



**CREATING A MORE SECURE FUTURE**  
**FOR**  
**KENTUCKIANS WITH AUTISM SPECTRUM DISORDERS**

**ASD ANNUAL REPORT 2007**



The Commonwealth of Kentucky  
Cabinet for Health Services

On Behalf of



**THE KENTUCKY COUNCIL ON DEVELOPMENTAL DISABILITIES**

Presents:

**2007 ASD ANNUAL UPDATE**

An Annual Submitted in Accordance with House Bill 296 to:

Governor Ernie Fletcher  
And the General Assembly

**October 1, 2007**

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## INTRODUCTION

About 1 in every 1000 people in the United States has autism and a 2007 Centers for Disease Control report found that 1 in 150 children in America today have an autism spectrum disorder (ASD). The Autism Society of America (ASA) estimates that 1.5 million Americans and their families are now affected. Autism is a national health crisis, costing the U.S. at least \$35 billion annually. Autism affects all races, ethnic groups, and socioeconomic levels. (Reference: <http://www.autismsociety.org>, 6/2007)

Kentucky's population according to the 2000 census was 4,058,633. Using the prevalence data of 1/150, the number of individuals with ASD in Kentucky would be over 27,000.

### Autism Spectrum Disorder Defined

Autism Spectrum Disorder (ASD) is the name given to describe the wide range of behaviors amongst the Autistic population. Children with autism are less able to interact with the world as other children do. Typically they have deficits in three key areas:

- Verbal and non-verbal Communication
- Social awareness and interactions
- Imaginative play (variable interests and behaviors). (Reference: Diagnostic and

Statistical manual of Mental Disorders (DSM-IV), 6/2007)

There are separate labels given to children with autism for different points on the Autism spectrum. At the least affected end, you may find labels such as "Asperger's Syndrome", "High Functioning Autism" and "Pervasive Developmental Disorder - Not Otherwise Specified" (PDD-NOS). At the other end of the spectrum you may find labels such as "Autism", "Classic Autism" and "Kanner Autism". (Reference: [http://www.autism.net.au/Autism\\_Definition.htm](http://www.autism.net.au/Autism_Definition.htm), 6/2007)

Individuals diagnosed with ASD have an extremely diverse range of needs, limitations and challenges. The subcategories of ASD are characterized by varying degrees of impairment in communication skills, social interactions, and restrictive, repetitive and stereotyped patterns of behavior. (Reference: [www.nichd.nih.gov/health/topics/asd.cfm](http://www.nichd.nih.gov/health/topics/asd.cfm), 6/2007) This complexity leads individuals who are diagnosed with ASD, their families and other caregivers to routinely characterize their challenge as lonely and uphill. Providers who care for and support individuals with ASD often experience overwhelming feelings of frustration and isolation in the search for appropriate diagnostic and treatment services. The lack of resources available for individuals with ASD, including adequate funding for critical services, appropriate diagnostic tools for very young children, early intervention systems, crisis intervention, continuum of services through the adult years, and professional training of educators and service providers, leaves a substantial void in the care of individuals with ASD and often prevents them from reaching their full potential as contributing members of society. (Reference: [www.theautismprogram.org](http://www.theautismprogram.org); 6/2007).

## **KENTUCKY COMMISSION ON AUTISM SPECTRUM DISORDERS**

House Bill 296 was enacted by the Kentucky General Assembly during its 2005 regular session and signed into law by Governor Ernie Fletcher on March 18, 2005, to establish the Kentucky Commission on Autism Spectrum Disorders. (See the full text of House Bill 296 in [Appendix C](#) to this Report.) The stated purpose of the Commission was to develop a 10 year comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD, and to make recommendations regarding legislation, administrative regulations, and policies to the Governor of Kentucky and the Kentucky General Assembly.

The Commission was formed in response to the significant increase in the number of Kentuckians diagnosed with ASD over the last 10 to 15 years and to build upon the work of the Autism Spectrum Disorders Advisory Consortium (ASDAC). ASDAC was formed in March, 2002, at the request of the State Interagency Council for Services to Children with an Emotional Disability (SIAC). ASDAC was charged with providing a unified voice to assist SIAC in understanding the needs of children and youth with autism spectrum disorders.

House Bill 296 mandated that the Commission develop a comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD make recommendations regarding legislation, administrative regulations, and policies to the Governor and the General Assembly based on the following:

Needs for services and supports for individuals who have ASD.

Funding needs and sources, including state, federal, private, and any other appropriate funding sources.

Training needs and a plan to implement a comprehensive training system, which shall include the Kentucky Autism Training Center.

Standards for provider training and qualifications, best practice standards for services, and the need for additional providers.

Goals for developing health benefit plans that provide insurance coverage for the treatment of ASD.

A plan for the identification of individuals of all ages with ASD and for the creation of a statewide ASD registry.

Consistent program and services eligibility criteria.

The need for coordinated, enhanced, and targeted special education and treatment programs for individuals with ASD.

Strategies and timelines for establishing an accountable, cost-efficient, and cooperative system of services that integrates and builds upon existing public and private agencies, programs and resources.

A timeline for implementing and monitoring the recommendations of the plan statewide.

Based on the above criteria, hours of research and work the Commission developed a set of 15 recommendations in their final report.

The final report was submitted to Governor Ernie Fletcher, the Kentucky Council on Developmental Disabilities and the Legislative Research Commission on October 1, 2006, as directed by House Bill 296. The Commission was dissolved on October 1, 2007, following the fulfillment of their duties as defined by HB 296.

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## 2007 ANNUAL REPORT

The Kentucky Council on Developmental Disabilities (KCDD) has the responsibility under House Bill 296 to monitor the implementation of the state plan, where appropriate, make recommendations on the need for modifications to the state plan and to submit an annual report to the Governor by October 1<sup>st</sup> of each year beginning in 2007 and continuing until 2016.

The following sets forth the annual update on the recommendations of the Commission regarding the legislation, administrative regulations and policies necessary to develop and implement a comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD.

During the 2007 legislative session two (2) bills were filed HB109 and HB91. Both bills were well received but did not pass during session. They did however lay the foundation for the 2008 session.

[HB 109 \(BR 419\)](#) –An Act relating to autism spectrum disorders was introduced in the House of Representative on January 2, 2007. The sponsors of the bill include [S. Brinkman](#), [C. Belcher](#), [K. Bratcher](#), [B. DeWeese](#), [C. Embry Jr](#), [C. Hoffman](#), [S. Lee](#), [C. Miller](#), [B. Montell](#), [D. Osborne](#), [D. Owens](#), [T. Riner](#), [C. Rollins II](#), [S. Rudy](#), [B. Smith](#), [J. Tilley](#), [S. Westrom](#). The Bill had several components that specifically addressed many of the recommendation from the Commission. (See [Appendix E](#) for a full copy). The bill was assigned to the House Health and Welfare committee on January 3, 2007; on February 7, 2007 posting was waived and it was posted in committee. The Bill was reported favorably on 1<sup>st</sup> reading on February 15, 2007 and was posted to the Calendar. On February 16<sup>th</sup>, 2007 following the 2<sup>nd</sup> reading the bill was sent to the Rules Committee. On February 21<sup>st</sup> the bill was posted for passage in the Regular Orders of the Day. On February 23<sup>rd</sup> the bill received the 3<sup>rd</sup> reading and passed the House with a 96-0 vote. On February 26<sup>th</sup> it was sent to the Senate and on February 28<sup>th</sup> it was assigned to the Senate Appropriations and Revenue Committee. No further action was taken on the bill during the 2007 legislative session.

This legislation was written to support and enact recommendation #'s 1, 2, 3, 6, 7, 12, 13, 15

[HB 91/HM \(BR 36\)](#) – An act relating to treatments for autism spectrum disorders was also introduced by in the House of Representatives on January 2, 2007 by [S. Brinkman](#), [C. Embry Jr](#), [D. Floyd](#), [T. Riner](#). This bill specifically addressed recommendations #8 and #9 regarding insurance for individuals with Autism. (See Appendix \_ for full copy) This bill was assigned to the House Health and Welfare Committee on January 3, 2007; the posting was waived on February 6<sup>th</sup>, 2007 and was posted in Committee. No further action was taken on the bill during the 2007 legislative session.

This legislation was written to support and enact recommendations #8 and #9

Recommendation #'s 4, 5, 10, 11, 14 were not addressed in any legislation

Further advocacy group and agencies that provide support and services to individuals with ASD from around the state continue to promote best practices within the service system for individuals with ADS and their families.

### **RECOMMENDATION NUMBER 1**

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation creating a “Supports for Individuals with Autism Spectrum Disorders Program” (the Program) within the Cabinet for Health and Family Services. The Program would be responsible for implementing and monitoring services and supports for individuals with ASD and their families and caregivers. In support of the Program, the General Assembly should enact biennium budgets that provide targeted funding for the services and supports for individuals with ASD, their families and caregivers, receiving services through the Program using both state general fund revenues as well as funds available under the Medicaid program. The Program would be staffed with qualified personnel assigned exclusively to the Program. The administrative costs of staffing and operating the Program would also be financed with a combination of state general fund revenues as well as Medicaid funds. The Program would serve as a state-centric office and coordinating body to keep an active inventory of services and resources available to individuals with ASD, their families and caregivers that would be posted on a user-friendly website and promoted to individuals with ASD, their families and caregivers, educators, health care providers and other service providers. The Program would establish clear guidelines and criteria for service providers to participate in the Program, and the Program would contract with these service providers throughout Kentucky to deliver approved services to individuals with ASD covered under the Program. The Program should incorporate, to the fullest extent permitted under the Medicaid program, provisions authorizing self-determination and establishing a consumer directed option, whereby individuals with ASD, their families and caregivers would have wide discretion in determining the services best-suited to meet the needs of the individual with ASD and the service providers best-situated to deliver those services. The implementation of this Recommendation is critical to the implementation of many of the Recommendations set forth later in this Report

[HB 109](#) (BR 419) –An Act relating to autism spectrum disorders ; create new sections of KRS Chapter 194A to create the Supports for Individuals with Autism Spectrum Disorders Program within the Cabinet for Health and Family Services; require the program to serve as a central coordinating body, keep an inventory of services, establish guidelines and criteria for service providers, contract with services providers, incorporate provisions of self-determination and consumer-directed options, and promote the creation of a comprehensive resource network; require the program to develop a comprehensive training plan and contract with the Kentucky Autism Training Center to implement the plan; require the program to enter into an interagency agreement with the Kentucky Department of Education for the effective delivery of services to children with ASD; define ASD; create an advisory board to ensure citizen involvement in the program; require the cabinet to fund and staff the operation of the board; require the board to provide consultation, serve as a communication conduit, and provide input to the program.

## **Recommendation Number 2**

The legislation creating the Program should include the creation of an advisory board consisting of family members, including parents and siblings, as well as legal guardians, of individuals with ASD, service providers, adults with ASD and other interested citizens that would consult regularly with the executive management personnel of the Program regarding the functions, duties and mission of the Program. The advisory board should be appointed and functioning contemporaneously with the creation of the Program to help ensure citizen involvement from the outset in helping to implement and maintain the Program. The administrative budget for the Program should include appropriate financial support for members of the advisory board, including reimbursement of approved travel expenses and perhaps a per diem stipend and reimbursement of reasonable child care or respite care expenses, to ensure that all members of the advisory board can afford to attend its meetings. The advisory board would serve as a conduit between the public and the Program in order to provide structured input to the Program regarding the quality and quantity of the services being provided through the Program as well as all other aspects of the Program.

[HB 109](#) (BR 419) –An Act relating to autism spectrum disorders - Create an advisory board to ensure citizen involvement in the program; require the cabinet to fund and staff the operation of the board; require the board to provide consultation,

## **RECOMMENDATION NUMBER 3**

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation directing the Department of Medicaid Services (DMS) of the Cabinet for Health and Family Services to submit an application to the Center for Medicare and Medicaid Services (CMS) of the federal Department of Health and Human Services for a waiver (the Waiver) that will authorize DMS to develop and implement flexible reimbursement and payment strategies that reflect the individually determined needs for services and supports by individuals with ASD receiving services through the Program. The Waiver should be submitted under the provisions of federal law that will grant DMS the greatest latitude in structuring payment provisions for individuals receiving services through the Program and reimbursement provisions for service providers participating in the Program. The Cabinet for Health and Family Services, in collaboration with the Kentucky Council on Developmental Disabilities, should have the primary responsibility to draft and submit the Waiver including making the determination of whether to pursue the Waiver as a demonstration waiver under Section 1115 of the federal Social Security Act, as a Home and Community Based Services (HCBS) waiver under Section 1915(c) of the federal Social Security Act, as a combined waiver under Sections 1915(b) and Section 1915(c) of the federal Social Security Act, as a combined waiver under Section 1915 of the federal Social Security Act and the Deficit Reduction Act of 2005, as a separate waiver under the Deficit Reduction Act of 2005, or under other provisions of federal law. In determining the most

appropriate legal basis for the Waiver, the Cabinet for Health and Family Services and the Kentucky Council on Developmental Disabilities should select the course of action that will assure the greatest likelihood of success in implementing this Recommendation. The Waiver should be written broadly to accommodate the use of a number of revenue streams, including state general fund revenues as well as funds available under the Medicaid program, in order to provide adequate reimbursement to providers of services to individuals with ASD, their families and caregivers. The Commission strongly recommends that the legislation authorizing and directing the preparation and submission of the Waiver ensure that individuals with ASD have the option to continue to receive services under, or to first seek to receive services under, any other waiver program approved by CMS or under the authority of the Deficit Reduction Act or other provisions of federal and state law, and who otherwise meet the applicable eligibility guidelines, instead of receiving services through the Program. The Commission recognizes the importance of ensuring that individuals with ASD and their families and caregivers retain the option to seek or to otherwise continue to receive services under different waiver programs or under other provisions of federal and state law.

[HB 109](#) (BR 419) –An Act relating to autism spectrum disorders - Create a new section of KRS Chapter 205 to require the Cabinet for Health and Family Services to submit an application for a Medicaid waiver to develop and implement flexible reimbursement and payment strategies for services and supports for individuals with autism spectrum disorders (ASD) within three months of the effective date of this Act; require a report on the use of the waiver if approved

#### **RECOMMENDATION NUMBER 4**

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation that will appropriate state general funds in each biennium budget that provide targeted funding for the services and supports needed by individuals with ASD who do not meet the eligibility guidelines for Medicaid waiver services. This Recommendation is supplementary to Recommendation Number 3.

NOT ADDRESSED

#### **RECOMMENDATION NUMBER 5**

The executive and legislative branches of state government should continue indefinitely full funding of the First Steps program based upon the number of children participating in the program and the actual costs of providing services to these children, which should include additional funding to the extent necessary to ensure that all children with ASD participating in the First Steps program receive all needed services for effective early intervention.

NOT ADDRESSED

## **RECOMMENDATION NUMBER 6**

The Program should enter into an interagency agreement with the Kentucky Department of Education to ensure a coordinated and effective system of delivery of services to children with ASD who are enrolled in the public school system. The Program and the Kentucky Department of Education should maximize the services received by a student with ASD through both the Program and under the federal Individuals with Disabilities Education Improvement Act (IDEIA). The elements of the interagency agreement should include, at a minimum, the following components:

The requirement that the Kentucky Department of Education expand its current classification eligibility criteria for autism to be consistent with the DSM-IV-TR for Pervasive Developmental Disorders. An expanded definition that matches the DSM-IV-TR will allow children with Pervasive Developmental Disorders Not Otherwise Specified and Asperger's Disorder (as well as the less commonly identified Rett's Disorder and Childhood Disintegrative Disorder) to receive educational services under the educational classification of autism.

The requirement that, as part of the Program's statutory duties, mission and budget, qualified staff of the Program will serve as advocates for children with ASD to ensure that these children receive through the public school system all services that are guaranteed to them under IDEIA, together with the requirement that the Program provide trained personnel to assist parents and guardians in negotiating Individual Education Plans (IEPs) for these children that will include the provision of all guaranteed services under IDEIA.

The inclusion of provisions guaranteeing that all children with ASD qualify for extended school day services and extended school year services without the need to show regression in the absence of participation in the programs. The Commission believes that the Kentucky General Assembly has adequately funded for the current biennium the extended school day and extended school year services programs.

The requirement that the Kentucky Department of Education hire more complex needs consultants to ensure adequate staffing within each special needs cooperative within the Commonwealth of Kentucky.

The requirement that the Kentucky Department of Education inform parents or legal guardians of children with ASD enrolled in the public school system of the desirability of the referral of the child for a medical evaluation prior to graduation to help facilitate the child accessing federal and state benefits that, depending upon the eligibility guidelines of the particular program, may be available to the child when he or she reaches the age of 21.

Require the program to enter into an interagency agreement with the Kentucky Department of Education for the effective delivery of services to children with ASD.

[HB 109](#) (BR 419) –An Act relating to autism spectrum disorders – require the program to enter into an interagency agreement with the Kentucky Department of Education for the effective delivery of services to children with ASD; define ASD – amended to add one representative from the Education Cabinet to the advisory board.

## **RECOMMENDATION NUMBER 7**

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation that mandates specific screening for ASD of all children at each of the 18 month well-baby check, the 2-year old well-child check, the 4-year old well-child check, the initial school physical, and the 6<sup>th</sup> grade school physical. ASD specific screening should also occur at all initial visits to the First Steps program of children 18 months and older and other early intervention programs should also be encouraged to perform ASD specific screenings.

All ASD specific screenings should utilize the most current, evidence-based screening tools as endorsed by the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry and the American Academy of Neurology. These screening tools currently include, at a minimum, the MCHAT (Modified Checklist for Autism in Toddlers) for children from 18 months to 24 months of age, the Social Communication Questionnaire (Berument, Rutter, Lord, Pickles & Bailey, 1999) for the wellness check at age 4 and the school physical at age 6, and the Autism Spectrum Screening Questionnaire (Ehlers, Gilberg & Wing 1999) for children from 6 through 17 years of age. The Program should also have the statutory authority and qualified staff to investigate other screening tools and programs employed in other states to determine and report to health care providers, educators and other professionals the effectiveness of these other screening tools and programs based upon data and findings that the Program deems reliable. An example of the type of program that may merit investigation by the Program is the First Signs® program (not to be confused with Kentucky's First Steps program), which has been implemented in a number of states.

If ASD is suspected following a screening, a formal diagnosis should be made within 90 calendar days after the initial screening. The formal diagnosis should be made by qualified professionals in good standing who have the right and ability to diagnose ASD within their lawful scope of practice as authorized under KRS Chapters 311, 314, 319, or 335 and administrative regulations promulgated by the professional's board or council of licensure.

[HB 109](#) (BR 419) –An Act relating to autism spectrum disorders - create new sections of KRS Chapter 157 to require screening for autism spectrum disorders (ASD) at 18 months, 2 years, 4 years, upon school enrollment, and at the time of the sixth grade physical; require the cabinet to establish requirements for ASD screening; require schools to have a record of ASD screening; require a formal diagnosis after screening positive within 90 days; define "autism spectrum disorders"

## **RECOMMENDATION NUMBER 8**

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation modeled after the legislation enacted in Indiana in 2001 mandating insurance coverage for individuals with pervasive developmental disorder that is far more expansive than the autism benefit mandated in KRS 304.17A-143 (i.e., a monthly benefit of \$500 for certain services for individuals with autism). The Indiana legislation should however be modified by the Kentucky General Assembly in several respects as noted below.

The Indiana legislation defines pervasive developmental disorder as a neurological disorder and not as a mental health or emotional disorder, and thus precludes insurance companies from denying or restricting coverage for services to covered individuals with pervasive developmental disorder on the basis that the condition is a mental and not a medical condition. The legislation also mandates insurance coverage for all services prescribed by the attending physician under a treatment plan formulated for the individual with pervasive developmental disorder. Self-insured plans are, however, exempt from the mandate. Although the Indiana legislation does not include a statutory dollar limitation on the required insurance coverage for pervasive development disorder comparable to Kentucky's current \$500 per month limitation on the mandated coverage for services to children with autism, the Indiana legislation does permit the insurer to impose dollar limits, deductibles, and coinsurance provisions with respect to the mandated insurance coverage for pervasive development disorder provided that such dollar limits, deductibles, and coinsurance provisions are no less favorable to the insured than the dollar limits, deductibles, and coinsurance provisions that are imposed with respect to physical illness covered under the insurance policies regulated by the legislation.

The Kentucky General Assembly and the Governor of Kentucky should modify and improve the Indiana legislation in three respects. First, Kentucky's version of the legislation should explicitly provide coverage for all disorders within ASD as defined in the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association, fourth edition (DSM-IV). The Indiana legislation covers individuals with pervasive developmental disorder, which may not be as broad as autism spectrum disorders. Second, Kentucky's version of the legislation should explicitly eliminate the need for a dual diagnosis of an insured with ASD and instead provide coverage to an insured diagnosed with ASD regardless of whether Kentucky law, the insurance industry, the particular insurer or experts in the field of ASD considers ASD a neurological disorder, a medical condition or a mental health or emotional disorder. Indiana's legislation explicitly defines pervasive developmental disorder as a neurological condition, which can result in certain services being denied coverage on the basis that such services treat a mental condition as opposed to a medical condition. Third, Kentucky's version of the legislation should not impose any dollar limitation on the mandated insurance benefit but instead require coverage for all services prescribed by the attending physician under a treatment plan formulated for the individual with ASD. Indiana's legislation permits an insurer to impose a dollar limit on the insurance coverage equal to any dollar limit imposed with respect to physical illness covered under the insurance policy. The Commission believes that the treatment plan formulated by the insured's attending physician should be the basis for determining the scope of coverage provided under the insurance policy and not an artificial dollar limitation that may result in the insured receiving inadequate coverage for necessary services under the insurance policy.

**HB91** AN ACT relating to treatments for autism spectrum disorders.

Amend KRS 304.17A-143 to provide that "autism spectrum disorders" or "ASD" has same meaning as in KRS 194A.620; prohibit deductibles, coinsurance, or co-payments for covered ASD health benefits; require the maximum benefit for ASD to increase in accordance with the nonseasonally adjusted annual average Consumer Price Index for All Urban Consumers (CPI-U), U.S. City Average, all items, between the two (2) most recent calendar years available, as published by the United States Bureau of Labor Statistics for the prior calendar year; define "child" as a person from birth through 21 years.

### **Recommendation Number 9**

The Commission recognizes that Recommendation Number 8 is ambitious. Although the Commission encourages Kentucky's policy makers to be bold in addressing the need to improve insurance coverage for individuals diagnosed with ASD, the Commission equally recognizes the political difficulties in enacting a broad insurance mandate for services to individuals with ASD during a time of increasing health care costs and health insurance premiums. Accordingly, if Kentucky's legislators and executive branch are not prepared to enact legislation modeled after the Indiana legislation described in Recommendation Number 8, with the modifications noted in Recommendation Number 8, the Commission makes the following recommendations, which should serve as interim measures until such time as the Kentucky General Assembly and the Governor of Kentucky are prepared to fully implement Recommendation Number 8. Specifically, the Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation amending KRS 304.17A-143 to expand the mandated benefit of \$500 per month for children covered under a health benefit plan to all children diagnosed with any condition identified under ASD. Currently, KRS 304.17A-143 limits the insurance benefit to children diagnosed with autism. In addition, the Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation amending KRS 304.17A-143 and 806 KAR 17:460 to eliminate the imposition of any deductibles, coinsurance, and co-payments to this benefit, as well as to provide that the \$500 per month benefit shall increase annually by a percentage equal to the percentage increase in the Cost of Living Index for the prior year. The Kentucky Office of Insurance should also amend the definition of therapeutic or rehabilitative care set forth in 806 KAR 17:460(5) to include within this definition both Applied Behavior Analysis (ABA) therapy as well as other evidenced-based therapies that have been widely documented to improve the verbal, learning, social and other skills of children with ASD. The \$500 per month benefit for therapeutic, respite and rehabilitative services for a child with ASD should be on a "first dollar" basis, thereby ensuring that the full benefit is available for children with ASD covered under a health benefit plan, and the monthly benefit should keep pace with the rate of inflation. The Commission also recommends that the Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation amending KRS 304.17-310 to specifically include ASD with mental retardation and physical disability as a condition which will not preclude a child from continuing to be covered under a family health insurance policy. KRS 304.17-310 currently mandates the continuation of coverage for children under the family health insurance policy, regardless of age, who are incapable of self-sustaining employment by reason of mental retardation or physical disability. Finally, advocacy groups involved in ASD should be encouraged to aggressively inform all parents and caregivers of children with any condition identified under ASD of the existence of this statutory mandate for all fully insured health benefit plans issued or renewed in Kentucky.

The recommendations set forth in this Recommendation Number 9, if implemented, would clearly improve insurance coverage for insureds diagnosed with ASD but, in the opinion of the Commission, would not be as effective as Recommendation Number 8 in assisting insureds diagnosed with ASD to access critical services.

**HB91** Amend KRS 304.17A-143 to provide that "autism spectrum disorders" or "ASD" has same meaning as in KRS 194A.620; prohibit deductibles, coinsurance, or co-payments for covered ASD health benefits; require the maximum benefit for ASD to increase in accordance with the nonseasonally adjusted annual average Consumer Price Index for All Urban Consumers (CPI-U), U.S. City Average, all items, between the two (2) most recent calendar years available, as published by the United States Bureau of Labor Statistics for the prior calendar year; define "child" as a person from birth through 21 years.

#### **RECOMMENDATION NUMBER 10**

The Commission carefully considered the formulation of a plan for the identification of individuals of all ages with ASD and the creation of a statewide ASD registry. The Commission believes that, based upon comments received at public hearings held to consider the preliminary draft of this Report as well as at meetings of the full Commission, there currently exists strong opposition by parents of children with ASD to the creation of a statewide ASD registry. The Commission does not therefore believe that the creation of a statewide ASD registry at this juncture is politically feasible. The Commission does however recognize that, if the Program is created, the Program will gather information regarding individuals in Kentucky with ASD who receive services through the Program. Although the Program will be required under existing law to maintain the confidentiality of such information, the Program will be able to identify those individuals with ASD residing in Kentucky who are receiving services through the Program. Accordingly, the more success the Program achieves in facilitating the delivery of services to Kentuckians with ASD, the more certainty will exist in the determination of the actual number of Kentuckians of all ages with ASD.

NOT ADDRESSED

#### **RECOMMENDATION NUMBER 11**

Advocacy groups involved in ASD should consider formally requesting Kentucky's federal congressional delegation to introduce legislation amending the federal Employee Retirement Income Security Act (ERISA) to incorporate a mandate for covered insureds diagnosed with ASD comparable to the mandate set forth in KRS 304.17A-143 (as amended in accordance with Recommendation Number 8) with respect to all self-funded health insurance plans governed under ERISA. These advocacy groups should also consider formally requesting government employers with self-funded plans to include a comparable benefit in their health insurance plans for covered insureds diagnosed with ASD.

NOT ADDRESSED

## **RECOMMENDATION NUMBER 12**

The stated mission of the Program should include the development of a comprehensive training plan for the systematic training of professionals and paraprofessionals to deliver necessary services to individuals with ASD, their families and caregivers. Consistent with House Bill 296, the Program should utilize the Kentucky Autism Training Center to implement the comprehensive training plan pursuant to a written contract that clearly sets forth the duties and obligations of the Kentucky Autism Training Center and the goals and objectives of the Program, and that creates appropriate oversight of, and requires accountability from, the Kentucky Autism Training Center. In turn, the Kentucky Autism Training Center, consistent with its statutory duties, should maintain extension partnerships at the public universities in Kentucky to create a statewide model for delivery of training to pre-service and service providers and evaluators in their respective regions that will incorporate best practices, which is defined by the Kentucky Department of Mental Health and Mental Retardation (DMHMR) as a continuum of practices and programs ranging from promising to evidence-based to science-based. University partners will be expected to provide an approved plan for training pre-service and service providers and evaluators in their region as well as a plan for tracking and monitoring the quantitative and qualitative effectiveness of services delivered to individuals with ASD, their families and caregivers in their region in order to receive and maintain grants approved through the Program. The public universities should also be encouraged to develop associate, baccalaureate and graduate service and training programs and research opportunities that are staffed by both faculty and students. The Commission recommends that the Kentucky General Assembly increase the annual funding provided to the Kentucky Autism Training Center to a level sufficient to enable it to perform its traditional training functions as well as the training functions envisioned in this Recommendation. Private universities and colleges that choose to train pre-service and service providers and evaluators as part of their academic and public service missions should not be precluded from also establishing extension partnerships with the Kentucky Autism Training Center.

The Program should also enter into memoranda of agreements with other regional centers that may include, without limitation, education cooperatives, regional early childhood training centers and community mental health centers, in order to coordinate the education and training of educators, health care providers and other service providers who interact on a professional basis with individuals with ASD as well as to coordinate the education and training of families and caregivers of individuals with ASD. The Program should utilize these regional centers to develop statewide training activities that are coordinated and collaborative, are sensitive to and based on local needs, are individualized for specific type of service provider, and are continuously monitored for outcomes. In developing statewide training activities, the regional centers should incorporate the following:

The conduct of periodic surveys of educators, health care providers, other service providers and individuals with ASD, their families, and caregivers to assess the quantitative and qualitative aspects of services provided.

The utilization of the results of the periodic surveys to determine the fiscal and programmatic needs of educators, health care providers, other service providers, and individuals with ASD,

their families, and caregivers, and the dissemination of such results and determinations to Kentucky's policy makers including the Office of the Governor and the General Assembly.

The periodic assessment of efforts in other states in providing services to individuals with ASD, their families and caregivers, and the formulation of recommendations to policy makers, educators, health care providers, other service providers, families and caregivers, where appropriate, regarding the implementation of successful practices in other states.

The provision of research opportunities to assess the quality and effectiveness of services, the provision of best practices' training, and the provision of supportive care for parents and caregivers through continued public funding and the development of private source funding streams.

As part of the comprehensive training plan, the Program should identify regional centers that are willing to review, assemble, formulate, update and disseminate information regarding best practices for treating individuals with ASD to educators, health care providers, other service providers, families and caregivers in their region, and the Program should enter into memorandum of agreements with these regional centers to provide training on a regular basis to these individuals that incorporate best practices for treating individuals with ASD. In developing statewide training activities, the regional centers should incorporate the following:

The application of best practices to training techniques that includes direct observation, feedback and coaching, follow-up, and access to ASD consultants.

The development of local training of trainers including through direct interactions with individuals with ASD, structured problem solving, and coordinated planning and implementation of strategies.

The establishment of accountability in publicly funded service systems, the creation of incentives for training service providers, and the development of the systematic compilation and reporting of outcomes.

The development of effective systems to timely disseminate current information regarding best practices to educators, health care providers, other service providers, and families and caregivers.

The development of a systematic approach to the incorporation of best practices in public and private school systems and with providers of services to individuals with ASD. The Program should have the statutory authority to contract with entities in the private sector, including non-profit organizations, to assist in the training of educators, health care providers and other service providers as well as the education and training of families and caregivers of individuals with ASD.

Require the program to develop a comprehensive training plan and contract with the Kentucky Autism Training Center to implement the plan.

[HB 109](#) (BR 419) –An Act relating to autism spectrum disorders – require the program to develop a comprehensive training plan and contract of a comprehensive training and contract with Kentucky Autism Training Center to implement the plan

### **RECOMMENDATION NUMBER 13**

The Program should promote the creation of a comprehensive resource network, including interagency transition teams within agencies responsible for providing services to individuals with ASD, to help facilitate successful transitions for individuals with ASD from childhood to adulthood. The Program should pursue the following strategies in developing the resource network:

Seek Program representation on the Kentucky Interagency Transition Council for Persons with Disabilities.

Seek Program representation on regional Interagency Transition Teams.

Enter into memorandum of agreements with the state agencies responsible for administering programs and services for adults with disabilities such as vocational rehabilitation, supported living and supported employment to help assist individuals with ASD in making the transition from childhood to adulthood including transitioning from the public school system or private school to employment within a workplace environment appropriately structured to enable the adult with ASD to perform a job that matches the demands of the position with the skills and capabilities of the individual.

Assist the Office of Vocational Rehabilitation in expanding services for individuals with ASD to address their diverse range of needs, limitations and challenges. The expansion of services for individuals with ASD should focus particularly on social skills training, including strategies to develop communication skills, as well as support to address restrictive, repetitive and/or stereotyped patterns of behavior that might otherwise preclude these individuals from securing employment. Assistance should also be provided to the Office of Vocational Rehabilitation in obtaining increased supported employment funding from the Kentucky General Assembly to adequately provide these services.

Provide general and ASD-specific training to participating state agencies that targets both the development and the implementation of comprehensive transition plans for individuals with ASD.

Identify and make available to participating agencies and appropriate service providers resources such as books, videos and other appropriate information to address ASD- specific issues for instruction and generalization of skills across settings.

Incorporate both person-centered and practical strategies into individual plans, such as Individualized Transition Plans (ITPs) and Individualized Plans for Employment (IPEs), as a means to create better outcomes in transition.

Encourage the teaching of self-determination skills as a component of the transition process.

Develop, disseminate and maintain a current reference guide that provides a description of agencies and services provided to individuals with ASD.

Identify schools and agencies that are demonstrating exemplary implementation of transition strategies and activities with positive outcomes for students. Provide incentives for these successful programs to become “model” or “demonstration” sites for other schools and agencies.

Develop requests for proposals for schools and other adult service agencies to develop state-of-the-art programs for transition from childhood to adulthood based on the latest evidence-based practices and innovative ideas. The Program should also have the statutory authority and qualified staff to collaborate with the Office of Vocational Rehabilitation to investigate programs in other states that encourage employers to train, support and hire individuals with ASD. Based on reliable data and findings regarding the effectiveness of these programs in accomplishing their stated mission, the Program’s staff should have the authority to make recommendations to policy makers and the public regarding the establishment of comparable programs in the Commonwealth of Kentucky.

**HB 109 (BR 419)** –An Act relating to autism spectrum disorders - require the program to enter into an interagency agreement with the Kentucky Department of Education for the effective delivery of services to children with ASD;

#### **RECOMMENDATION NUMBER 14**

The Legislative Research Commission should establish a permanent subcommittee of the Interim Joint Committee on Health and Welfare of the Kentucky General Assembly to focus on issues pertaining to ASD during each annual interim period of the General Assembly. The focus of the subcommittee should be to review any administrative regulations adopted that pertain to the Program or its duties and obligations, as well as other issues involving ASD. The subcommittee should also be responsible for reviewing and discussing any proposed legislation necessary to effectuate the recommendations of the Kentucky Commission on Autism Spectrum Disorders or to otherwise enhance the quality of life for individuals with ASD, their families and caregivers. These issues may include issues pertaining to the education of individuals with ASD, the health care needs of individuals with ASD, and the services and supports needed by individuals with ASD in order to lead lives with dignity and opportunity.

NOT ADDRESSED

#### **RECOMMENDATION NUMBER 15**

The Kentucky Department of Education should prepare an updated version of the statewide Technical Assistance Manual on Autism for Kentucky Schools that was published in 1997 in order to incorporate more recent data, best practices, strategies and other relevant information developed since 1997 in order to assist school districts and educators to more effectively educate children with ASD. The Department of Education should encourage all school districts within the Commonwealth to fully utilize the Manual in order to ensure that all teachers of children with ASD as well as other school personnel who interact on a professional level with these children are fully informed of the unique challenges associated with the

education of children with ASD and the proven strategies known to enhance the learning experience of the child. The Kentucky Department of Education should be proactive in seeking input from parents, guardians, caregivers and other concerned citizens as part of the process of updating the Manual. Finally, the Kentucky Department of Education should adopt a policy of updating the Manual on a periodic basis to ensure the effectiveness and relevancy of the Manual in assisting all Kentucky school districts to provide, to the greatest extent possible, a meaningful and outcome-driven educational experience for children with ASD.

[HB 109](#) (BR 419) –An Act relating to autism spectrum disorders -require the Department of Education to update the statewide Manual on Autism.

## **TIMELINE FOR IMPLEMENTING AND MONITORING THE RECOMMENDATIONS OF THE PLAN STATEWIDE**

Legislation to implement the recommendations of the Commission was drafted and reviewed by all necessary stakeholders prior to the commencement of the 2007 regular session of the Kentucky General Assembly, and the legislation should be introduced during the 2007 regular session and each subsequent session of the General Assembly until all legislation necessary to implement the recommendations of the Commission has been enacted into law. The Commission affirmatively recognizes that the sustained, focused and continuing education of public officials and other policy makers regarding the needs of individuals with ASD, their families and caregivers will be critical to the implementation of the recommendations set forth in this Report as well the adoption of other public policy initiatives intended to address the growing challenges to society presented by ASD. Effective advocacy by groups and individuals involved with ASD will be critical to the successful implementation of the recommendations of the Commission. These groups and individuals should collaborate to the greatest extent possible in order to avoid factionalism and conflict that may cause confusion among legislators and other policy makers when considering policy initiatives designed to improve the services and supports for individuals with ASD and their families and caregivers. A focused advocacy effort within a single umbrella organization could help facilitate the obtaining of grants, private funding and donations in order to effectively advocate for the enactment of legislation, change in administrative policies, and other matters of concern to individuals with ASD and their families and caregivers.

If enabling legislation necessary to implement the recommendations of the Commission is timely enacted into law, Kentucky should establish as a goal the complete implementation of all of the recommendations of the Commission, including the provision of adequate funding for the implementation of all of the recommendations, by the year 2016.

## CLOSING

The positive reception of the HB 109 and HB 91 by the legislature provides advocates with sustained hope that there will be positive outcomes during the 2008 session. Both of the bills, when passed and enacted into law will provide individuals with ASD and their families needed support and services that are currently not available in Kentucky.

The U.S. House and Senate are both currently working on legislation to promote support, services and research in the area of Autism. On June 22, 2007 the Senate Fully Funds the Combating Autism Act

The Senate Labor, Health and Human Services and Education Appropriations Committee approved its version of the FY 2008 spending bill, including a 52 percent increase for autism-related activities at the CDC and Health and Resources Services Administration. This is the full amount authorized for these programs under the Combating Autism Act.

Specifically, the bill provides \$37 million for the Neurodevelopmental Disabilities Residency Program and the Developmental-Behavioral Pediatrics Training Program, which both provide long-term, graduate-level interdisciplinary training, as well as services and care for infants, children and adolescents with disabilities. The Committee also provided \$16.5 million for CDC's autism programs, which include the Centers for Autism and Developmental Disabilities Epidemiology (CADDRE) and the Autism and Developmental Disabilities Monitoring (ADDM) Network. The House also provided \$16.5 million for these programs.

Because funding levels for autism are different in the House and Senate bills, they will need to be worked out in a conference committee. (<http://www.autism-society.org/site/MessageViewer/>, June 22, 2007)

The Council urges all advocates, legislators at the state and federal level to continue to support measures that will enhance the lives of persons with autism spectrum disorders.