropriate entity to administer the Children's Autism Waiver program.
- d) The waiver should include the following services: parent training, Applied Behavioral Analysis Therapy, or an analogous habilitative methodology, delivered within the home by trained family members and trained technician/personal support staff and led by a trained professional who assesses the individual's needs and who supervises the design, implementation, and revision of therapy/habilitation program; social skills training; transportation; in-home supports; dietary consultation; occupational, physical, and communication therapy (not duplicative of the basic State Medicaid Plan services); environmental modifications to the home; technological aids to assist with the individual's safety and security; a monetary advance to purchase therapy/habilitation supplies and equipment needed for implementing the service plan; transition services to employment; and transition services to independent living. These services are not currently widely available and will need to be developed, particularly in less-populated areas of the State. Case management services may be a desirable service, and their place in the waiver should be further explored.
- e) Each family participating in the waiver should receive a financial allotment for services and supports and should be able to select individualized services from the array of available services. The financial allotment should be ample enough to provide an adequate array of services that can effectively meet the child's needs, but efficient enough to allow a large number of families to participate. The Committee recommends a moderate array of services available to more people, rather than a rich array of services for a few people.
- f) Rates should be established that would allow for the purchase of the skills and services needed for serving persons with ASD.
- g) An assessment tool should be developed to determine eligibility for waiver services. The tool should assess that the individual will require an institutional level of care if it were not for the availability of the home and community-based services. The tool should take into consideration the following elements:
 - A child between the ages of three and eighteen years, must be diagnosed with an ASD currently in accordance with DSM IV Pervasive Developmental Disorder by a professional qualified to make such a diagnosis. Additionally, the child must exhibit at least two of the following criteria:
 - Engages in behaviors or activities that may result in serious physical injury to themselves or others;

- Lacks age appropriate comprehension to predict outcomes for actions and behaviors. May act impulsively without regard for consequences, i.e. runs into traffic;
 - Is unable to verbalize or functionally communicate basic information or needs;
 - Is unable to comprehend the age appropriate meaning of language or other forms of communication;
 - Is unable to complete age appropriate daily living activities such as toileting, bathing, dressing, and feeding;
 - Engages in self-stimulation and/or behaviors to a degree that hinders age appropriate participation in home and community environments;
 - Lacks age appropriate social skills and understanding to a degree which hinders them from participating in the educational and community environment;
 - Exhibits a degree of rigidity, obsessions, or compulsive behaviors, which hinder them from participating in their home or community environment.
- h) If necessary, initial waiver services may be delivered through a pilot project in several geographic areas of the State.
- i) Federal match for these waivers should go into a dedicated fund to support additional services in this waiver.
- j) The proposed waiver should waive family income as a consideration for participation.
- k) DHS and ISBE should coordinate educational services with other home and community services not based in the educational system.

2. Adult Programs and Services

- a) DHS Division of Developmental Disabilities should immediately analyze and clarify its guidelines for determination of eligibility in regard to adult persons with ASD and train its Pre-Admission Screening agencies in their use.
- b) Elements recommended for consideration regarding an assessment tool for eligibility in the Children's ASD Waiver should be used for adults with ASD also.
- c) The DHS Division of Developmental Disabilities should immediately examine rates for adult persons with ASD who have high needs and, if necessary, implement appropriate adjustments to ensure that persons with high needs are properly served.
- d) The Division of Developmental Disabilities should immediately assess whether adult individuals with the most severe needs are going underserved when individuals with less severe needs are accepted for services. If the assessment indicates that this is happening, the Division of DD should immediately develop and implement procedures for ensuring that individuals with the most severe needs are receiving services.

3. Workforce Development

- a) DHS should facilitate programs of specialized training on ASD for traditional providers of DD services and also for medical schools, dental schools, and other professional and non-professional providers of services.
- b) The DHS Division of DD should explore the need for and feasibility of providing highly specialized transportation as an available service within the adult DD waiver, with a rate structure sufficient to support the service.

- c) The adult DD Waiver capacity should immediately be analyzed to determine whether an increase in capacity is needed to serve individuals with ASD as they transition from children's services to adult services.

V. Information Clearinghouse

Committee Members: Ruth Ann Sikora - Acting Chairperson, Laura Cellini, Christopher Fichtner, Audrey Gorman, Janet Gully, Kirsten Hammock (representing Janet Gully), Dave Landers, Dylan Livingearth, James Nam, Peter Nierman, M.D., Kelvin Oliver, Ted Sunder, M.D., Jeremy C. Viscomi, Georgia Winson,.

A. Findings: What's Working

1. Some agencies and service providers are doing a good job of communicating information and educating some professionals and parents about Autism and the services available.
2. Some agencies have done a good job of disseminating information, especially on the state and regional level. A smaller number have plans to address dissemination on the local level.
3. Pediatricians are being made aware of the early signs of ASD, resulting in more children entering public schools with an ASD diagnosis.
4. DHS and The Autism Program are currently funding the Early Childhood Intervention Clearinghouse (ECIC). The ECIC currently provides resources relevant for children, adolescents, and adults.
5. An IATF website is developed that provides access to a wide range of resources, allowing internal and external communications of IATF activities. It is awaiting content.

B. Findings: Challenges

1. There is insufficient coordination or sharing of information among the wide range of agencies (state, nonprofit, for-profit) that provide information and services across the State. As a result, there are duplications of effort and lack of a "big picture" plan for getting information out efficiently and effectively.
2. At the local level in particular, people seeking information about Autism of available services too often do not know where to turn. This is, in part, due to historic tendencies among agencies to centralization or broad regionalization. Even when services exist locally, it is frequently very difficult to identify them and gain access.
3. Most information on ASD is in the text format, whether on paper or web-based. There is an extreme shortage of appropriate multi-sensory and alternative formats, such as radio, streaming video, and multimedia presentations like those found on www.childnet.tv and some other sources.
4. Many, if not most, web sites and other information tools are not designed to be accessible for people with disabilities. Given the rate of co-morbidities and

particular the reading and communication difficulties experienced by people with Autism, this represents a serious barrier to accessing information and services.

C. Recommendations

1. An Illinois Autism Information Clearinghouse should be established that provides “big picture” planning and broad inclusive collaboration on Autism information dissemination for stakeholders, providers, and consumers of services for individuals with ASD.
2. The Illinois Autism Information Clearinghouse should be charged with coordinating information identification and dissemination, product development to fill gaps and training for key stakeholders (parents, librarians, service providers, medical and mental health professionals) in collaboration with all Autism-related entities statewide.
3. The Illinois Autism Information Clearinghouse web site should have a dedicated webmaster as a prime, cost-effective vehicle for information dissemination. The web site should be written in plain language and designed for usability and accessibility. It would link to key Autism information on other web sites. Written policies should be established on linking outside DHS’s website, such as disclosures as to the non-endorsement of providers, methods, products, etc., and limiting bias and favoritism as to which web links are listed and which are not.
4. A coordinated ASD awareness and information campaign should be developed for Illinois. This campaign should make use of local information dissemination expertise, particularly that of local libraries.
5. A toll-free number and service should be established which is mostly automated and keyed to the Illinois Autism Information Clearinghouse web site information but backed as appropriate by service providers.

VI. Research/Training/Workforce Development Committee

Committee Members: Bennett Leventhal, M.D. and Peter Nierman, M.D. – Co-chairs, Laura Cellini, Dr. Anne Cutler, Mina Dulcan, M.D., Chris Kennedy, Dr. Marie Weissbourd.

A. Findings: What’s working

1. Illinois is home to an extensive research community that has the talent and the commitment to become a world leader in the area of ASD.
2. New, effective, and evidence-based practices are continuously emerging that affect identification and services for individuals with Autism and ASD.
3. Illinois has strong clinical and academic institutions to lead the State toward developing a system that advances clinical and scientific knowledge while improving services for Illinois citizens.
4. Adult education programs have increasingly implemented more effective approaches and technologies to improve quality and adapt competencies in the workforce.
5. Family members, physicians, community based providers, vocational and occupational counselors, educators and other stakeholders in Illinois are eager to

learn new strategies to address the needs of individuals with Autism and Autism Spectrum Disorders.

6. The Autism Program is nearing completion of a best practice guide that is based on expert consensus and national standards.
7. Parents are instrumental in developing new treatments and therapies.

B. Findings: Challenges

1. The workforce is not in place to provide the array of services to address the needs of individuals with Autism and ASD across the lifespan.
2. ASD impacts individuals across the lifespan. There are key periods of transition and certain life stages that require specialized and expert attention.
3. Primary care physicians, psychologists, clinicians and educators too often do not have the knowledge or time to address the comprehensive needs of individuals with ASD.
4. Agencies and institutions that have a stake in the system are extremely diverse – from schools to hospitals, from rural to urban, local to national, and from simple to bureaucratically complex. Multiple strategies are needed to impact the quality of services.
5. There is excessive variability in services for individuals with ASD indicating a greater need for specificity in assessment and improved fidelity to modalities of treatment.
6. Individuals with ASD have underlying and/or co-morbid disorders that are not being diagnosed or treated adequately.

C. Recommendations

1. Evidence-based Practices

- a) The State must make an investment in the implementation of evidence-based practices (EBP). Evidence-based practices take root from rigorous evaluation and research, are reproducible, and are effective. The implementation of EBPs must encompass screening, evaluation, treatment, housing, and family supports across the lifespan.
- b) The State should encourage the pursuit in all areas of basic and clinical science that leads to a better understanding of the causes, prevention, and treatment of ASD.

2. Research

- a) The need for research in certain specific areas is strongly recommended: nosology and nomenclature, genetic underpinnings and phenotypic subtypes, screening tools for early identification, assessment of environmental contributions, medical and psychiatric co-morbidities, assessment of effective interventions and treatments, and translating such research into practices.
- b) Research partners must have the capacity to respond quickly to public health concerns that periodically arise and are related to Autism and ASD.
- c) The State should embrace a public health approach with resources on call

to respond, assess, and inform the public regarding issues of concern (e.g. mercury in vaccines), best practices and effective interventions at various stages of development and for various subtypes and skill sets within the Autism community.

- d) The State should assess practices that are anecdotally effective to seek out new clinical approaches that are effective and to protect citizens from practices that are ineffective or potentially harmful.
- e) The State should develop strategies to rapidly translate promising areas of research into practice, including best practices and effective interventions at various stages of development and for various subtypes and skillsets within the Autism community.

3. Work Force Development and Training

- a) The Department should commission a report to look at extant curricula regarding developmental disorders in Illinois schools of nursing, social work, medicine, psychology, occupational therapy, speech and language, and education.
- b) There should be additional curriculum development to bolster the workforce of the future with regard to their competencies for serving individuals with ASD across the lifespan.
- c) Review must assess the state of education with respect to screening, assessment, treatment, education, ancillary services and supports.
- d) The State should commit to commissioning a description of core competencies for a desirable workforce at multiple levels of endeavor and affiliation with respect to working knowledge regarding Autism and ASD which may be accomplished by (a) promoting professional certification and recognition of these specialties by DHS and ISBE and (b) establishing scholarship programs and loan forgiveness programs.
- e) There is recognition that within the systems there is a need for competencies of both “generalists” and “specialists.”
 - There needs to be cross-agency commitment to the development of special competencies in the areas of early childhood, youth, transitional services to young adults, adult services, and services of seniors.
 - Schools should have trained professionals with specialized skills in devising, implementing, and overseeing effective education plans for youth and transitional populations with ASD.
 - Financing mechanisms that reimburse services must provide adequate incentive for specialization and professionalism as it pertains to current and future desired competencies in the workforce.
 - Specialized ASD training should be developed for QMRPs and QMHPs.
- f) The Department should provide technical assistance to schools, institutions, and other providers to introduce quality assurance measures and strategic planning goals for enhancement of services for individuals with Autism and ASD across the lifespan.
- g) The State should establish a plan to develop workforce competencies in ASD across the life span, including through continuing adult and

- professional education.
- h) There must be ongoing access to skilled supervisors and interactive educational technologies. Evaluation of training efforts must be undertaken to analyze how training efforts have resulted in desired quality improvements in approach at the levels of effective screening, assessment, treatment, and adjunctive services.
 - i) Continuing Medical Education credit on ASD for primary care physicians should be developed over the next two years to improve clinical competencies in screening, assessment, early intervention, treatment, and adjunctive services throughout the lifespan.
 - j) The Research/Training/Workforce Development Subcommittee of the Autism Task Force should be sustained and function in an advisory capacity to recommend strategic objectives and track progress of any investments the State may make as a result of the Autism Task Force. The Task Force should be allowed to invite national experts, specialists, researchers, and family members to assist in the development of strategic plans and recommendations to the Autism Task Force. Membership in the Task Force should be reviewed to ensure adequate representation of parents, advocates, education specialists, and providers of various types and methods of services, so as to encourage diverse viewpoints and enhance the expertise and effectiveness of the Task Force.

VII. Insurance Committee

Members: Christopher Kennedy – Chairperson, Patrick W. Knepler.

A. Findings: What’s working

1. Illinois is among those states with insurance parity for “mental illness” includes Autism by statute, providing a floor of coverage for some individuals with Autism.
2. Illinois is home to a large community of providers who are capable of providing quality services and treatments. Many providers are willing to accept varying types of health insurance and are willing to work with parents to assist in coverage disputes.
3. Proper treatments and interventions have proven to result in improved prognosis and lower long-term costs.
4. Insurance industry cost projections associated with the original mental health parity law were not realized; mandating parity did not have a negative financial impact on insurance providers.
5. Other states provide models for reasonable measures to enhance families’ access to insurance as a means of providing necessary and proper health care for their children with Autism.

B. Findings: Challenges

- 1. Mental health insurance parity has limited effects:**
 - a) Most policies cap vital therapies far below needed levels of intervention. For example, a typical policy requires only 20 hours per year of speech therapy, which a child with Autism may use up within two months.
 - b) The mental health insurance parity law does not affect all health insurance policies, such as those of small employers and self-insured programs; such policies often exclude Autism entirely as a covered condition.

- 2. Limitations and exclusions:**
 - a) For those who do receive coverage for Autism treatment, lifetime caps can be exhausted in early childhood.
 - b) Most policies do not cover behavioral intervention in any amount. Such coverage is typically declined as either “medically unnecessary,” “experimental,” or “educational services.”
 - c) Coverage is often declined on the basis of habilitative vs. rehabilitative; because therapies are not for the purpose of “restoring” previous levels of functioning, but rather for improving functionality, they are excluded.
 - d) No guidelines exist in Illinois defining what is “medically necessary” or defining best practices for Autism. For example, other states define preferred treatments for Autism, providing practitioners with evidence that such treatments are no longer experimental.
 - e) No guidelines exist in Illinois defining treatment protocols. For example, although studies indicate as many as 30% of all children with Autism also have epilepsy, EEG’s and brain imaging studies are not typically ordered for children with ASD.
 - f) Affordable access to effective advocacy is limited.
 - g) Insurance industry initiatives have begun in states around the country seeking to limit coverage by allowing employers and insurers to offer a “choice” of policies that do not include various mandated coverage (see, e.g., “Illinois Consumer Choice of Benefits Health Insurance Plan Act,” HB500/SB2024 (not passed, 94th G.A.)).

- 3.** Insurance exclusions and limitations have resulted in increased parent/family costs, increased reliance on schools to provide necessary care, and increased reliance on State insurance programs to provide needed medical care to children with ASD.
- 4.** Illinois is home to a powerful insurance lobby and parent advocates have limited resources to effect meaningful changes in the Insurance Code.

C. Recommendations

- 1.** New legislation should be introduced to require health insurance policies to cover ASD and all disorders above and beyond minimums required by mental health parity law. Covered treatments should include therapeutic, respite and rehabilitative care, including but not limited to additional speech therapy, occupational therapy, physical therapy, behavioral therapy, and medical/surgical

care that includes brain imaging and EEGs. Cost-containment provisions may include monthly or annual limits on the amount paid in excess of that which is otherwise covered.

2. Legislation should be introduced to amend the mental health insurance parity law to include HMO's and individual policies.
3. Insurance "choice" initiatives aimed at evading mandated coverage must be opposed, or, in the alternative, Autism must be included among those conditions that may not be avoided through such "choice" policies.
4. Medical necessity, treatment protocols and medically necessary therapies for Autism must be defined and must include diagnostics, proven behavioral therapies, speech/language therapies, and other co-morbid conditions.

Conclusion

Autism is a severe disability requiring intensive and expensive intervention and treatment. As a neurodevelopmental disorder traditionally classified under mental health conditions, Autism has not fit within established programs. Current services are inadequate to meet the needs of either the adult or childhood Autism populations in Illinois. The rapid rise in identified cases of children with Autism in the past several years has exacerbated these problems and poses a looming disaster for the State and its families if not addressed immediately. Past legislative and administrative approaches to Autism have been piecemeal and of limited effectiveness. Gaps in funding are often left to be filled by parents, when possible, typically at great sacrifice and with a concomitant toll on families; more often, individuals with Autism simply go without necessary care. It is imperative that Illinois' policymakers act with the same sense of urgency as that of parents seeking help for their affected children and that the product of this Task Force not be relegated to the heap of past promises and missed opportunities to build a system of services and supports for our citizens.

Illinois is emerging from a difficult economic period. New revenues may soon become available to help support individuals with Autism and Autism Spectrum Disorders. The Autism Task Force has sparked a spirit of coordination and integration among State agencies, schools, administrators, service providers, and families. Now is the right time to turn the attention of Government to this long neglected and growing population and fulfill the intent of this legislation by enacting laws and policies recommended in this report.

Glossary

ASD – Autism Spectrum Disorder
BASIC – Business Approach to Social Integration and Communication
CFC – Child and Family Connection
DCFS – Department of Children and Family Services
DD – Developmental Disabilities
DDD – Division of Developmental Disabilities
DHS – Department of Human Services
DPH – Department of Public Health
EBP – Evidenced-Based Practices
EC – Early Childhood
ECIC – Early Childhood Intervention Clearinghouse
ECE – Early Childhood Education
EI – Early Intervention
EPSDT – Early Prevention Screening Detection and Treatment
FAPE – Free Appropriate Public Education
HFS – Department of Healthcare and Family Services
HMO – Health Maintenance Organization
IATF – Illinois Autism Task Force
IATTAP – Illinois Autism Training and Technical Assistance Project
IBHE – Illinois Board of Higher Education
IDEA – Individuals with Disabilities in Education Act
IDEIA – Individuals with Disabilities in Education Improvement Act
IEP – Individualized Education Program
IFSP – Individualized Family Service Plan
ISBE – Illinois State Board of Education
MH – Mental Health
PAS – Pre-Admission Screening
PDD – Pervasive Developmental Disorder
PUNS – Prioritization of Urgency of Need for Services
QMHP – Qualified Mental Health Professional
QMRP – Qualified Mental Retardation Professional
StarNet – Support and Technical Assistance Regional Network
STEP – Secondary Transition Experience Program
TAP – The Autism Program
TOTAL – Transition Outreach to Adult Living