



CREATING A MORE SECURE FUTURE
FOR
KENTUCKIANS WITH AUTISM SPECTRUM
DISORDERS

ANNUAL UPDATE 2008



The Commonwealth of Kentucky

Cabinet for Health Services

On Behalf of



**THE KENTUCKY COUNCIL ON DEVELOPMENTAL
DISABILITIES**

Presents:

2008 ANNUAL UPDATE

An Annual Submitted in Accordance with House Bill 296 to:

Governor Steve L. Beshear

And the General Assembly

October 1, 2008



KENTUCKY COUNCIL ON DEVELOPMENTAL DISABILITIES

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September 18, 2008

The Honorable Steven L. Beshear
Governor of Kentucky
700 Capitol Avenue
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Dear Governor Beshear,

Pursuant to house Bill 296, the Kentucky Council on Developmental Disabilities has been granted the authority and responsibility to monitor the implementation of the comprehensive state plan set forth in the Report until October 1, 2015. Enclosed please find the annual update and recommendations of the Kentucky Commission on Autism Spectrum Disorders State Plan of which the Kentucky Council on Developmental Disabilities has had the opportunity to monitor.

The passage of HB 109 this upcoming 2009 Legislative session would have a positive affect on many individuals with Autism Development Disorders and their families. The Council looks forward to monitoring the future success of HB 109 and of the State Plan's overall achievement.

Sincerely,

Donna Brinkman

Donna Brinkman
Chairperson

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Pat Seybold, Executive Director, KY Council on Developmental Disabilities
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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)

Autism is defined in the Diagnostic and Statistical manual of Mental Disorders (DSM-IV). 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: http://www.autism.net.au/Autism_Definition.htm, 7/2008)

Autism is a complex developmental disability that causes problems with social interaction and communication. Symptoms usually start before age three and can cause delays or problems in many different skills that develop from infancy to adulthood. (Reference: www.nichd.nih.gov/health/topics/asd.cfm, 10/2008) 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; 10/2008).

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 B](#) 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. [Appendix C](#) to this Report sets forth the members of the Commission and, to the extent applicable, the organization which such individual represented on the Commission.

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.

ANNUAL UPDATE

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 1st 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 2008 legislative session one bill was filed HB 188. This bill passed the House of Representatives but was not heard in the Senate. This bill originally included most of the recommendations from the Commission report. However, an amendment was made in February and most of the language was removed. The final version of the bill was the creation of the 'Program on Autism'.

[HB 188/FN \(BR 148\) - S. Brinkman, D. Butler, M. Dossett, C. Embry Jr., D. Floyd, C. Hoffman, D. Horlander, B. Montell, R. Palumbo, T. Riner, S. Rudy, A. Webb-Edgington, A. Wuchner](#)

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; 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"; permit a religious exemption for testing a child with ASD; amend the interagency agreement with the Department of Education to coordinate services; require the Department of Education to update the

statewide Manual on Autism; 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.

HB 188 - AMENDMENTS

HCS/FN - Delete previous provisions of the bill; add new language to amend KRS 194A.620 to establish an office to coordinate and monitor training, treatments, supports and services for individuals of all ages with an ASD and their families and caregivers; delete references to the autism commission; amend KRS 194A.622 to establish the Office for Autism Spectrum Disorders attached to the Cabinet for Health and Family Services; delete references to the Commission on Autism Spectrum Disorders which ceased to exist October 1, 2006; require the office to implement the recommendations of the Commission on Autism Spectrum Disorders, to the extent possible; require the office to service as a centralized coordinating body, promote the creation of a comprehensive resource network and work with the Kentucky Autism Training Center to develop a comprehensive training plan, to the extent possible; require the office to prepare and submit an annual report in coordination and consultation with the Kentucky Council on Developmental Disabilities; permit the office to accept gifts, grants and bequests.

HFA (1, S. Brinkman) - Retain provisions of the bill; add a representative from the Kentucky Council on Developmental Disabilities to the regional teams of the comprehensive resource network.

HFA (2, S. Brinkman) - Retain provisions of the bill; add reporting requirements and require an annual report due October 1.

Jan 8-introduced in House

Jan 10-to Health & Welfare (H)

Jan 30-posted in committee

Feb 14-reported favorably, 1st reading, to Calendar with Committee Substitute

Feb 15-2nd reading, to Rules; floor amendment (1) filed to Committee Substitute

Feb 19-posted for passage in the Regular Orders of the Day for Wednesday, February 20, 2008

Feb 20-floor amendment (2) filed to Committee Substitute

Mar 11-3rd reading, passed 97-0 with Committee Substitute, floor amendments (1) and (2)

Mar 12-received in Senate

Mar 14-to Health & Welfare (S)

Mar 20-reassigned to Appropriations & Revenue (S)

<http://www.lrc.ky.gov/record/08RS/HB188.htm> 7/08

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 188 :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.

The Bill did not pass.

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 188: 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.

The Bill did not pass.

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 188: 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.

This portion was removed via an amendment.

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 188: 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.

This portion was removed via an amendment.

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 6th 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 188: 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"; permit a religious exemption for testing a child with ASD;

This portion was removed via an amendment.

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, a copy of which is included as Appendix M to this Report, 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.

Not addressed

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.

Not Addressed

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. A more detailed description of this recommendation is set forth in Appendix N to this Report. 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 188: require the program to develop a comprehensive training plan and contract with the Kentucky Autism Training Center to implement the plan;

This portion was removed via an amendment.

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 188: 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;

This portion was removed via an amendment.

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 188: require the Department of Education to update the statewide Manual on Autism

This portion was removed via an amendment.

*** The Department of Education, the Kentucky Autism Training Center and the Human Development Institute at the University of Kentucky has received a grant to address this recommendation

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.

DRAFT LEGISLATION FOR IMPLEMENTING THE COMPREHENSIVE STATE PLAN DEVELOPED BY THE COMMISSION

The implementation of many of the recommendations of the Commission set forth in the Report will require the enactment of legislation in the Commonwealth of Kentucky. The Commission believes that most, if not all, of those recommendations requiring statutory changes to Kentucky law will be embodied in proposed legislation that will be filed in advance of the 2007 regular session of the Kentucky General Assembly. The Commission encourages individuals with ASD, their families and caregivers, service providers and other interested citizens to monitor such legislation, whether through the internet, interaction with their elected State Senators and Representatives, active participation in advocacy and support groups involved with ASD, or through other means, both during the 2007 regular session of the Kentucky General Assembly and any subsequent session of the Kentucky General Assembly in which any such legislation is introduced.

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 person with autism spectrum disorders.

Appendix A



Glossary of Terms

ABA	=	Applied Behavior Analysis
ARC	=	Admissions and Release Committee
ASD	=	Autism Spectrum Disorders
ASDAC	=	Autism Spectrum Disorders Advisory Consortium
CMS	=	Center for Medicaid and Medicare Services
DMHMR	=	Department of Mental Health and Mental Retardation
DMS	=	Department of Medicaid Services
DSM-IV-TR	=	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR®)
EPSDT	=	Early and Periodic Screening, Diagnosis and Treatment Program
ERISA	=	Employee Retirement Income Security Act
HCBS	=	Home and Community Based Services
IDEIA	=	Individuals with Disabilities Education Improvement Act
IEP	=	Individual Education Plan
IPE	=	Individualized Plans for Employment
ITP	=	Individualized Transitions Plans
KCDD	=	Kentucky Council on Developmental Disabilities
KEIS	=	Kentucky Early Intervention System
MCHAT	=	Modified Checklist for Autism in Toddlers
NRC	=	National Research Council
SIAC	=	State Interagency Council for Services to Children with an Emotional Disability

Appendix B



House Bill 296

1. **AN ACT relating to the Kentucky Commission on Autism Spectrum Disorders.**

Be it enacted by the General Assembly of the Commonwealth of Kentucky:

2. **SECTION 1. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO READ AS FOLLOWS:**

(1) The Kentucky General Assembly finds that the various departments, agencies, and entities providing care and treatment to individuals with an autism spectrum disorder, otherwise known as ASD, often do so without the necessary collaboration or sharing of information on training, treatments, and services. The General Assembly declares that the purpose of Sections 1 and 2 of this Act is to establish:

(a) A commission to develop and monitor the implementation of a comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with an ASD; and

(b) A timeline for implementing and monitoring the recommendations of the plan, as appropriate, in all geographic regions of the state.

(2) As used in Sections 1 and 2 of this Act, "autism spectrum disorders" or "ASD" has the same meaning as "pervasive developmental disorders" in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV). The term includes five (5) diagnostic subcategories:

(a) Autistic disorder;

(b) Asperger's disorder;

(c) Pervasive disorder not otherwise specified;

(d) Rett's disorder; and

(e) Childhood disintegrative disorder.

3. **SECTION 2. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO READ AS FOLLOWS:**

(1) There is hereby created the Kentucky Commission on Autism Spectrum Disorders, which shall consist of the following twenty-three (23) members who shall be initially appointed by July 1, 2005:

(a) The secretary of the Cabinet for Health Services or his or her designee;

(b) The secretary of the Cabinet for Families and Children or his or her designee;

(c) The commissioner of the Department for Medicaid Services or his or her designee;

- (d) The director of the Kentucky Early Intervention System, Department for Public Health or his or her designee;
- (e) The commissioner of the Department for Mental Health and Mental Retardation Services or his or her designee;
- (f) The director of the Office of Aging Services or his or her designee;
- (g) The chair of the Council on Postsecondary Education or his or her designee;
- (h) The director of the Division of Exceptional Children Services or his or her designee;
- (i) The commissioner of the Department of Vocational Rehabilitation or his or her designee;
- (j) The commissioner of the Department of Insurance or his or her designee;
- (k) Two (2) nonvoting ex officio members from the House of Representatives, one (1) representing the majority party and one (1) representing the minority party, who shall be appointed by and serve at the pleasure of the Speaker of the House;
- (l) Two (2) nonvoting ex officio members from the Senate, one (1) representing the majority party and one (1) representing the minority party, who shall be appointed by and serve at the pleasure of the President of the Senate;
- (m) Four (4) professional ASD treatment providers, including at least one (1) mental health provider, one (1) physical health provider, and one (1) complex needs consultant from a special education cooperative, to be appointed by the Governor; and
- (n) Five (5) parents, including three (3) who, at the time of their appointment to the commission, have a child with an ASD who is under eighteen (18) years of age and two (2) who, at the time of their appointment to the commission, have a child with an ASD who is eighteen (18) years of age or older, to be appointed by the Governor.
- (2) In making appointments to the commission, the Governor shall ensure broad representation of Kentucky's citizens who are concerned with the health and quality of life of individuals with an ASD, may appoint individuals who are also members of the Kentucky Council on Developmental Disabilities, and shall consider candidates recommended by the Autism Spectrum Disorders Advisory Consortium of Kentucky.
- (3) Members shall serve without compensation, but shall be reimbursed for their actual expenses incurred in the performance of commission duties in accordance with KRS 45.101 and administrative regulations promulgated thereunder. Members of the commission shall serve until the commission ceases to exist, a successor has been appointed, or until removed for good cause.
- (4) The Cabinet for Health Services and the Cabinet for Families and Children shall provide staff and administrative support for the commission.

- (5) The chair of the commission shall be designated by the Governor and may be a member in addition to those listed in subsection (1) of this section. The chair of the commission shall establish procedures for the commission's internal procedures.
- (6) The commission shall meet at least three (3) times per year. The commission shall also meet as often as necessary to accomplish its purpose upon the call of the chair, the request of four (4) or more members, or the request of the Governor.
- (7) The commission shall develop a comprehensive state plan for creating an integrated system of training, treatments, and services for individuals of all ages with an ASD. The commission shall utilize relevant data and research and consult with appropriate professionals, agencies, institutions, and organizations representing the private and public sectors, including the Kentucky Autism Training Center, to develop the state plan. The state plan shall include the following:
- (a) An assessment of the diverse needs for services and supports for individuals with an ASD;
- (b) Identification of state, federal, private, and any other appropriate funding sources;
- (c) Development of a comprehensive training plan, which shall include the Kentucky Autism Training Center, to meet training needs;
- (d) An analysis of standards for provider training and qualifications, best practice standards for services, and the need for additional service providers;
- (e) An evaluation of health benefit plans and insurance coverage for the treatment of ASD;
- (f) A plan for the identification of individuals of all ages with an ASD and for the creation of a statewide ASD registry;
- (g) An analysis of program and service eligibility criteria;
- (h) An assessment of the need for coordinated, enhanced, and targeted special education and treatment programs for children with an ASD; and
- (i) A timeline for implementing and monitoring the recommendations of the plan statewide. The timeline shall include input from the following:
1. The Cabinet for Health Services;
 2. The Cabinet for Families and Children;
 3. The Department for Medicaid Services;
 4. The Department for Public Health;
 5. The Department for Mental Health and Mental Retardation Services;
 6. The Kentucky Early Intervention System;

7. The Division of Exceptional Children Services;

8. The Department of Vocational Rehabilitation;

9. The Department of Insurance;

10. The Department of Education;

11. The Council on Postsecondary Education; and

12. Other appropriate agencies, professionals, institutions and organizations representing the public and private sectors, including the Kentucky Autism Training Center.

(8) Based upon the comprehensive state plan for an integrated system of training, treatment, and services for individuals of all ages with an ASD, the commission shall make recommendations regarding legislation, administrative regulations, and policies to the Governor and the General Assembly on the following:

(a) Needs for services and supports for individuals who have an ASD;

(b) Funding needs and sources, including state, federal, private, and any other appropriate funding sources;

(c) Training needs and a plan to implement a comprehensive training system, which shall include the Kentucky Autism Training Center;

(d) Standards for provider training and qualifications, best practice standards for services, and the need for additional providers;

(e) Goals for developing health benefit plans that provide insurance coverage for the treatment of ASD;

(f) A plan for the identification of individuals of all ages with an ASD and for the creation of a statewide ASD registry;

(g) Consistent program and service eligibility criteria;

(h) The need for coordinated, enhanced, and targeted special education and treatment programs for individuals with an ASD; and

(i) 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.

(9) The commission shall submit the comprehensive state plan and recommendations to the Governor, the Kentucky Council on Developmental Disabilities, and the Legislative Research Commission by October 1, 2006, at which time the commission shall cease to exist unless reauthorized by the General Assembly.

(10) The Kentucky Council on Developmental Disabilities shall appoint a subcommittee, which shall include members of the commission, to monitor the implementation of the state plan as developed by the commission beginning October 1, 2006. The subcommittee shall prepare and the council shall submit a report to the Governor and Legislative Research Commission that assesses progress in the implementation of the state plan and that makes recommendations on the need for modifications to the state plan as developed by the Kentucky Commission on Autism Spectrum Disorders. The subcommittee shall prepare and the council shall submit the report as it deems appropriate, but no less than biennially, until October 1, 2015.

4. **Section 3. KRS 194A.135 is amended to read as follows:**

- (1) **The Kentucky Council on Developmental Disabilities is created within the cabinet.**
- (2) **The Kentucky Council on Developmental Disabilities is established to comply with the requirements of the Developmental Disabilities Act of 1984 and any subsequent amendment to that act.**
- (3) **The members of the Kentucky Council on Developmental Disabilities shall be appointed by the Governor to serve as advocates for persons with developmental disabilities. The council shall be composed of twenty-six (26) members.**
- (a) **Ten (10) members shall be representatives of: the principal state agencies administering funds provided under the Rehabilitation Act of 1973 as amended; the state agency that administers funds provided under the Individuals with Disabilities Education Act (IDEA); the state agency that administers funds provided under the Older Americans Act of 1965 as amended; the single state agency designated by the Governor for administration of Title XIX of the Social Security Act for persons with developmental disabilities; higher education training facilities, each university-affiliated program or satellite center in the Commonwealth; and the protection and advocacy system established under Public Law 101-496. These members shall represent the following:**
 1. Department for Vocational Rehabilitation;
 2. Department for the Blind;
 3. Division of Exceptional Children, within the Department of Education;
 4. Office of Aging Services;
 5. Department for Medicaid Services;
 6. Department of Public Advocacy, Protection and Advocacy Division;
 7. University-affiliated programs;
 8. Local and nongovernmental agencies and private nonprofit groups concerned with services for persons with developmental disabilities;

9. Department for Mental Health and Mental Retardation Services; and
 10. Department for Public Health, Division of Adult and Child Health.
- (b) At least sixty percent (60%) of the members of the council shall be composed of persons with developmental disabilities or the parents or guardians of persons, or immediate relatives or guardians of persons with mentally impairing developmental disabilities, who are not managing employees or persons with ownership or controlling interest in any other entity that receives funds or provides services under the Developmental Disabilities Act of 1984 as amended and who are not employees of a state agency that receives funds or provides services under this section. Of these members, five (5) members shall be persons with developmental disabilities, and five (5) members shall be parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves. Six (6) members shall be a combination of individuals in these two (2) groups, and at least one (1) of these members shall be an immediate relative or guardian of an institutionalized or previously institutionalized person with a developmental disability or an individual with a developmental disability who resides in an institution or who previously resided in an institution.**
 - (c) Members not representing principal state agencies shall be appointed for a term of three (3) years. Members shall serve no more than two (2) consecutive three (3) year terms. Members shall serve until their successors are appointed or until they are removed for cause.**
 - (d) The council shall elect its own chair, adopt bylaws, and operate in accordance with its bylaws. Members of the council who are not state employees shall be reimbursed for necessary and actual expenses. The cabinet shall provide personnel adequate to insure that the council has the capacity to fulfill its responsibilities. The council shall be headed by an executive director. If the executive director position becomes vacant, the council shall be responsible for the recruitment and hiring of a new executive director.**
 - (4) The Kentucky Council on Developmental Disabilities shall:**
 - (a) Develop, in consultation with the cabinet, and implement the state plan as required by Part B of the Developmental Disabilities Act of 1984, as amended, with a goal of development of a coordinated consumer and family centered focus and direction, including the specification of priority services required by that plan;**
 - (b) Monitor, review, and evaluate, not less often than annually, the implementation and effectiveness of the state plan in meeting the plan's objectives;**
 - (c) To the maximum extent feasible, review and comment on all state plans that relate to persons with developmental disabilities;**
 - (d) Submit to the secretary of the cabinet, the commissioner of the Department for Mental Health and Mental Retardation Services, and the Secretary of the United States Department of Health and Human Services any periodic reports on its activities as**

required by the United States Department of Health and Human Services and keep records and afford access as the cabinet finds necessary to verify the reports;

- (e) Serve as an advocate for individuals with developmental disabilities and conduct programs, projects, and activities that promote systematic change and capacity building;**
 - (f) Examine, not less than once every five (5) years, the provision of and need for federal and state priority areas to address, on a statewide and comprehensive basis, urgent needs for services, supports, and other assistance for individuals with developmental disabilities and their families; and**
 - (g) Prepare, approve, and implement a budget that includes amounts paid to the state under the Developmental Disabilities Act of 1984, as amended, to fund all programs, projects, and activities under that Act.**
- (5) The Kentucky Council on Developmental Disabilities shall appoint a subcommittee, which shall include members of the Kentucky Commission on Autism Spectrum Disorders, to monitor the implementation of the state plan as developed by the commission beginning October 1, 2006. The subcommittee shall prepare and the council shall submit the report as required under subsection (10) of Section 2 of this Act.

Appendix C



Members of the ASD Commission

KENTUCKY COMMISSION ON AUTISM SPECTRUM DISORDERS

Representative	Scott W. Brinkman, Chair 6001 Two Springs Lane Louisville, KY 40207 (502) 582-1601 sbrinkman@ogdenlaw.com	Representative	Charles E. "Chuck" Meade P.O. Box 222 Allen, KY 41647 (606) 285-0196 cemeade1@bellsouth.net
Senator	Denise Harper Angel 2521 Ransdell Ave. Louisville, KY 40204 (502) 452-9130 dhangel@bellsouth.net	Senator	Damon Thayer 102 Grayson Way Georgetown, KY 40324 (859) 621-6956 LRC contact: susan.rambo@lrc.ky.gov
Cabinet for Health and Human Services Secretary	Mark Birdwhistell 275 East Main St. Frankfort, KY 40621 (502) 564-7042 Mark.Birdwhistell@ky.gov	Department for Medicaid Services Commissioner	Shannon Turner 275 East Main St. Frankfort, KY 40621 (502) 564-4321 ShannonR.Turner@ky.gov
Department for Public Health Kentucky Early Intervention System Director	Germaine O'Connell 275 East Main Street Frankfort, KY 40601 (502) 564-3756 Germaine.O'Connell@ky.gov	Professional ASD Treatment Provider Mental Health	Lisa A. Ruble, Ph.D 1358 South First Street Louisville, KY 40209 (502) 852-5331 lisa.ruble@louisville.edu
Department for MH/MR Services Commissioner	John Burt 100 Fairoaks Lane Frankfort, KY 40621 (502) 564-4527 John.Burt@ky.gov	Professional ASD Treatment Provider Physical Health	Thomas H. Pinkstaff, M.D. #10 Court of Champions Nicholasville, KY 40356 Thpink01@gwise.louisville.edu
Office of Aging Services Director	Bill Cooper 275 East Main St. 3W-F Frankfort, KY 40621 (502) 564-6930 Bill.Cooper@ky.gov	Professional ASD Treatment Provider	Carla M. Jordan 2095 Kentucky 1304 Bimble, KY 40915 Carla.Jordan@KEDC.org
Council on Postsecondary Education Director Designee (Linda Linville) Linda.Linville@ky.gov	Thomas Layzell 1024 Capital Center Dr., Suite 320 Frankfort, KY 40601 (502) 573-1555 Tom.Layzell@ky.gov	Professional ASD Complex Needs Consultant	Myra Beth Bundy, Ph.D. Eastern Kentucky University Psychology Department 104 Cammack Hall Richmond, KY 40475 (859) 622-1003 myrabeth.bundy@eku.edu
Division of Exceptional Children Director	Larry Taylor 8 th Floor, Capital Plaza Tower 500 Mero Street Frankfort, KY 40601 (502) 564-4970 ltaylor@kde.state.ky.us	Parent of Child with an ASD under 18 years of age	David K. Lane 1660 Woodlake Road Stamping Ground, KY 40379 (502) 535-5919 david@dlane.org
Office of Vocational Rehabilitation Executive Director Designee: (Carol Estes) CarolH.Estes@ky.gov	Beth Smith 209 St. Clair St., 2 nd Fl. Frankfort, KY 40601 (502) 564-4440 Beth.Smith@ky.gov	Parent of Child with an ASD under 18 years of age	Virginia E. Gibbs 601 Maryhill Lane Louisville, KY 40207 (502) 895-5363 bgibbs@turningpoint1.org
Department of Insurance Executive Director Designee: (Gene Coverston) Gene.Coverston@ky.gov	R. Glenn Jennings 215 West Main Street Frankfort, KY 40601 (502) 564-6026 Glenn.Jennings@ky.gov	Parent of Child with an ASD under 18 years of age	Trudy L. Abshire 1408 Fairlane Dr. Richmond, KY 40475 (859) 626-3555 twinmom1948@yahoo.com
Parent of Child with an ASD over 18 years of age	Gayla Hayes 401 Peebles Avenue Franklin, KY 42134 (270) 586-3367 gayla.hayes@wku.edu	Parent of Child with an ASD over 18 years of age	Cheryl R. Dunn 4485 Roosevelt Rd. Dexter, KY 42036 (270) 762-6965 cheryl.dunn@coe.murraystate.edu

Appendix D



House Bill 159

State Autism Training Center (2005 HB 159 as codified)

164.981 Definitions for KRS 164.981 to 164.9819.

As used in KRS 164.981 to 164.9819:

(1) "Autism" means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three (3), that adversely affects educational performance. Characteristics of autism include:

- (a) Irregularity and impairment in communication;
- (b) Engagement in repetitive activity and stereotyped movement;
- (c) Resistance to environmental change or change in daily routine; and
- (d) Unusual responses to sensory experience.

The term does not include children with characteristics of an emotional-behavioral disability as defined in KRS 157.200;

- (2) "Council" means the Council on Postsecondary Education in Kentucky;
- (3) "Center" means the autism training center;
- (4) "Client" means a person with the primary diagnosis of autism or autistic-like behavior; and
- (5) "Expenses" means those reasonable and customary expenditures related to training and treatment of eligible clients as defined in administrative regulations promulgated by the council pursuant to KRS 13A.

Effective: May 30, 1997

History: Amended 1997 (1st Extra. Sess.) Ky. Acts ch. 1, sec. 133, effective May 30, 1997. -- Created 1996 Ky. Acts ch. 221, sec. 1, effective July 15, 1996.

164.9811 State autism training center.

(1) The Council on Postsecondary Education in Kentucky is authorized to operate a state autism training center, including:

- (a) The acquisition by purchase, lease, gift, or otherwise of necessary lands;
- (b) The construction of necessary buildings;
- (c) The expansion, remodeling, altering, or equipping of necessary buildings; and
- (d) The making of contracts by the council or its designee with any nonprofit institution, or any state, county, or local agency for the equipment, expenses, compensation of personnel, operation, and maintenance of any facility of an agency or institution used for the purposes of KRS 164.981 to 164.9819.

(2) The council shall select and contract with a public institution of higher education to carry out the provisions of KRS 164.981 to 164.9819.

Effective: May 30, 1997

History: Amended 1997 (1st Extra. Sess.) Ky. Acts ch. 1, sec. 134, effective May 30, 1997. -- Created 1996 Ky. Acts ch. 221, sec. 2, effective July 15, 1996.

164.9813 Functions of center.

The center shall provide:

- (1) A staff that has expertise in autism and autistic-like behavior and in sensory impairments;
- (2) Individual and direct family assistance in the home, community, and school. A center's assistance should not supplant other responsibilities of state and local agencies, and each school district is responsible for providing an appropriate education program for clients of a center who are school age;
- (3) Technical assistance and consultation services, including specific intervention and assistance for a client of the center, the client's family, and the school district, and any other services that are appropriate;
- (4) Professional training programs that include developing, providing, and evaluating preservice and in-service training in state-of-the-art practices for personnel who work with the populations served by the centers and their families; and
- (5) Public education programs to increase awareness of the public about autism, autistic-related disabilities of communication and behavior, dual sensory impairments, and sensory impairments with other handicapping conditions.

Effective: July 15, 1996

History: Created 1996 Ky. Acts ch. 221, sec. 3, effective July 15, 1996.

164.9815 Authority for administrative regulations.

The council, after consultation with the center, shall promulgate administrative regulations pursuant to KRS Chapter 13A providing for:

- (1) The establishment, operation, eligibility for services, cost reimbursement, fees for services, maintenance, and government control of the center established pursuant to KRS 164.981 to 164.9819;
- (2) Standards necessary for cooperation under and compliance with any federal law with respect to grants-in-aid for client training or facilities; and
- (3) Any other administrative regulations as may be necessary to implement KRS 164.981 to 164.9819.

Effective: July 15, 1996

History: Created 1996 Ky. Acts ch. 221, sec. 4, effective July 15, 1996.

164.9817 Citizens' advisory board -- Composition.

The public institution selected pursuant to KRS 164.9811(2) shall appoint a citizens' advisory board to advise the center director on matters of policy. The advisory board shall be composed of: fifty percent (50%) parents or guardians of clients eligible for the center's program; forty percent (40%) persons from professional fields relating to autism, such as special education, psychology, hearing and speech, neurology, and pediatrics; and ten percent (10%) knowledgeable lay persons. The director of the center shall be an ex officio nonvoting member of the advisory board.

Effective: July 15, 1996

History: Created 1996 Ky. Acts ch. 221, sec. 5, effective July 15, 1996.

164.9819 Trainee teams -- Composition -- Administrative regulations regarding fees and expenses.

- (1) The primary method of providing services through the center shall be by the use of

trainee teams. A trainee team shall consist of an eligible client, a professional from a local service agency, and the client's guardian or one or both of the client's parents.

(2) The council, after consultation with the center, shall promulgate administrative regulations relating to:

(a) Fees charged to sending agencies;

(b) Reimbursement of trainee team or client expenses; and

(c) Provision of, or reimbursement for, reasonable and customary expenses incurred by trainee teams, clients, or otherwise eligible persons which are not covered by the fees charged to sending agencies. These expenses may include child care for other children of attending parents, guardians, or other persons pursuant to subsection (1) of this section.

Effective: July 15, 1996

History: Created 1996 Ky. Acts ch. 221, sec. 6, effective July 15, 1996.

Appendix E



**Definitions of Best Practices Used
by the Department of Mental Health
and Mental Retardation**

"Best Practices" is a continuum of practices and programs ranging from promising to evidence-based to science-based

Promising Practice means a practice that:

1. Incorporates the philosophy, values, characteristics and indicators of other positive and effective public health interventions.
2. Is based on guidelines, protocols, standards or preferred practice patterns that have been proven to lead to effective public health outcomes.
3. Is a process of continual quality improvement that:
 - i. Accumulates and applies knowledge about what is working and not working with the practice in different situations and contexts.
 - ii. Continually incorporates lessons learned, feedback, and analysis to lead toward improvement/positive outcomes.
 - iii. Allows for and incorporates expert review, feedback, and consensus from the public health field.
4. Has an evaluation component in place to move toward demonstration of effectiveness. It does not yet, however, have sufficient evaluation data available to demonstrate positive outcomes.

Evidence-Based Practice means a practice that has been or is being evaluated, and it:

1. Has some quantitative and qualitative data showing positive outcomes, but does not yet have sufficient research or replication-related data to support general positive public health outcomes.
2. Has been subject to expert/peer review that has determined that this particular approach or strategy has a significant level of evidence of effectiveness in public health research literature.

Science-Based Practice means a practice that results from a rigorous process of research and evaluation that indicates effectiveness in improving public health outcomes for a target population. A science-based practice:

1. Has been evaluated using a theory-based research methodology.
2. Was implemented as intended in order to clearly link positive effects to the program/practice being evaluated and not to extraneous factors.
3. Has been reviewed and substantiated by experts in the public health field according to predetermined standards of empirical research.
4. Is replicable, and produces desirable results in a variety of settings.

Source: http://mhmr.ky.gov/kdmhmrs/best_practices.asp;

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[Appendix F](#)



[Recommendations Grid](#)

Number	Recommendation	Action	Status
1	Creation on Supports for Individuals with Autism Spectrum Disorders Program	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008- Legislation successfully passed the House with floor amendment, was not heard in Senate.
2	Creation of an Advisory Board for the Program	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008 – HB 188 was amended in House; removed stipulation.
3	Developmental of a waiver for support for individuals with ASD	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008 – HB 188 was amended in House; removed stipulation.
4	Develop a non-waiver program for those who do not meet Medicaid eligibility	2007 – Not addressed 2008- Not addressed	
5	Full funding for First Steps	2007 – Not Addressed 2008 – Not Addressed	
6	Interagency agreement between the Program and the Department of Education (DOE)	2007 – Legislation introduced HB 109 (amended to include a member from DOE on the program advisory board) 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008 -HB 188 was amended in House; removed stipulation.
7	Well baby checks, 18-24 months, age 4, 6 thru 17 for ASD – treatment within 90 days	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate; was not heard in the Senate. 2008 – HB 188 was amended in House; removed stipulation.
8	Change insurance regulations to prohibit deductibles, coinsurance, or co-payments for covered ASD health benefits and other changes to promote equal access	2007 – Legislation introduced HB 91 2008 – Not Addressed	2007 -Legislation posted to committee; not heard during session

9	Change insurance regulations to prohibit deductibles, coinsurance, or co-payments for covered ASD health benefits and other changes to promote equal access	2007 – Legislation introduced HB 91 2008 – Not Addressed	2007 -Legislation posted to committee; not heard during session
10	State wide registry	2007 - Not addressed 2008 – Not Addressed	
11	State wide advocacy request Kentucky federal delegation to amend federal Employee Retirement Income Act (ERISA) to cover insured with ASD	2007 - Not addressed 2008 – Not Addressed	
12	Develop a training plan for professional and paraprofessionals under contract with KATC, develop regional centers, provide assessment, treatments and research	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate. 2008 – HB 188 was amended in House; removed stipulation. DOE, KATC and HDI has made application for a training grant. Application pending. The Autism Task force – Dept. of Ed, KATC, ECU, IHDI, received a grant for National Professional Development Center on Autism Spectrum Disorders (NPDC).
13	The Program to develop a comprehensive network, including interagency transition teams for all individual with ASD	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate. 2008 – HB 188 was amended in House; removed stipulation. DOE, KATC and HDI has made application for a training grant. Application pending
14	Establish a permanent subcommittee of the Interim Joint Committee on Health and Welfare of the KY General Assembly	2007 -Not addressed 2008 – Not Addressed	

15	Department of Education update the statewide technical assistance manual on Autism	2007 -Not addressed 2008 – Grant application	2008 -DOE, KATC and HDI filed grant application. Grant was received.
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