

**PRELIMINARY REPORT OF THE KENTUCKY
COMMISSION ON AUTISM SPECTRUM DISORDERS**

June 8, 2006

INTRODUCTION

The number of individuals diagnosed with autism spectrum disorders (ASD) ([Appendix A](#) sets forth a Glossary of Terms) has grown exponentially in recent years both nationally and in the Commonwealth of Kentucky and is becoming a crisis that threatens to overwhelm public and private organizations devoted to the care and education of persons with disabilities. Today, approximately 1 in 166 individuals born in this country will be diagnosed with ASD ([Chakrabarti & Fombonne, 2001; 2005](#)). Based upon the national prevalence of ASD, it is estimated that more than 24,000 individuals with ASD are living in Kentucky. Table 1 shows the estimated number of Kentuckians with ASD by county.

Table 1. Estimated Prevalence of Individuals with ASD by County

County	2000 Census	Number of individuals with ASD (1/166)
Adair County	17244	103.88
Allen County	17800	107.23
Anderson County	19111	115.13
Ballard County	8286	49.92
Barren County	38033	229.11
Bath County	11085	66.78
Bell County	30060	181.08
Boone County	85991	518.02
Bourbon County	19360	116.63
Boyd County	49752	299.71
Boyle County	27697	166.85
Bracken County	8279	49.87
Breathitt County	16100	96.99
Breckinridge County	18648	112.34
Bullitt County	61236	368.89
Butler County	13010	78.37
Caldwell County	13060	78.67
Calloway County	34177	205.89
Campbell County	88616	533.83
Carlisle County	5351	32.23
Carroll County	10155	61.17
Carter County	26889	161.98
Casey County	15447	93.05
Christian County	72265	435.33
Clark County	33144	199.66
Clay County	24556	147.93
Clinton County	9634	58.04
Crittenden County	9384	56.53
Cumberland County	7147	43.05
Daviess County	91545	551.48
Edmonson County	11644	70.14

Elliott County	6748	40.65
Estill County	15307	92.21
Fayette County	260512	1569.35
Fleming County	13792	83.08
Floyd County	42441	255.67
Franklin County	47687	287.27
Fulton County	7752	46.70
Gallatin County	7870	47.41
Garrard County	14792	89.11
Grant County	22384	134.84
Graves County	37028	223.06
Grayson County	24053	144.90
Green County	11518	69.39
Greenup County	36891	222.23
Hancock County	8392	50.55
Hardin County	94174	567.31
Harlan County	33202	200.01
Harrison County	17983	108.33
Hart County	17445	105.09
Henderson County	44829	270.05
Henry County	15060	90.72
Hickman County	5262	31.70
Hopkins County	46519	280.23
Jackson County	13495	81.30
Jefferson County	693604	4178.34
Jessamine County	39041	235.19
Johnson County	23445	141.23
Kenton County	151464	912.43
Knott County	17649	106.32
Knox County	31795	191.54
Larue County	13373	80.56
Laurel County	52715	317.56
Lawrence County	15569	93.79
Lee County	7916	47.69
Leslie County	12401	74.70
Letcher County	25277	152.27
Lewis County	14092	84.89
Lincoln County	23361	140.73
Livingston County	9804	59.06
Logan County	26573	160.08
Lyon County	8080	48.67
McCracken County	65514	394.66
McCreary County	17080	102.89
McLean County	9938	59.87
Madison County	70872	426.94

Magoffin County	13332	80.31
Marion County	18212	109.71
Marshall County	30125	181.48
Martin County	12578	75.77
Mason County	16800	101.20
Meade County	26349	158.73
Menifee County	6556	39.49
Mercer County	20817	125.40
Metcalfe County	10037	60.46
Monroe County	11756	70.82
Montgomery County	22554	135.87
Morgan County	13948	84.02
Muhlenberg County	31839	191.80
Nelson County	37477	225.77
Nicholas County	6813	41.04
Ohio County	22916	138.05
Oldham County	46178	278.18
Owen County	10547	63.54
Owsley County	4858	29.27
Pendleton County	14390	86.69
Perry County	29390	177.05
Pike County	68736	414.07
Powell County	13237	79.74
Pulaski County	56217	338.66
Robertson County	2266	13.65
Rockcastle County	16582	99.89
Rowan County	22094	133.10
Russell County	16315	98.28
Scott County	33061	199.16
Shelby County	33337	200.83
Simpson County	16405	98.83
Spencer County	11766	70.88
Taylor County	22927	138.11
Todd County	11971	72.11
Trigg County	12597	75.89
Trimble County	8125	48.95
Union County	15637	94.20
Warren County	92522	557.36
Washington County	10916	65.76
Wayne County	19923	120.02
Webster County	14120	85.06
Whitley County	35865	216.05
Wolfe County	7065	42.56
Woodford County	23208	139.81
Total	4,041,769	24,348

Autism spectrum disorders are distinguished by an overlapping hierarchical array of unique conditions. The Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV), includes five diagnostic subcategories of ASD:

- Autistic disorder
- Asperger's disorder
- Pervasive disorder not otherwise specified
- Rett's disorder
- Childhood disintegrative disorder.

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.nih.gov/publicat/autism.cfm; 4/2006) This complexity leads individuals who are diagnosed with ASD, their families, and other care givers to routinely characterize their challenge as lonely and uphill. Providers who care 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, leave 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; 4/2006)

KENTUCKY COMMISSION ON AUTISM SPECTRUM DISORDERS

House Bill 296 was enacted by the Kentucky General Assembly in 2005 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). The stated purposes of the Commission are 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 ASD, and to make recommendations regarding legislation, administrative regulations, and policies to the Governor of Kentucky and the Kentucky General Assembly. Appendix C sets forth the 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 as well as 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. ASDAC published its findings in June, 2002 (See a copy of Recommendations: A Framework for the Future, in Appendix D).

The Commission formed four subcommittees to analyze relevant data, to hear testimony from interested parties, and to make specific recommendations to be incorporated into the comprehensive state plan as required by House Bill 296. These subcommittees included:

- Early Identification and Intervention
- Best Practices and Training of Services Providers
- Services and Transition
- Funding Sources

Early Identification and Intervention Subcommittee

The Early Identification and Intervention subcommittee consisted of Dr. Thomas Pinkstaff, M.D., Chair, Betsy Gibbs, David Lane, Germaine O’Connell, Kentucky Early Intervention Systems, and Senator Damon Thayer. This subcommittee performed the following tasks:

- Identified ways to train health care providers and educators to identify ASD symptoms in children in order to alert parents and guardians.
- Considered the creation of an ASD Registry to track children and adults with ASD.
- Reviewed policies and procedures of other states regarding early identification and intervention of individuals with ASD.
- Considered legislation and administrative regulations to implement the proposals of the subcommittee.

Best Practices and Training of Services Providers Subcommittee

The Best Practices and Training of Services Providers subcommittee consisted of Dr. Lisa Ruble, Chair, Dr. Myra Beth Bundy, Gayla Hayes, Carla Jordan, and Representative Chuck Meade. This subcommittee performed the following tasks:

- Identified organizations that will assemble, formulate, update and disseminate information regarding best practices for treating people with ASD.
- Considered how to effectively disseminate current information regarding best practices.
- Considered how to incorporate best practices in the school system and with providers of services to people with ASD.
- Identified organizations that can provide training on a regular basis to health care providers and educators that incorporate best practices for treating people with ASD.
- Reviewed policies and procedures of other states regarding best practices and training of providers.
- Considered legislation and administrative regulations to implement the proposals of the subcommittee.

Services and Transition Subcommittee

The Services and Transition subcommittee consisted of Senator Denise Harper-Angel, Chair, Cheryl Dunn, Carol Estes, Office of Vocational Rehabilitation, Linda Linville, Council on Post-Secondary Education and Jan Richards, Division of Exceptional Children. This subcommittee performed the following tasks:

- Reviewed existing services and service providers in Kentucky to individuals with ASD.
- Made recommendations regarding minimum level of services to be made available to people with ASD.
- Formulated proposals regarding more effective transition from the school system to the workforce/adult day care programs including identifying the necessary stakeholders.
- Reviewed policies and procedures of other states regarding services to and transition of individuals with ASD.
- Considered legislation and administrative regulations to implement the proposals of the subcommittee.

Funding Sources Subcommittee

The Funding Sources subcommittee consisted of Representative Scott Brinkman, Trudy Abshire, Gene Coverston, Office of Insurance, Mary Walker, Department of Medicaid Services and Marnie Mountjoy, Office of Aging Services. This subcommittee performed the following:

- Identified current funding sources of services to individuals with ASD.
- Considered a Medicaid waiver to expand services to individuals with ASD.
- Reviewed current private insurance options including mandates.
- Considered alternative methods of funding services to individuals with ASD including means testing.
- Reviewed policies and procedures of other states regarding the funding of services to individuals with ASD.
- Considered legislation and administrative regulations to implement the proposals of the subcommittee.

This report represents the work of the Commission, its sub-committees and many individuals from around the Commonwealth who offered input and support to the Commission. As mandated under House Bill 296, this report presents a comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD as well as the recommendations of the Commission for legislation, administrative regulations and policies to the Governor and the General Assembly based upon the comprehensive state plan. The Kentucky Council on Developmental Disabilities (KCDD) has the responsibility under House Bill 296 to monitor the implementation of the state plan and, where appropriate, make recommendations on the need for modifications to the state plan.

This Report will be 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

COMPREHENSIVE STATE PLAN

The Kentucky Commission on Autism Spectrum Disorders has developed the following comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD that incorporates the following elements specifically set forth in House Bill 296:

1. An assessment of the diverse needs for services and supports for individuals with ASD.

Over 24,000 Kentuckians of all ages and backgrounds are estimated to have ASD. This represents approximately six-tenths of one percent of the total population of Kentucky. Many of these individuals are of school age, living at home with parents or other care givers, and receiving various services through the public school system. As these individuals age out of the public school system, and as their parents and care givers become physically, financially and/or emotionally unable to care for them, tremendous demands will be placed upon public agencies to provide shelter, food, clothing and other services to satisfy the needs of this segment of the population. There is no single agency or program in Kentucky that has been created to address the diverse needs of individuals with ASD. Instead, depending on eligibility guidelines, adequacy of service providers and public funding, individuals with ASD are currently receiving services of varying degrees of adequacy under existing programs described in this report.

The lack of a single public agency devoted to serving individuals of all ages diagnosed with ASD has resulted in service gaps throughout Kentucky and throughout the age span for individuals with ASD. There are numerous credible studies supporting the proposition that intensive early intervention behavior therapy services for children diagnosed with ASD, as well as appropriate supports for adults with ASD, enhance the social, learning and living skills of these individuals. Appendix E lists several of these studies.

2. Identification of state, federal, private, and any other appropriate funding sources.

There is not an existing integrated system in Kentucky to coordinate state, federal, private or other funding sources for individuals with ASD, their families, and care givers. Yet, financial resources are warranted to assure that needed services and supports are available. Today, some children receive services through the public education system under the mandate of the federal Individuals with Disabilities Education Improvement Act (IDEIA). Other programs, depending upon eligibility guidelines, existence of service providers, and adequacy of funding, are providing various services to individuals with ASD, their families and care givers. Often, services are not available or accessible by families with children with ASD. These programs include

- First Steps (Kentucky Early Intervention System-KEIS)
- Kentucky Impact
- Impact Plus

- Early and Periodic Screening, Diagnosis & Treatment Program (EPSDT)
- Home and Community Based Waiver/Comprehensive Choices Plan
- Supports for Community Living/Optimum Choices Plan
- Vocational Rehabilitation
- Supported Living
- Supported Employment
- Private Insurance Mandate (Maximum of \$500 per month for covered individuals with ASD whose plans are not self-funded or based out of state).

Appendix F sets forth the eligibility guidelines and services offered under each of these programs. Appendix G sets forth the results of a survey developed and distributed by the Subcommittee on Best Practices and Training of Providers. The results represent a sample of the service providers currently providing services to individuals with ASD. This information is not conclusive as to the current status of the number of Kentuckians with ASD receiving services from service providers located in the Commonwealth.

Children with ASD who have a Medicaid card may still have problems accessing needed services. For instance, access to services under EPSDT can be problematic. Providers may have difficulties in obtaining reimbursement for services because the Medicaid program may consider the therapy as educationally relevant rather than medically necessary. Further, behavioral health services, which include behaviorally-based therapies, may only be accessed through the community mental health centers due to their status as the only providers for behavioral health services reimbursed through the Medicaid program.

3. Development of a comprehensive training plan, which shall include the Kentucky Autism Training Center, to meet training needs.

House Bill 159, enacted into law in 1996, established the Kentucky Autism Training Center to provide individual and direct family assistance, technical assistance and consultation services, professional training programs, and public education programs. (See Appendix H for the full text of House Bill 159). Additional training programs are currently provided through a number of organizations including (a) those housed at a number of public universities in the Commonwealth, including the University of Louisville (Kentucky Autism Training Center and the Systematic Treatment of Autism Related Disorders Program (STAR), Western Kentucky University (Kelly Autism Center), Eastern Kentucky University (EKU Developmental Disabilities Clinic), and the University of Kentucky (Interdisciplinary Human Development Institute), (b) private organizations and agencies, and (c) education co-operatives and early childhood regional training centers.

4. An analysis of standards for provider training and qualifications, best practice standards for services, and the need for additional service providers.

Individuals with ASD represent a heterogeneous group of consumers who require individualized approaches to treatment planning and intervention. Currently, individuals with ASD are under-served and under-represented in the service system. There is a need to monitor the

number of individuals receiving services and the outcomes that result from the services as well as a need to address the barriers in service delivery and outcomes.

There is a pressing need to train service providers on effective methods to deliver services to individuals with ASD and how to effectively use evidence-based methods for teaching and managing behavior. Exposure to relevant readings and conferences/workshops may be helpful, but these tools must be accompanied by ongoing support from, and problem solving with, others who have the necessary expertise and experience specific to ASD. Effective training must include hands-on training and feedback and follow-up monitoring and accountability. The survey results presented in [Appendix G](#) previously referenced include comments from service providers regarding existing training deficiencies and gaps.

The Kentucky Department of Mental Health and Mental Retardation (DMHMR) has defined best practices as a continuum of practices and programs ranging from promising to evidence-based to science-based. Best practices follow guidelines for effective public health interventions and either have evaluation components in place, have collected some data showing positive outcomes, or have been thoroughly evaluated and found effective in a replicable format. [Appendix I](#) sets forth the complete definitions used by DMHMR in defining best practices. [Appendices J, K and L](#) include detailed information on the best practice research literature for children, adolescents, and adults with autism. For children with ASD who are 8 years of age and younger, best practice research has been summarized by a 2001 report of the National Research Council (NRC). For adolescents and adults with ASD, best practices are less established but follow a structure similar to the recommendations for children. Although there are no known cures for autism, the following are core elements of effective programs:

Early Transition Planning

Individuals with ASD should be systematically prepared for transitions to future educational, residential, and/or vocational settings. Programming for generalization to other settings should be included in all teaching.

Functional Approach to Behavior

Behavioral methods are the primary mode of treatment and teaching. A functional approach to problem behaviors is needed.

Individualization of Services

Individualized programs should be developed using assessment information.

Systematic, Planned Teaching/Training

Individuals with ASD need planned and repeated teaching opportunities appropriate to developmental and age level. Ongoing assessment should measure progress and make adjustments.

Specialized Curriculum

A comprehensive curriculum should be developed by integrating different therapeutic/educational approaches. Key elements include social and communication training at all ages. Young children need intervention in imitation and play skills.

Adolescents and adults need assistance with sexuality, independence skills, and vocational functioning.

Intensity of Engagement/Support

Entry into intervention programs should occur immediately after diagnosis. Children should be actively engaged in intensive (individually assessed and including, but not limited to, services delivered one to one) programming for a minimum of 25 hours per week, with full year programming based on the child's age and developmental level. For success, adults require ongoing social relationship intervention and vocational support, rather than as short term training needs.

Family Involvement

Primary care givers should have access to training, support, and consultation and should be involved in decision-making and planning.

Structured Environment

Young children with ASD should have a low teacher to student ratio of at least 1 adult for every 2 children. Structured environmental and instructional programming should be used in teaching new skills and supporting skill use.

Age and Developmentally Appropriate Practices

Opportunities for adult roles and self-determination are needed for adults.

Access to Natural Settings/Environments

Opportunities for supported interactions with peers should be included. Evidence points to greater satisfaction and benefits in a number of life areas for individuals with ASD working in community rather than sheltered employment.

A survey conducted by ASDAC and summarized in a report examined the impact of specific services on child and family outcomes. Families reported that in-home behavior therapy had the best outcome for the child, and respite care had the best outcome for the family. Families also reported more positive outcomes when they had access to a wide range of services and choices. (See full report at <http://www.starautism.louisville.edu/images/pdf/summary%20reportfinal.pdf>) Currently, there are few respite programs and even fewer resources for effective in-home behavioral support and therapy.

5. An evaluation of health benefit plans and insurance coverage for the treatment of ASD.

KRS 304.17A-143 mandates that all health benefit plans provide coverage, including therapeutic, respite, and rehabilitative care services, for the treatment of autism of a child covered under the policy. The mandate is limited to \$500 per month per child and is limited to only those services related to the treatment of autism. The statute defines a child as a person from 2 to 21 years of age. The administrative regulation adopted under this legislation expressly provides that deductibles, coinsurance, and co-payments may be applied to therapeutic, respite and rehabilitative care services for a child with autism. 806 KAR 17:460.

The autism benefit required under Kentucky law is listed on the website maintained by the Kentucky Office of Insurance. The Office of Insurance has also prepared an educational handout explaining the benefit.

Informal surveys of families and care givers of children with ASD who are covered under health benefit plans suggest that many families and care givers are either unaware of the autism benefit or have experienced difficulty in accessing the benefit. Many families and care givers have registered complaints regarding the difficulty experienced in obtaining the benefit with the Kentucky Office of Insurance, which has the statutory obligation to regulate insurance companies and investigate complaints received regarding insurance benefits mandated under Kentucky law.

The Kentucky Health Choices Plan that has been developed for covered individuals under Kentucky's Medicaid program does not contain a similar benefit for individuals with autism. However, the Kentucky Health Choices Plan does not change the benefits currently provided to individuals with autism under Kentucky's existing Medicaid waiver programs.

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

Early and intensive intervention can have a profound impact on the quality of life for both children at risk and their families. (See Appendix E for a listing of several studies that support this proposition) The key to good long-term outcomes is early detection and intervention. Recognizing the first signs of ASD can be a challenge for parents, health care providers and educators alike. It is imperative that appropriate diagnostic tools and health care provider education and training be accessible. The development of a system of tracking the prevalence of ASD will lead to greater opportunities for intervention and resource development. The purpose of early diagnosis and treatment is to assure that children diagnosed with ASD receive appropriate services at an early age. Over time, intervention can often alleviate many of the symptoms associated with ASD.

Kentucky currently lacks a systematic approach to early identification, intervention and tracking of individuals with ASD. Kentucky does not have a centralized registry to help track individuals with ASD. Certain states, including Missouri, Idaho, West Virginia and Iowa, have created a statewide registry for this purpose. Currently, various departments within state government may report the people they serve with ASD, but there is no centralized system currently in place to monitor the services provided to individuals with ASD, their families, and care givers including the possible duplication of services provided. As a result, one individual with ASD may receive three or four needed services while another individual with ASD may receive fewer services. A Kentucky Autism Registry, if created, could serve as a comprehensive information resource that would direct families and care givers to state agencies responsible for coordinating the delivery of services to individuals with ASD and to service providers in their region, provide families, health care providers, other service providers and public officials with supportive, relevant information regarding the incidence of ASD in Kentucky, and facilitate research that may improve the outcomes of Kentucky children and adults with ASD. A goal of a Kentucky Autism Registry would be to unite the autism-related resources of Kentucky state agencies, health care providers, other service providers, researchers at Kentucky universities, private service agencies and families of children with ASD.

7. An analysis of program and service eligibility criteria.

Appendix F sets forth the eligibility guidelines and services offered under existing programs providing services to individuals with ASD. As noted previously, due to funding issues and the lack of service providers in many regions of Kentucky, there are numerous gaps in both the quantity and quality of services provided to individuals with ASD, their families, and care givers.

8. An assessment of the need for coordinated, enhanced, and targeted special education and treatment programs for children with ASD.

For children and adults with ASD, seamless, integrated transition planning and preparation are fundamental in ensuring that needed services and supports are available for a successful transition from school to post-secondary services or child to adult services. As noted above, there are a number of agencies providing services to those Kentucky children and adults diagnosed with ASD.

These agencies are both government-directed and sponsored or affiliated through and with the Kentucky Department of Education. Services provided through these agencies and organizations are in addition to public and private medical services, psychological services, vocational services, and other services provided to children with ASD. However, these services are often insufficiently funded, fractured and not collaborative with one another, leading to either duplication or limited access to services by those in need, as well as additional costs to society and individual families. The Kentucky Autism Training Center has been established as a resource to provide training to educators and parents. Some educational cooperatives in Kentucky also provide specialized training to educators in their school districts. There are also various private organizations that provide workshops for educators and parents. Finally, the Department of Education created a statewide Technical Assistance Manual on Autism for Kentucky Schools in November, 1997 that, based upon anecdotal evidence, has not been uniformly utilized by school districts throughout Kentucky.

Kentucky's special education monitoring process, completed by both district and Kentucky Department of Education personnel, includes several indicators that address the transition of students from high school to post-secondary settings. Transition services, as defined in 707 KAR 1:280 Section 1(55), are a coordinated set of activities for a student with a disability that is designed within an outcome-oriented process that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. Transition services are based on the individual student's needs, taking into account the student's preferences and interests, and include instruction, related services, community experiences, employment and other post-school adult living objectives, and (if appropriate) the acquisition of daily living skills and functional vocational evaluation.

Beginning at age 14, or younger if determined appropriate by the admissions and release committee (ARC) of the local education agency, the Individual Education Plan (IEP) for a child with a disability shall include a statement of the transition service needs of the child under the applicable components of the child's IEP that focus on the child's course of study. This statement must be updated annually. 707 KAR 1:320 Section 6(1)

Beginning at age 16, or younger if determined appropriate by the ARC, the IEP for a child with a disability shall include a statement of needed transition services for the child, including, if appropriate, a statement of the interagency responsibilities or any needed linkages. 707 KAR 1:320 Section 6(2)

The unique aspects of ASD, characterized by varying degrees of impairment in social interactions and communication skills coupled with restrictive and repetitive patterns of behavior, require comprehensive planning for ongoing services and support beyond the school environment. Consistent implementation of federal law (IDEIA) and state administrative regulations would facilitate an increase in the number of adults with ASD participating in appropriate post-school activities.

Federal law as well as Kentucky administrative regulation (707 KAR 1:320 Section 6(4)) requires completion of transition planning by age 17 years, one year before reaching the age of majority, for children with disabilities. Benefits from earlier implementation of this process for ASD students are well documented. The unique aspects of ASD, characterized by varying degrees of impairment in social interactions, communication skills, and behaviors require careful planning for ongoing services and support as early as possible.

RECOMMENDATIONS FOR IMPLEMENTING THE STATE PLAN

House Bill 296 mandates that the Commission, based upon the 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 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.

The following sets forth the recommendations of the Commission regarding the legislation, administrative regulations and policies necessary to implement the comprehensive state plan developed by the Commission:

1. 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” (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 care givers. 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 care givers, receiving services through the Program using state general fund revenues as well as funds available under the Medicaid program. 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 care givers that would be posted on a user-friendly website and promoted to individuals with ASD, their families and care givers, educators, health care providers and other service providers. The Program would contract with pre-qualified service providers throughout Kentucky to deliver approved services to individuals with ASD covered under the Program.

2. Recommendation Number 2:

The executive and legislative branches of state government should create a separate line item within the biennium budget for the Cabinet for Health and Family Services to adequately fund the administration of the Program including the salaries and benefits of all administrative personnel assigned to the Program.

3. 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 of Medicare and Medicaid Services (CMS) of the federal Department of Health and Human Services for a Section 1115 Demonstration Waiver (Section 1115 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 Section 1115 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 care givers.

4. Recommendation Number 4:

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation that will appropriate 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.

5. Recommendation Number 5:

The executive and legislative branches of state government should continue indefinitely full funding of the First Steps program as well as additional funding to ensure that all children with ASD participating in the First Steps program receive all needed services for effective early intervention.

6. Recommendation Number 6:

The Program should enter into an interagency agreement with the Kentucky Department of Education to ensure a coordinated, 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, without duplication, the services received by a student with ASD through the Program and under IDEIA.

7. 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 18th 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 First Steps of children 18 months and older, and other early intervention programs should also be encouraged to perform ASD specific screenings.

The MCHAT (Modified Checklist for Autism in Toddlers) should be used for screening those children 18 months to 6 years of age, and the Australian scale should be used at the 6th grade school physical. If ASD is suspected following a screening, a formal diagnosis should be made within 90 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.

8. Recommendation Number 8:

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 child 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 \$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. Finally, advocacy

groups involved in ASD should be encouraged to aggressively educate all parents and care givers of children with any condition identified under ASD that this benefit is mandated under law for all health benefit plans covering Kentuckians.

9. Recommendation Number 9:

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation creating a task force to consider the development of a Kentucky Autism Registry to be maintained within the Program. The Kentucky Autism Registry would track children and adults in Kentucky with ASD for the purpose of providing an accurate and continuing source of data concerning ASD to families, public officials, health care providers, other service providers, educators and other concerned agencies and individuals. The Kentucky Autism Registry would help disseminate critical information regarding the incidence of ASD in Kentucky that may help facilitate the delivery of critical services to individuals with ASD, their families, and care givers as well as help public officials more effectively develop programs and policies to meet this growing challenge to society.

In determining the appropriateness of creating a Kentucky Autism Registry (Registry), the Commission recommends that the task force consider the following:

- The Registry should be created, maintained and administered within the Program.
- The specific design of the Registry would include the following considerations: age at screening; age at diagnosis; diagnosis within DSM (se. 299) – as a primary or secondary diagnosis; gender; date of birth; and any other notable diagnosis.
- A diagnosis of ASD, without individually identifying information, shall be promptly provided to the Registry by the referring diagnostician.
- Individuals with ASD and their families should have the choice of excluding identifiable information from the Registry as well as the subsequent removal of such information from the Registry if previously provided. However, the Registry will not exclude the fact that an individual has been diagnosed with ASD.
- The Registry must be cost effective, accurate, avoid duplication of data, and link individuals with ASD, their families and care givers to services throughout the life span of the individual.
- The Registry should gather data to assist with prevalence estimation, cluster investigation, risk factor identification, and outcome assessment.
- The Registry should develop statistical data to include without limitation: time between screening and diagnosis; gender related information; environmental factors; quantity (DSM breakdown and age and category); geographical information (to be used for service/training); and non-identifiable information to be made available to the public.
- The Registry should coordinate with Kentucky's e-Health Network Board created under Senate Bill 2 enacted in 2005 to avoid redundancy and inefficiency.

10. Recommendation Number 10:

Kentucky should develop a comprehensive training plan to meet training needs. As part of the comprehensive training plan, the Kentucky Autism Training Center, consistent with its statutory duties, should maintain extension partnerships at the public universities to create a statewide model for delivery of training to service providers that will incorporate current best practices. University partners will be expected to provide an approved plan for training service providers 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 care givers 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 M. 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 Program should also seek to enter into memorandum of agreements with other regional centers in addition to the public universities 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 to coordinate the education and training of families and care givers 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 care givers 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 care givers, and the dissemination of such results to 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 care givers, and making recommendations to policy makers, educators, health care providers, other service providers, families and care givers, where appropriate, regarding the implementation of successful practices in other states.
- The provision of research opportunities to assess the quality and effectiveness of services, to provide best practices' training, and to provide supportive care for parents and care givers 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 care givers 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 care givers.
- 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.

11. Recommendation Number 11:

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, in order to help promote 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.
- Increase collaboration among participating agencies to help promote seamless transitions to adult activities.
- Provide both general, and ASD-specific, training to participating state agencies which targets both the development and implementation of comprehensive transition plans.
- 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.
- Continue to 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.
- 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 based on the latest evidence-based practices and innovative ideas.

12. Recommendation Number 12:

The Legislative Research Commission should establish a permanent subcommittee of the Interim Joint Committee of 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 shall 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 care givers. 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.

13. Recommendation Number 13:

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.

14. Recommendation Number 14:

The sustained, focused and continuing education of public officials and other policy makers regarding the needs of individuals with ASD, their families, and care givers 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. Accordingly, the Commission recommends that a not-for-profit organization, whether currently existing or hereafter formed, serve as a representative of individuals with ASD, their families, and other concerned citizens, for the primary purpose of seeking grants, private funding and donations in order to effectively advocate for the enactment of legislation, change in administrative policy, and other matters pertaining to ASD.

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

Legislation to implement the recommendations of the Commission should be drafted and reviewed by all necessary stakeholders prior to the commencement of the 2007 session of the General Assembly, and the legislation should be introduced during the 2007 session and each

subsequent session until all legislation necessary to implement the recommendations of the Commission has been enacted into law.

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 _____ (to be determined after the public comment period).

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

Following the public comment period, the Commission intends to draft proposed legislation implementing the comprehensive state plan developed by the Commission with input from the public.