# Report of the Colorado Autism Commission for Senate Bill 08-163

A Study Of Autism Issues Including A Ten-Year Strategic Plan For The State Of Colorado To Address The Growing Number Of Individuals With Autism Who Need Services From One Or More Systems

October 1, 2009

Colorado Autism Commission

# Contents

# Introduction

In 2008, the Colorado General Assembly created the Colorado Autism Commission (SB08-163) in order to obtain additional information on people with Autism Spectrum Disorders (ASD) in the State. The Commission was tasked with identifying existing services and the gaps in these services as experienced by the Autism Spectrum Disorders community, and to determine appropriate actions to remedy these shortcomings through the preparation of a Ten-Year Strategic Plan for the State of Colorado. The legislation that authorized the Autism Commission is included in Appendix A.

The Colorado General Assembly charged the Commission to:

- Define the autism spectrum for purposes of the scope of the Commission and identify the number of individuals affected by Autism Spectrum Disorders in the State;
- Identify existing services and gaps in services in Colorado for people with Autism Spectrum Disorders;
- Review services provided by other states that benefit people with Autism Spectrum Disorders and identify promising practices; and,
- Examine issues affecting the efficient delivery and coordination of services for people with Autism Spectrum Disorders that the Commission deemed necessary to study.

The Ten-Year Strategic Plan is designed to:

- Clarify the array of necessary services and supports that enable persons with Autism Spectrum Disorders to function to their individual potentials across their life spans and estimate the amount and sources of funding needed; and,
- Provide effectively coordinated services and supports to persons with Autism Spectrum Disorders in this State.

# The Work of the Commission

## Who We Are

Through Executive Order A208 08, Governor Bill Ritter, Jr. announced the formation of the Colorado Autism Commission which created this 24-member delegation including representatives from State agencies, advocacy organizations, professionals, parents of children with autism, and self advocates.

## Vision Statement

All Coloradans affected by Autism Spectrum Disorders shall have ready access to the services and supports they need to be safe, educated, healthy, productive, and able to pursue happy and fulfilling lives.

## Mission Statement

To develop and promote a Ten-Year Strategic Plan to identify, integrate, coordinate, and expand services for all Coloradans affected by Autism Spectrum Disorders and to implement new programs as science advances our understanding of the causes of and treatments for Autism Spectrum Disorders.

## Core Values

The Commission adopted the following core values and emphasized their importance for development and implementation of the Strategic Plan:

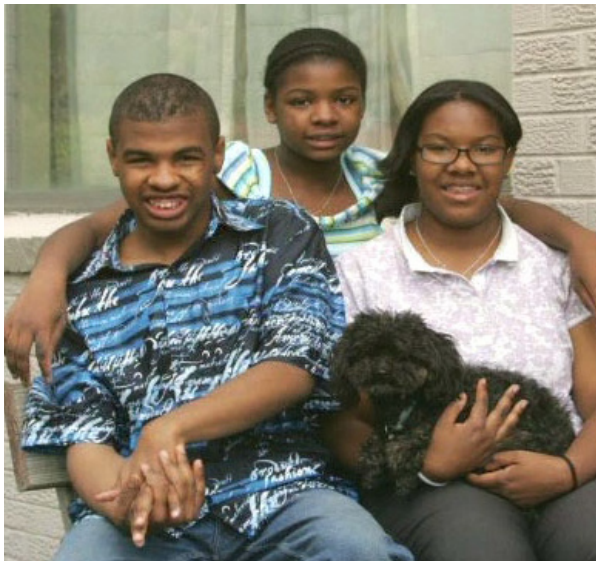
**People with Autism Spectrum Disorders are valuable.** People with Autism Spectrum Disorders are important members of their families, good employees, colleagues, classmates, and friends, and play important roles in the communities in which they live, play, and worship.

**There is an urgent need to improve systems of care.** Due to the dramatic increase in the incidence of ASD, the service systems for people with neurodevelopmental disabilities are unable to respond to the current need. Immediate and proactive steps must be taken to improve systems and services. The State of Colorado must focus on what steps must be taken to respond rapidly and efficiently to the needs and challenges of individuals and families affected by ASD. The sooner treatment begins in the life of a person with ASD, the better the outcomes.

**Abilities differ.** There is a wide range of abilities inherent in ASD. The full range of functional abilities and limitations must be considered when planning services and supports. Those with the capacity for more self-direction must be afforded the opportunity to build on individual strengths to maximize independence.

**Individual needs are a significant factor in treating people with Autism Spectrum Disorders.** There is a complex constellation of needs, some distinct from those of individuals with intellectual disabilities, in the areas of receptive and expressive communication, social skills, behavior, sensory issues, and environmental needs.

**Families live at the center of the service system.** As a vital part of the service system, families have different needs, expectations, resources, values, and priorities, which must be honored in the service delivery process.



**Cultural Competency is an essential element of universal access.** Each Colorado resident on the autism spectrum deserves ready access to appropriate information and services irrespective of age, co-morbidity, culture, ethnicity, gender, Intelligence Quotient (IQ), place of residence, primary language or literacy level, race, socio-economic status or other distinguishing characteristics.

**Autism Spectrum Disorders and other neuro-developmental disabilities – Common cause** While the work of the Commission has by definition been focused on ASD, the Commission recognizes that the needs identified are relevant to other neurodevelopmental disabilities. The perspective that provides common cause is a "needs-based" perspective. People with neurodevelopmental disabilities and their families require services and supports based upon a combination of individual needs, abilities, and life circumstances that are faced by the individuals and their families. While our recommendations speak specifically to Autism Spectrum Disorders, the Commission believes these recommendations are applicable to the needs of Colorado citizens with neurodevelopmental disabilities.

# Scope of Work

The full Commission began meeting in September 2008 and met thereafter twice monthly. The Commission organized into four committees: Testimony Committee, Where We Are in Colorado Committee, Other States Committee, and the Deliverables Committee. Each committee met additional times outside of the full Commission. Commissioners contributed over 4,000 hours of their time to complete this Report.

In the preparation of this Report, the Commission reviewed legislation and plans from numerous other states. The committees researched Local, State, and National services for individuals with ASD and their families. In addition, the Commission conducted twenty-one hearings around the State where the successes, concerns, and stories of individuals and families affected by ASD were heard. Approximately 180 people participated in the hearings. Written comments and testimony were received from approximately 275 people. Appendix B contains a summary of written comments and testimony. A complete record of the testimony is available for viewing at Autism Society of Colorado, 550 S. Wadsworth Blvd # 100 Lakewood, CO 80226-3116, 720-214-0794.

Throughout the testimony, the Commission witnessed the wide range of abilities and needs reflecting the diversity of persons with ASD. The Commission heard testimony about adolescents who were intellectually gifted but whose inability to read social cues or understand humor or sarcasm exposed them to terrible bullying by their classmates; individuals across the lifespan who needed 24/7 supervision in order to be safe; individuals without functional language skills who had undiagnosed medical problems that they could not describe, and who engaged in physical self-abuse or lashed out physically at those closest to them; and, children who were unable to speak or whose ability to communicate on any level was extraordinarily limited. From the testimony received, it was clear that families of children and adults with ASD and the professionals who are working to assist them face numerous and significant challenges in Colorado.

# Our Charge and Findings

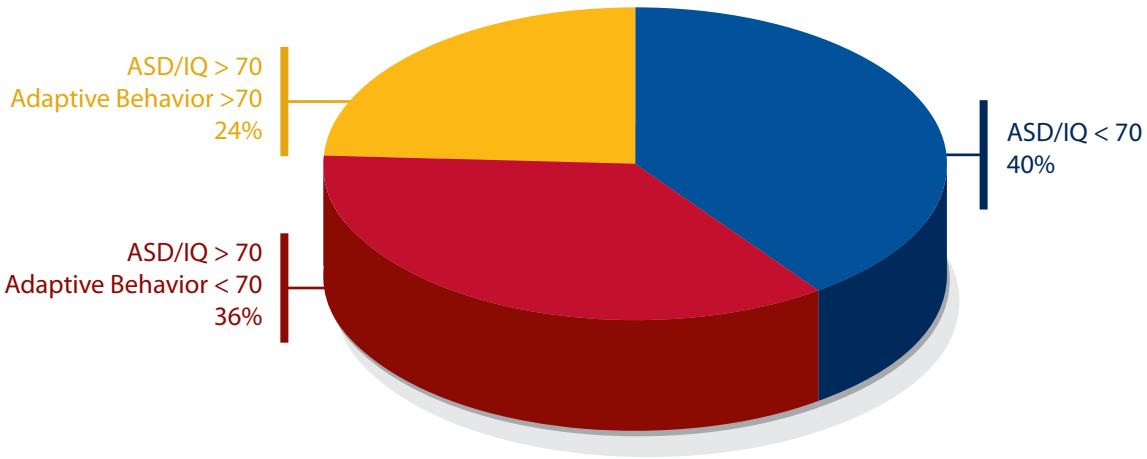
## Task 1: Define Autism Spectrum Disorders

The Commission decided to address the full spectrum of autism disorders as defined in the current Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000). Using this standard for purposes of this Report, the term "Autism Spectrum Disorders" means developmental disabilities that cause substantial impairments in the areas of social interaction, communication, and behavior often characterized by the presence of restricted interests and/or repetitive behavior. In short, Autism Spectrum Disorders affect normal brain development related to social and communications skills. Presentation can range from an individual who appears to be completely cognitively impaired, with no communication strategy, no give and take social interaction, and melt-down behavior; to an individual who is extremely bright, talks a lot and is socially awkward; and, everything in between. The term Autism Spectrum Disorders includes Autistic Disorder, Pervasive Developmental Disorder (Not Otherwise Specified), and Asperger's Syndrome, (Bonfardin, Zimmerman, & Gaus. 2007; Mandell, et.al. 2007; Rapin, 1997).

Over the past decade, the number of individuals in the United States diagnosed with ASD has risen dramatically from two per 1,000 children 15 years ago to six per 1,000 children in 2007. The Centers for Disease Control and Prevention (CDC) estimates the prevalence rates of Autism Spectrum Disorders in the State of Colorado for children 8 years of age are 1 in 169 (CDC, 2007). The disorder has a ratio expression of males to females of 4.3 to 1. ASD is the fastest growing developmental disability in the United States, affecting more children than childhood cancer, Type I diabetes or cystic fibrosis (Jepson, B, 2007).

Colorado specific data regarding the number of individuals with ASD comes from two sources, the State child count and the CDC surveillance data. Students, ages 3-21 identified as having an ASD through the annual child count increased from 505 in 2002 to 2,258 students in 2007 (ideadata.org, 2009). The Colorado Department of Education believes that the population is much greater than this because many students with Asperger's Syndrome and PDD-NOS are identified and served under other disability categories (Boezio, 2009). Through participation in the CDC surveillance program (ADDM), the prevalence for Colorado was determined to be one in every 169 children in third grade at the time of the study. Based upon CDC data, we expect that about 40 percent of these individuals will have IQ's less than 70. Another 36 percent will have adaptive behavior scores below 70 and will as a consequence be eligible for services as a person with a developmental disability. A more complete explanation of the manner in which these figures were derived is provided in Appendix C.

## Figure 1: Autism Spectrum Disorders in Colorado



## Task 2: Identify existing services and gaps in services in Colorado for people with Autism Spectrum Disorders

In order to understand the service system in Colorado it is essential to begin with the Division for Developmental Disabilities (DDD) and the Community Centered Boards. DDD, a division of the Colorado Department of Human Services, is the state office that provides leadership for the direction, funding, and operation of services to persons with developmental disabilities within Colorado www.cdhs.state.co.us/ddd/. In 1963 the Colorado State Legislature authorized the State to contract with private Community Centered Boards that serve as the entry point for locally managed community based services for individuals with developmental disabilities. As was noted in Figure 1, a significant proportion of individuals with Autism Spectrum Disorders qualify for service through the DD system. Additionally given the responsibility that the CCB's have for early intervention services most children with ASD's will be known to the CCB's.

### Exhibit 1: The Community Centered Board System

In 1963 the Colorado State Legislature authorized the State to contract with private Community Centered Boards (CCBs), which serve as the entry point for locally managed community based services for individuals with developmental disabilities. There are currently 20 CCBs throughout Colorado serving specific geographic regions.

Case management and coordination for all funded services for eligible individuals with developmental disabilities (as defined by the State of Colorado) are provided by the CCBs. CCB functions also include Early Intervention services for all eligible children aged birth to three, coordination of the Children with Autism Waiver for children aged birth to six, and administration of the Family Support Services Program (FSSP) for the entire lifespan of eligible individuals.

However, past the age of three, not all Colorado citizens with Autism Spectrum Disorders are considered eligible for services through CCBs for individuals with developmental disabilities. This fact is related to how the official State definition of a developmental disability has historically been interpreted. As a matter of practice, an IQ below 70 has been used as a requirement for eligibility. Many individuals with Autism Spectrum Disorders have IQs over 70, and in some cases much higher, but are significantly lacking in adaptive behavior skills. A change in the practice of using an IQ threshold as a key requirement for eligibility will result in a considerable increase in the number of individuals with Autism Spectrum Disorders who are eligible for DD services.

Since the mid-80s, there has been a dramatic increase in the prevalence of Autism Spectrum Disorders. In response, the State of Colorado enacted two laws pertaining to private insurance and the Children with Autism Medicaid Waiver (serving 75 young children from birth to six years of age). Unfortunately, Colorado has been unable to create and fund the necessary services to meet the increased needs for people with Autism Spectrum Disorders and their families. Colorado's culture around local control presents unique challenges for consistent delivery and coordination of services. For example: the Colorado Department of Education may recommend best practices for the education of children with autism but not mandate that these practices be implemented locally. Colorado is 51st (Auge, 2009) in the nation in funding for special education. It is also in the bottom 10 states in most safety net markers (DeParle, 2009) and 46th in per capita funding for people with developmental disabilities (Braddock, 2008). The resultant strain on social services, first responders, judicial systems, education, housing, long term care, and support services is immense.

## Exhibit 2: Colorado Health Insurance Laws and Autism

| Bill Number | Bill Title | Key Provisions |
|---|---|---|
| 1993<br>10-16-104.5, C.R.S.<br>Senate Bill 93-113<br>Sponsors: Senator Mares and Rep. Prinster | Concerning the Coverage for Autism in Health Care Coverage Policies | • Requires health benefit plans which provide coverage for autism to provide such coverage under policy provisions other than the provisions which outline coverage for the treatment of mental illness.<br>• Specifies that autism is not a mental illness for insurance purposes. |
| 2004<br>25.5-6-801 through 25.5-6-805, C.R.S.; rules 10 C.C.R. 2505-10, Section 8.519<br>Senate Bill 04-177<br>Sponsors: Senator Gordon and Rep. Hefley | Concerning Home and Community-Based Services under the State's Medicaid Program for Children with Autism | • Required the Department of Health Care Policy and Financing to create a Home and Community-Based Services Medicaid Waiver for Children with Autism.<br>• The waiver gave children birth to the age of six access to various therapies under the Medicaid State plan as well as behavioral interventions from Lead Behavioral Therapists, Senior Behavioral Therapists, and Line Staff (Para-professionals).<br>• Behavioral services were capped at $25,000 per year and the number of children enrolled at a given time was capped at 75. |
| 2009<br>10-16-104 (1.4), 10-16-104 (1.3)g and 10-16-104.5 and 25.5-8-107 (1) (a), C.R.S.<br>Senate Bill 09-244<br>Senator Shaffer and Rep. Primavera | Concerning Health Insurance Benefits for the Treatment of Autism Spectrum Disorders | • Defines autism spectrum disorders to include Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified.<br>• Requires health insurance to cover assessment, diagnosis, and, treatment of autism.<br>• Prohibits carriers from denying issuance or renewal of policies due to autism diagnosis.<br>• Delineates which health care professionals are eligible to provide treatment, and requires appropriate certification and credentialing.<br>• Applies to small and large State of Colorado group plans, not individual or ERISA plans.<br>• Provides parity with other medical illnesses.<br>• States the annual cap on treatment payments for ABA therapies:<br>1. Birth – age 8: $34,000<br>2. Age 9-18: $12,000. |

As the epidemic of ASD has grown, so has the media coverage of the truths and myths surrounding these conditions. This coverage has left the general public and those affected by ASD in a state of flux and confusion. There are unprecedented rifts in the community about causes, the appropriate treatments, and how to educate and support people with ASD. Testimony revealed that some families are using complementary and alternative treatments with anecdotal success. To decrease the general confusion surrounding the treatment of ASD, more research is needed to develop and substantiate effective and affordable treatments.

Children with ASD in Colorado are primarily supported by: Early Intervention Services (www.eicolorado.org), Special Education (www.cde.state.co.us/index_special.htm), Family Support Services Program (www.cdhs.state.co.us/ddd/FSSP_Main.htm), and Family Preservation services (www.childwelfare.com/Family%20Preservation.htm). The best researched and most successful interventions for children with ASD are behavioral (i.e. applied behavior analytic principles such as functional analysis of behavior) that focus on communication, socialization, developmental sequencing, and decreasing harmful and interfering behaviors. Although small pockets of services available for these children exist, most of the costs are born by families due to long waiting lists for the Medicaid Children with Autism Waiver, Family Support Services Program, and the Children's Extensive Support Waiver. In 2009, a law was created to ensure that private health insurance companies under the State Insurance Commission purview pay for services for children with ASD. The number of trained service providers is small and the demand is great, making the cost of these services high while availability is limited. People with ASD may also need Mental Health services funded by public and private sources in addition to developmental disability services, which can result in payment and access problems for those persons.

## Exhibit 3: Colorado Medicaid Waivers for Children

**Colorado Medicaid Waiver for Children** – this waiver serves children aged birth-6 with the medical diagnosis of autism who show a need for ICF-MR level of care. Services have an annual cap of $25,000 per year and only 75 children may receive services at one time. This waiver has a waiting list. www.colorado.gov/cs/Satellite/HCPF/HCPF/1223894303509?rendermode=preview

**Children's Extensive Support Medicaid Waiver (CES)** – this program offers behavioral interventions, community access, respite, personal care and other services. Only children with autism and other neurodevelopmental disorders who show a need for ICF-MR level of care are eligible. Caregivers/family members may only get 4 hours of un-interrupted sleep to be eligible for this waiver. This wavier has a waiting list. www.cdhs.state.co.us/ddd/CES_Main.htm

**Children's Home and Community Based Services Medicaid Waiver** – only children with autism and other neuro-developmental disorders who require a hospital or nursing home level of care are eligible for this program that gives Medicaid State Plan benefits to children who live in a family that is over-income for Medicaid. This wavier has a waiting list. http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1213781362679

**Children's Pediatric Hospice Waiver** – very few children with autism will qualify for this waiver as the child must have a "life-limiting" illness as defined by a doctor. There is currently no wait list for this waiver. http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1213781362679

**The Children's Habilitation Residential Program** (CHRP) is designed to provide residential services to children and youth in foster care who have a developmental disability and extraordinary needs. This waiver serves children from birth to age 21 who are placed through the county departments of social services. www.cdhs.state.co.us/childwelfare/CHRP.htm

Approximately 75% of adults with ASD are eligible for services under the developmental disability system in Colorado, meaning that at least 25% of these individuals are unserved by that system. Adults with ASD are also generally underserved in Colorado as these programs are inadequately funded. The waiting lists for long-term care supports and services are long (10+ years), creating a potential ten-year gap between special education services and adult services. Adults with ASD who are not eligible for services under the developmental disability system may receive minimal support through Vocational Rehabilitation and the Independent Living Centers if funding is available.

## Exhibit 4: Overview of Service System for Adults with Autism

**Division of Vocational Rehabilitation** – provides services for people with disabilities who want to be employed in the community. www.cdhs.state.co.us/DVR. [under order of selection]

**Supported Living Services Waiver** – provides support services for individuals with developmental disabilities who are eligible. Allocations are capped based on a needs-based screening measure. Currently the program has a waiting list. www.cdhs.state.co.us/ddd/PDFs/DIR_SLS.pdf

**Comprehensive/Residential Waiver** – provides access to 24 hour long-term care services such as personal care, supported employment, behavioral supports and supervised community access. Currently the program has a waiting list.
www.cdhs.state.co.us/ddd/PDFs/DIR_ResDayHabilitationInterimRateTiers.pdf

**Independent Living Centers** - Independent Living Centers are non-residential, private, non-profit, consumer-controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. www.virtualcil.net/cils/query-iandr.php?state=co

**Supplemental Security Income or Social Security Disability Income** – these programs offer monthly allocations of funding from the Social Security Administration for people with disabilities.
www.cdhs.state.co.us/AAS/adultfinancial_supplemental.htm

**Section 8 Housing** – HUD offer housing assistance to some adults who live in poverty.
Currently the program has a waiting list.
http://portal.hud.gov/portal/page/portal/HUD/topics/housing_choice_voucher_program_section_8

**A Parent's Perspective:**

*"My son received OT in 2008 1 time/week. The cost was almost $5000 and our health insurance covered 50% of the cost. We now owe more than we can afford to pay, so our son is not receiving any therapy."*

Molly W. 80487, Steamboat Springs

There is a critical shortage of trained service providers in medicine, mental health, long-term care systems, and education for children and adults with ASD in Colorado. While Universities and various organizations such as the Colorado Department of Education, some Mental Health Service Agencies, and Community Centered Boards have tried to respond to the demand with training opportunities and behavioral programs, the State is currently unable to meet the increased needs. This shortage will worsen as youth with ASD become adults, critically impacting the State unless action is taken now.

**A Parent's Perspective:**

*"At seven years old my son Kerry spent six month in a residential treatment program because I didn't know how to keep him safe. He was not accurately diagnosed until he was eighteen years old. He is now twenty-three. I had to quit jobs to take care of him when school wasn't in session. There was no child care facility that was equipped to care for him. Eventually I took graveyard shift jobs to be able to go to the school at a moment's notice in the event of a meltdown or other disaster."*

Laurie Y. 80918, Colorado Springs

## Exhibit 5: Promising Programs in Colorado

**Imagine! Autism Spectrum Disorders Program**
http://imaginefamilyservices.org/ASDhome.htm

**Neuropsychiatric Special Care Program**
www.thechildrenshospital.org/conditions/psych/neuropsych.aspx

**Respite** – The Autism Society of Colorado is creating statewide capacity for respite
www.autismcolorado.org/membership/givemeabreak.html

**Behavior Support Teams** – some Community Centered Boards and some local school districts have created behavior support teams. www.ddrcco.com/services_behavioral_health_intro.asp

**The University of Colorado Denver** offers a series of three graduate-level courses specifically designed to help licensed teachers develop the skills necessary to work effectively with students on the autism spectrum. General and special education teachers will utilize their certificate to become more effective PreK-12 instructors in inclusive and self-contained classrooms.
www.ucdenver.edu/academics/colleges/SchoolOfEducation/Academics/ContinuingEducation/Certificates/Pages/AutismSpectrumDisorderCertificate.aspx

**Autism Treatment Network** – The ATN is the nation's first network of hospitals and physicians dedicated to developing a model of comprehensive medical care for children and adolescents with autism. www.autismspeaks.org. JFK Partners UCD School of Medicine and The Children's Hospital are the Colorado ATN site.

**The Autism Task Force** – In 1997, the Colorado Department of Education created the Colorado Autism Task Force to review and address the educational needs of students with autism. The task force was comprised of parents, educators, and other professionals with an interest in autism. The task force provided recommendations and best practices to the Colorado Department of Education for the education of students with autism. Brochures, fact sheets, and manuals were developed as resources for parents and educators of students with autism. www.cde.state.co.us/cdesped/SD-Autism.asp

## Task 3: Review services provided by other states that benefit people with Autism Spectrum Disorders and identify promising practices

The Commission reviewed information from national bodies and a variety of states that helped form these recommendations. Noteworthy among National efforts is PL109-416 the Combating Autism Act of 2006, as amended (http://www.govtrack.us/congress/bill.xpd?=s109-843). This act mandated the reestablishment of the Interagency Autism Coordinating Committee (IACC) to coordinate ASD research and other efforts within the Department of Health and Human Services. The IACC Ten-Year Strategic Plan for Autism Spectrum Disorders Research was issued on January 26, 2009 (http://iacc.hhs.gov/reports/2009/iacc-strategic-plan-for-autism-spectrum-disorder-research-jan26.shtml).

The Combating Autism Act included a number of other initiatives related to research about and preparation of personnel to treat and serve individuals with Autism Spectrum Disorders. A number of entities at the federal level were charged with implementation of aspects of the legislation. The Maternal Child Health Bureau was given responsibility to award additional grants under the Leadership Education in Neurodevelopmental Disabilities program. JFK Partners at the University of Colorado Denver School of Medicine received one of these new grants. The CDC and MCHB were jointly charged with expanding the Learn the Signs Act Early Campaign (www.cdc.gov/ncbddd/actearly) to enhance screening efforts, and MCHB also awarded an Autism Medical Home grant to the University of Wisconsin (Fleischfresser, 2004; Waisman Center, 2008 (www.waisman.wisc.edu)). Funding under the act was also awarded to the University of Massachusetts and Autism Speaks for expansion of the Autism Treatment Network (www.autismspeaks.org). JFK Partners and the Child Development Unit of The Children's Hospital are joint grant recipients of the Colorado site of the Autism Treatment Network.

## Task 4: Examine issues affecting the efficient delivery and coordination of services for people with Autism Spectrum Disorders that the Commission deemed necessary to study.

**Identification of children with Autism Spectrum Disorders.** Parents often struggle to obtain an accurate explanation for their child's atypical behavior, lack of communication, and overall development. Their struggle is complicated when their primary care providers are not trained to recognize the early warning signs for ASD. In addition, while increasing attention is being given to diagnostic instruments that are based on the symptom patterns of infants and children (Filipek, et.al. 2000; Johnson et.al., 2007), diagnosis remains challenging with very young children because the symptoms are complex, evolving, and vary from child to child (Rogers, 2001).

**A Parent's Perspective:**

*"I fear that many parents are not being heard and many children are not being treated because the medical community in this valley is less than knowledgeable about the disorder."*

Sara M. 81611, Aspen

**Access to early and effective intervention programs.** Families and service providers are faced with the difficult task of sorting through a wealth of information and research about programming approaches to work with children with ASD. In 2001 the National Research Council (NRC, 2001) recommended: entry into the following treatment as soon as an Autism Spectrum Disorder is suspected; 25 hours of intervention per week; parent training and involvement in treatment; ongoing assessment, program evaluation, and programmatic adjustment as needed; and, intervention that focuses on communication, social interaction, and play skills that can be generalized to the naturalistic setting. Consultants and treatment providers with expertise in ASD are in short supply in most areas of the country. Accessing intervention is a particularly difficult issue in Colorado due to its size, large rural nature, and a lack of consultants with expertise in Autism Spectrum Disorders, as well as training programs to support and prepare providers working with this population. The cost for this treatment is also prohibitive for many families.

**A Parent's Perspective:**

*"In Rural areas there are not yet medical professionals who are comfortable making diagnoses of Autism, or if they do, it may not be fully informed. They are not given specific recommendations, strategies, information about the broad spectrum...etc...Other families are given concerned advice to get a full evaluation, but the only option for us in Northern West Colorado at this point is JFK or Children's and this could take 6 months to a year on a waiting list to get in. Also, it's wonderful that we now have an Autism Waiver for children 0-5, but to tell a family who is at their wits end that you have something that might be helpful, sit with them for over an hour for a start and then have them slowly realize that this 'help' is at least 2 years away if their child hasn't reached his/her 6th birthday yet is close to ludicrous."*

Amy I.80477, Steamboat Springs

**Working from a family-centered perspective.** From the testimony it became apparent that in addition to the need for effective treatment, there is a critical need for respite care. While social support and the use of specific coping strategies can help, respite care is essential. In addition, families are impacted by Autism Spectrum Disorders in at least three ways (Seltzer, et al, 2000). First, in comparison to parents of children with other types of developmental disabilities, parents of children with Autism Spectrum Disorders experience greater stress, depression, anxiety, and other negative mental health outcomes. Studies also show a significant increase in maternal depression if there are children in the family who are on the spectrum (The Interactive Autism Network, www.ianproject.org/). Second, the consequences of ASD are pervasive and lasting, and will change across the lifespan. While in the earlier childhood years families welcome treatment programs to provide the best opportunities for responsive and normal functioning, in adolescence families often recognize that their child's level of functioning or capacity for a transition toward independence may not change dramatically. Third, social support and the use of specific coping strategies can ameliorate or buffer the magnitude and impact of stress among families. These findings from the Seltzer study were supported in testimony from parents and professionals during the hearing stages of the Commission work.

**Coordinating the organization and delivery of care.** For many families, the care and support required to raise their child with Autism Spectrum Disorders is very complicated and requires access to multiple service sectors. These sectors include primary and specialty health care, early intervention and special educational services, social, public health and home health services, and other community resources such as Community Centered Boards, child care, respite care, and waiver programs. As families and care providers strive to access these services, they find themselves interacting with a wide array of agencies and providers working from different missions, eligibility criteria, and funding mechanisms. These families often experience extreme difficulty and frustration gaining access to services, and may be unsure where to get assistance. An electronic system for coordinating care and services throughout the State is urgently needed (AAP, 1999).

**Information Systems.** Significant amounts of data do exist but are often inaccessible and inaccurate. The virtual explosion of ASD in Colorado renders accurate data difficult to obtain. Until the State can accurately account for the numbers of individuals with ASD, the severity of the disorder among individuals, and the geographic distribution and needs, development of effective systems for prevention, treatment, and recovery will be difficult. It is essential that accurate data be accumulated and used to inform planning.

**A Parent's Perspective:**

*"Once diagnosed, there doesn't seem to be much help out there as far as mental health services. My son would benefit from some kind of life coaching but there really aren't any services of this type available that aren't extremely expensive. We tried but at $150.00 per hour, after a short time we had depleted our funds and he was just getting comfortable with the counselor so they didn't make much progress. Also, my son was accepted at a university after high school (his grades were average but his ACT score was outstanding). Knowing what I know now, it was like sending a lamb to slaughter. It was almost impossible for him to be successful without some kind of understanding of how he processed information and help navigating the social world at college."*

Kathy G, 80127 Littleton.

**Addressing the complexity of funding.** Inability to access funding for diagnosis, treatments, long-term-care services, family preservation, employment, transportation, and education severely impedes the quality of life for individuals with ASD and their families in Colorado.

**Research.** A goal of the Commission is to encourage the various State departments to follow developments in research into the causes and treatment of Autism Spectrum Disorders. Dramatic increases in ASD may indicate a combination of genetic pre-dispositions coupled with environmental triggers (Eigsti & Shaprio, 2003). Implementation of recommendations arising from sound research on the risk factors and the environmental triggers for ASD ultimately may allow prevention of ASD in some at-risk children, or ameliorate the most serious disabilities in those affected.

**Safety.** Most individuals with ASD may either have limited abilities to process information or process information differently than individuals without one of these disorders. Individuals with ASD also often fail to pick up on normal social exchanges and have limited abilities to successfully interact with other people. As a result, the safety of people with ASD can be greatly compromised. First responders, teachers, employers, and the general public need to be educated on the characteristics of a person with ASD as well as proper responses to them.

**A Parent's Perspective:**

*"Not enough education for evaluators of early identification of autism or possible autism. Problems especially occur with behavioral, psychosocial, and sensory issues. Part C evaluation teams through school districts in our community (Pueblo) tend to look at speech/cognitive only. Parents' concerns are often discounted by statements from professionals such as 'my two year old does that too', and unbelievably, statements such as 'let's wait and see' or 'he'll grow out of it' still are made."*

Kathy S. 81007, Pueblo West

**Training.** In every area examined it became clear that there is a need for training of caregivers, support personnel, educators, and professionals who provide services to individuals with ASD and their families.

# Recommendations

In the course of its work, through testimony, investigation, and research, the Commission learned about many programs and initiatives in Colorado and other states. Some programs and initiatives are specific to Autism Spectrum Disorders and some are broader in focus. The Commission believes it is important that efforts on behalf of individuals with ASD and their families integrate with and build upon broader initiatives in Colorado, such as the Assuring Better Child Health and Development Developmental Screening Initiative (www.abcdresources.org/), Colorado Early Intervention Services (Part C Services & Supports; (www.eicolorado.org/), Colorado Department Public Health and Environment Medical Home Initiative (www.cdphe.state.co.us/ps/hcp/form/resources/Medical%20Home%20Summary041309.pdf), and Colorado Department of Education Autism Task Force.

Many different entities are responsible for covering the costs for ASD services and treatment. Parents often pay out-of-pocket or significantly supplement other payment methods to receive needed services, resulting in the depletion or exhaustion of financial and personal resources. For many families it means they cannot access critical services. Additional Local, State, and Federal funds are needed to adequately meet the needs of individuals with ASD, their families, and caregivers. Additional funding has implications for the implementation of all of the recommendations made by the Commisssion. Much of the work of the Commission occurred in the context of its' several committees. The reports and recommendations from the committees were assembled into the Ten-Year Strategic Plan, which is included in this report.

The Commission offers eighteen recommendations and corresponding strategies.

## Infrastructure, Funding, and Data

**Recommendation 1:** Establish a formal and sustainable mechanism to implement the Colorado Strategic Plan for Autism Spectrum Disorders to improve the lives of individuals with ASD. A detailed proposal regarding this recommendation is contained in Appendix D.

*The findings from the Commission work and testimony indicate a need for the formation of a system to support, update, and to oversee the implementation of the Ten-Year Strategic Plan outlined in this Report.*

1.1 Establish and fund a Legislative Oversight Committee and Taskforce.

- Duties/Functions of Entity
  - Ensure implementation of plan and recommendations – accountability/ authority;
  - Coordinate with existing departments to maximize outcomes;
  - Propose legislation as necessary to implement the plan;
  - Update this Plan as needed; and,
  - Advocate for the Strategic Plan and the continuing integration, coordination, and expansion of services/supports for all people with ASD.

1.2 Develop mechanisms to disseminate information about new treatments and guidelines once available.

1.3 Investigate the best means to establish and fund local programs for implementation of the Strategic Plan.

1.4 Establish an Autism Spectrum Disorders Ombudsman program.

**Recommendation 2:** Establish integrated data systems among State departments and stakeholders to track diagnosis, treatment, services, and outcomes, to improve coordination of care, and to disseminate information.

*The collection and dissemination of data on individuals with Autism Spectrum Disorders is insufficient on multiple levels. This lack of data has affected the ability of service providers, State departments, and stake holders to accurately track ASD populations, base changes in policy on the needs of the group, formulate and deliver new services, and develop best practices.*

2.1 Improve infrastructure and support for a comprehensive, statewide tracking system to accurately identify the number of individuals with Autism Spectrum Disorders in Colorado.

**Recommendation 3:** Increase the systemic capacity for diagnosis, treatment, coordination of care, and service delivery for individuals with Autism Spectrum Disorders across the lifespan.

*The research conducted by the Commission in conjunction with testimony strongly indicated a need in Colorado for a comprehensive, coordinated system of care across the life span for individuals with ASD and their families/caregivers. Currently, there is confusion about State programs, difficulties with information dissemination, poor access to service providers, and difficulties with multiple points of entry once there is a formal diagnosis.*

3.1 Revise the Colorado implementation of the definition of developmental disabilities to include an eligibility component, separate from the IQ component, which establishes eligibility based on the significant impairment of functional adaptive skills.

3.2 Adopt an incentive program to attract and retain a broad spectrum of higher education students preparing to serve and providers already serving individuals with ASD in professional disciplines.

3.3 Clarify, determine, and streamline a statewide, consistent process for all funding sources for procedures, treatment, and utilization review standards, and then crosswalk quality standards with treatments and payments.

3.4 Establish a sustainable means to monitor and address personnel capacity issues at all levels.

3.5 Build upon Medical Home efforts to provide ASD technical assistance and training to primary care and specialty care providers in the State.

3.6 Expand and support research into causes and treatments for individuals with ASD.

**Recommendation 4:** Coordinate access to services for individuals with Autism Spectrum Disorders across all systems.

*Within Colorado there is a problem with access and dissemination of information to individuals with ASD, their families, and caregivers. Testimony and Commission research has indicated wide-spread inability to access important long and short-term care services.*

4.1 Improve current local/regional systems that provide comprehensive information and referral to resources including: long-term care services, mental health services, medical/dental care, housing, employment, and community living.

**Recommendation 5:** Ensure and streamline access to services for all individuals with Autism Spectrum Disorders and their families.

*Communication services such as translation and other language supports are needed to assist individuals with ASD, their families, and caregivers with access to services.*

5.1 Ensure the provision of translation and other supports to ensure access to information and services for monolingual, non-English language individuals and families.

5.2 Improve local/regional service delivery system serving individuals with ASD and their families in rural communities with low identification rates and service capacity.

## Screening and Diagnosis

**Recommendation 6:** Improve educational and medical identification through screening and diagnosis of Autism Spectrum Disorders at the earliest possible age and across the lifespan.

*Testimony and other evidence obtained by the Commission shows the critical need for early detection and intervention for Autism Spectrum Disorders. Many testified on the extensive wait lists for obtaining a diagnosis and for receiving treatment and therapies. Studies reflect that the earlier a diagnosis is obtained and intervention begins the more effective the outcomes.*

*The American Academy of Pediatrics recently published guidelines for surveillance and screening at well child visits. These guidelines call for surveillance at all well child visits. Screening of development should occur at 9, 18, and 24 or 30 months. It is also recommended that Autism Spectrum Disorders specific screening should occur at the 18 and 24 month visits (Johnson, et.al, 2007).*

6.1 Expand public awareness and training models for screening for Autism Spectrum Disorders.

6.2 Develop and implement statewide guidelines to facilitate the timely educational identification of students with Autism Spectrum Disorders.

6.3 Create a consensus statement regarding screening and diagnosis for Autism Spectrum Disorders.

6.4 Create a referral process for timely comprehensive medical and educational diagnostic evaluation across the lifespan.

6.5 Develop a standard minimum core medical and educational multi-disciplinary evaluation.

## Early Intervention Services

**Recommendation 7:** Establish consistent quality standards for early intervention services across systems statewide.

*There is a need for early, intensive behavioral intervention for children with ASD. The National Research Council reviewed the available literature and recommended: entry into treatment as soon as ASD is suspected; 25 hours of intervention per week; parent training and involvement in treatment; ongoing assessment, program evaluation, and programmatic adjustment as needed; and, intervention that focuses on communication, social interaction, and play skills that can be generalized to a naturalistic setting.*

7.1 Appropriate stakeholders will review existing and newly developed standards and recommend a process for updating and monitoring the implementation of early intervention services.

**Recommendation 8:** Provide early intervention services as soon as a child is suspected of having an ASD due to delays in communication or social-emotional development.

8.1 Provide training to early intervention providers on how to monitor for the early signs of Autism Spectrum Disorder.

The Screening, Diagnosis, and Early Intervention committee report and presentation are contained in Appendix E.

## Education

Public Education plays a critical role in the identification and treatment of persons with Autism Spectrum Disorders, from three to twenty one years of age. To enhance public education's capacity to provide Free and Appropriate Public Education (FAPE) as required by federal law, the following recommendations are offered.

**Recommendation 9:** Create a new educational identification category of Autism Spectrum Disorders.

*Currently a gap exists in the identification and labeling process related to this area. Colorado is a 'needs-based' State with regard to educational services; however, many local school districts still consider an Autism diagnosis to be needed to provide certain services under their interpretation of local control. By aligning the State and Federal definitions of qualifying conditions to the broader category of ASD, the State of Colorado will eliminate confusion amongst educators, and comply with Federal guidelines.*

9.1 Amend the Exceptional Children's Educational Act (ECEA) rules and adopt the Autism Disability as stated in the Individuals with Disabilities Education Act (IDEA) rules 300.8 (c)(1)(i)-(iii) including the definition. The term "Autism Spectrum Disorders" will replace "Autism" to make clear that it includes Asperger Syndrome and Pervasive Developmental Disorders-Not Otherwise Specified.

9.2 Train multi-disciplinary teams to determine the Educational Identification of Autism Spectrum Disorders.

**Recommendation 10:** Establish a statewide training system for all educators and staff.

*There are significant challenges presented by the size and geography of the State of Colorado with regards to providing training to educators and staff. These challenges were reported in testimony by both educators and families.*

10.1 Create eight regional multi-disciplinary training teams to provide assistance with identification and education.

10.2 Ensure funding for training and retention of staff.

10.3 Provide regional training for multi-disciplinary teams using Quality Program Indicators to ensure programming consistency across the State.

**Recommendation 11:** Create certification programs within higher education that prepare professionals to serve people with Autism Spectrum Disorders.

*This is a critical recommendation that is unequivocally tied to the Commission's Vision, Mission, and Core Values. Without appropriate training for persons providing services, none of them may be achieved. Yet beyond broad training, there is a need for comprehensive and specific training in empirically supported protocols and methodologies to treat the symptoms of Autism Spectrum Disorders. Autism Spectrum Disorders are treatable! Colorado can do something about the epidemic now. Certification programs based on nationally recognized treatment standards must be created. Medicaid waiver programs and recently enacted legislation (i.e., SB09-244) recognize this need and hence require that external service providers hold such a credential to adequately serve persons with ASD. However, no such training programs are currently offered in the State. Teachers and para-educators are on the front line in the epidemic of Autism Spectrum Disorders; a robust certification process must be created to prepare them for their role in providing needed services and supports.*

11.1 Ensure the development of course curriculum on Autism Spectrum Disorders at institutions of higher education.

**Recommendation 12:** Establish a system of collaboration and information dissemination among all stakeholders including families, private and public service agencies, educational agencies, and the medical community to ensure wraparound services for individual students that are efficient, coordinated, and consistent.

*Currently, service systems for persons with ASD inadequately collaborate and share information. Likewise, treatment is reported as disjointed and inconsistent across the silos of care. These gaps in service continuity and consistency lead to poorer outcomes, decreased health status, and increased general costs within existing systems of care.*

12.1 Increase the number of high quality, specialized school programs needed to serve children with Autism Spectrum Disorders and co-occurring Mental Health disorders.

The Education committee report and presentation are contained in Appendix F.

## Medical and Mental Health

**Recommendation 13:** Improve access to quality health care for children and adults with Autism Spectrum Disorders.

*Training is needed for health care providers, from primary care providers to first responders and ER personnel, on how to work with individuals with developmental disabilities and ASD. Tele-health services would be highly effective in getting trainings to providers across the State. There is a paucity of primary care providers who are comfortable with adults with ASD. It is very difficult for families transitioning from pediatrics to adult medicine to find a provider for their child with ASD.*

13.1 Ensure awareness and training that ASD is a neurological disorder and that unaddressed medical conditions can have a negative impact on behavior and function. The management of ASD is a rapidly evolving field. A statewide mechanism is needed to coordinate awareness, training, and dissemination of guidelines once available.

13.2 Increase awareness, training, and coverage for the extra services needed to manage medical issues in individuals with ASD such as extra time to adjust to a setting, sedation for minor procedures or coordination of procedures when sedation is planned.

13.3 Expand research on treatments for individuals with ASD by providing funding and infrastructure.

13.4 Increase access to primary care providers for adults with ASD. Such an increase may be achieved through expansion of programs such as Federally Qualified Health Centers.

13.5 Increase availability of adult dental care.

13.6 Include training in management of individuals with ASD and developmental disabilities in Internal Medicine, Family Practice, Emergency Medicine, and first responder training programs.

13.7 Increase the availability of Tele-health services.

13.8 Provide appropriate reimbursement for screening, diagnosis, and treatment of ASD.

**Recommendation 14:** Improve access to quality mental health services for individuals with Autism Spectrum Disorders.

*Many system issues currently impede access to mental health services for individuals with ASD. Autism is a medical disorder that requires behavioral services and often requires mental health services. A system to address medical vs behavioral health coverage for individuals with ASD is needed. Some funding sources will exclude Autism Spectrum Disorders under medical coverage and others may exclude Autism Spectrum Disorders under behavioral health coverage.*

*Training is needed to increase the comfort level of providers to provide care to individuals with a "Dual Diagnosis" of Autism Spectrum Disorders and a mental health diagnosis. Coordination of care among primary care practitioners, developmental disabilities professionals, and mental health professionals is needed.*

*Crisis Intervention services are urgently needed. At this time in the State of Colorado, there are 3 inpatient beds for children with an IQ below 70, 2 potential inpatient beds for children with ASD and an IQ above 70, and no inpatient beds for adults with ASD or developmental disabilities. Inpatient programs must include treatments that are appropriate for individuals with ASD.*

14.1 Facilitate coordinated care between primary care practitioners, developmental disabilities professionals, and mental health professionals.

14.2 Train individuals to increase the comfort level of providers to manage individuals with "dual diagnosis" of an Autism Spectrum Disorder and a mental health diagnosis.

14.3 Crisis Intervention services are urgently needed, both Hospital Based and Pre-Hospital/In Home. The START Model has been successful in other states. The START Philosophy emphasizes a coordinated service approach.

14.4 Increase the availibility of inpatient and day treatment for children and adults with developmental disabilities and Autism Spectrum Disorders in Colorado. These programs must include treatments that are appropriate for individuals with ASD.

14.5 Develop a system for addressing medical vs. behavioral health coverage for individuals with ASD.

14.6 Residential/community based settings are needed that are appropriate for children and adults with a dual diagnosis.

14.7 There is a need for system changes that address the need for residential placement without using the term "neglect" or requiring the curtailing of parental rights.

The Medical and Mental Health committee report and presentation including information about the START model are contained in Appendix G.

## Community

**Recommendation 15:** Increase the availability of supports for community living for children and adults with Autism Spectrum Disorders in Colorado.

*Safety is a serious issue for the ASD community. Adequate data does not exist on the extent of the safety problems, but Emergency Room visits, Police Department interactions, and school disciplinary actions are frequent. Often first responders do not recognize they are dealing with people with ASD and inappropriate treatment may result.*

15.1 Ensure individuals with ASD have access to habilitative services to address activities of daily living.

15.2 Require training for all first responders including: law enforcement, fire, and medical personnel to increase safe interactions in the community.

**Recommendation 16:** Increase employment, transportation, and housing for adults with Autism Spectrum Disorders.

*Each individual with ASD requires different services and experiences different challenges in gaining access to jobs and employment assistance services, housing, and adequate transportation.*

16.1 Assure ongoing coaching and mentoring for employment.

16.2 Increase transportation in urban and rural areas and simplify routes and schedules for people who cannot drive.

**Recommendation 17:** Provide support for families and caregivers of individuals with Autism Spectrum Disorders.

*Needs of the caregivers are diverse, but have a similar theme: adequate respite, support groups, family preservation services, training, educational and financial guardianship, and planning services.*

17.1 Prioritize "family preservation" by increasing access to counseling and therapy for parents, siblings, and other family members.

17.2 Ensure adequately trained childcare is accessible and affordable for family caregivers.

17.3 Increase the frequency and duration of respite for all caregivers of persons with ASD.

**Recommendation 18:** Increase support for communication, recreation, and social development for individuals with Autism Spectrum Disorders.

*Communication is a core deficit for many people with ASD. Often the person is not understood and may even have unique ways of communicating needs and wants. Many persons with ASD have problems understanding typical verbal and non-verbal communication.*

18.1 Research and create access to technologies needed by persons with ASD.

18.2 Ensure public recreational staff have adequate training to support the inclusion of persons with ASD.

18.3 Increase training for communication professionals to provide effective interventions for persons with ASD.

The Community committee report and presentation are contained in Appendix H.

## Conclusion

In conclusion, The Colorado Autism Commission believes all Coloradans affected by Autism Spectrum Disorders deserve to have ready access to the services and supports they need to be safe, educated, healthy, productive, and able to pursue happy and fulfilling lives. To that end, we have developed this Ten-Year Strategic Plan to promote, integrate, coordinate, and expand services to all Coloradans affected by Autism Spectrum Disorders, including the creation of new programs as the science around the causes and treatment of ASDs expand. We believe a formal and sustainable mechanism to implement the recommendations within this report should be considered as a significant pathway towards these ends. Thank you for the opportunity to serve the Citizens of Colorado, and we hope to see these recommendations enacted in the coming years.

## Infrastructure, Funding and Data

| Recommendation | Strategy | When |
|---|---|---|
| 1. Establish a formal and sustainable mechanism to implement the Colorado Strategic Plan for Autism Spectrum Disorders to improve the lives of individuals with ASD. | 1.1 Establish and fund a Legislative Oversight Committee and Taskforce. | 2012 |
| | 1.2 Develop mechanisms to disseminate information about new treatments and guidelines once available. | 2020 |
| | 1.3 Investigate the best means to establish and fund local programs for implementation of the Strategic Plan. | 2020 |
| | 1.4 Establish an Autism Spectrum Disorders Ombudsman program. | 2016 |
| 2. Establish integrated data systems among State departments and stakeholders to track diagnosis, treatment, services and outcomes, to improve coordination of care, and to disseminate information. | 2.1 Improve infrastructure and support for a comprehensive, statewide, tracking system to accurately identify the number of individuals with Autism Spectrum Disorders in Colorado. | 2012 |
| 3. Increase the systemic capacity for diagnosis, treatment, coordination of care, and service delivery for individuals with ASD across the lifespan. | 3.1 Revise the Colorado implementation of the definition of developmental disabilities to include an eligibility component, separate from the IQ component, which establishes eligibility based on the significant impairment of functional adaptive skills. | 2016 |
| | 3.2 Adopt an incentive program to attract and retain a broad spectrum of higher education students preparing to serve and providers already serving individuals with ASD in professional disciplines. | 2016 |
| | 3.3 Clarify, determine and streamline a statewide, consistent process for all funding sources for procedures, treatment and utilization review standards, and then crosswalk quality standards with treatments and payments. | 2020 |
| | 3.4 Establish a sustainable means to monitor and address personnel capacity issues at all levels. | 2020 |
| | 3.5 Build upon Medical Home efforts to provide ASD technical assistance and training to primary care and specialty care providers in the state. | 2016 |
| | 3.6 Expand and support research of causes and treatments for individuals with ASD. | Ongoing |
| 4. Coordinate access to services for individuals with Autism Spectrum Disorders across all systems. | 4.1 Improve current local/regional systems that provide comprehensive information and referral to resources including: long-term care services, mental health services, medical/dental care, housing, employment, and community living. | 2016 |
| 5. Ensure and streamline access to services for all individuals with Autism Spectrum Disorders and their families. | 5.1 Ensure the provision of translation and other supports to ensure access to information and services for monolingual, non-English language individuals and families. | 2012 |
| | 5.2 Improve local/regional service delivery system serving individuals with ASD and their families in rural communities with low identification rates and service capacity. | 2016 |

## Screening and Diagnosis

| Recommendation | Strategy | When |
|---|---|---|
| 6. Improve educational and medical identification through screening and diagnosis of Autism Spectrum Disorders at the earliest possible age across the lifespan. | 6.1 6.1 Expand public awareness and training models for Autism Spectrum Disorders screening. | 2012 |
| | 6.2 Develop and implement statewide guidelines to facilitate the timely educational identification of students with Autism Spectrum Disorders. | 2012 |
| | 6.3 Create a consensus statement regarding Autism Spectrum Disorders screening and diagnosis. | 2012 |
| | 6.4 Create a referral process for timely comprehensive medical and educational diagnostic evaluation across the lifespan. | 2012 |
| | 6.5 Develop a standard minimum core medical and educational multi-disciplinary evaluation. | 2012 |

## Early intervention Services

| Recommendation | Strategy | When |
|---|---|---|
| 7. Establish consistent quality standards for early intervention services across systems statewide. | 7.1 Expand public awareness and training models for Autism Spectrum Disorders screening. | 2012 |
| 8. Provide early intervention services as soon as a child is suspected of having an Autism Spectrum Disorders due to delays in communication or social-emotional development. | 8.1 Provide training to early intervention providers on how to monitor for the early signs of Autism Spectrum Disorders. | 2012 |

## Education

| Recommendation | Strategy | When |
|---|---|---|
| 9. Create a new educational identification category of Autism Spectrum Disorders. | 9.1 Amend the Exceptional Children's Educational Act (ECEA) rules and adopt the Autism Disability as stated in the Individuals with Disabilities Education Act (IDEA) rules 300.8 (c)(1)(i)-(iii) including the definition. The term "Autism Spectrum Disorders" will replace "Autism" to make clear that it includes Asperger Syndrome and Pervasive Developmental Disorders-Not Otherwise Specified. | 2012 |
| | 9.2 Train multi-disciplinary teams to determine the Educational Identification of Autism Spectrum Disorders. | 2012 |
| 10. Establish a statewide training system for all educators and staff. | 10.1 Create eight regional multi-disciplinary training teams to provide assistance with identification and education. | 2016 |
| | 10.2 Ensure funding for training and retention of staff. | Ongoing |
| | 10.3 Provide regional training for multi-disciplinary teams using Quality Program Indicators to ensure programming consistency across the State. | 2012 |
| 11. Create certification programs within higher education that prepare professionals to serve people with ASD. | 11.1 Ensure the development of courses on diagnosis, treatment and education of individuals with curriculum on Autism Spectrum Disorders at Institutions of Education. | 2012 |
| 12. Establish a system of collaboration and information dissemination among all stakeholders including families, private and public service agencies, educational agencies, and the medical community to ensure wraparound services for individual students that are efficient, coordinated, and consistent. | 12.1 Increase the number of high quality, specialized school programs needed to serve children with Autism Spectrum Disorders and co-occurring Mental Health disorders. | 2012 |

## Medical and Mental Health

| Recommendation | Strategy | When |
|---|---|---|
| 13. Improve access to quality health care for children and adults with Autism Spectrum Disorders. | 13.1 Ensure awareness and training that ASD is a neurological disorder and that unaddressed medical conditions can have a negative impact on behavior and function. The management of ASD is a rapidly evolving field. A statewide mechanism is needed to coordinate awareness, training and dissemination of guidelines once available. | 2012 |
| | 13.2 Increase awareness, training, and coverage for the extra services needed to manage medical issues in individuals with ASD such as extra time to adjust to a setting, sedation for minor procedures or coordination of procedures when sedation is planned. | 2016 |
| | 13.3 Expand research of treatments for individuals with ASD by providing funding and infrastructure. | 2016 |
| | 13.4 Increase access to primary care providers for adults with ASD. | 2016 |
| | 13.5 13.5 Increase availability of adult dental care. | 2016 |
| | 13.6 13.6 Include training in management of individuals with ASD and developmental disabilities in Internal Medicine, Family Practice, Emergency Medicine, and first responder training programs. | 2016 |
| | 13.7 13.7 Increase the availability of Tele-health services. | 2016 |
| | 13.8 13.8 Provide appropriate reimbursement for screening, diagnosis and treatment of ASD. | 2016 |
| 14. Improve access to quality mental health services for individuals with Autism Spectrum Disorders. | 14.1 Facilitate coordinated care between primary care practitioners, developmental disabilities professionals, and mental health professionals. | 2012 |
| | 14.2 Training individuals to increase comfort level of providers to manage individuals with "dual diagnosis," i.e. an Autism Spectrum Disorder and a mental health diagnosis. | 2012 |
| | 14.3 Crisis Intervention services are urgently needed, both Hospital Based and Pre-Hospital/In Home. The START Model has been successful in other states. The START Philosophy emphasizes a coordinated service approach. | 2012 |
| | 14.4 Increase the number of inpatient and day treatment slots for children and adults with developmental disabilities and Autism Spectrum Disorders in Colorado. These programs must include treatments that are appropriate for individuals with Autism Spectrum Disorders. | 2016 |
| | 14.5 Develop a system for addressing medical vs behavioral health coverage for individuals with ASD. | 2016 |
| | 14.6 Residential/community based settings are needed that are appropriate for children and adults with a dual diagnosis. | 2016 |
| | 14.7 There is a need for system changes that address the need for residential placement without using the term "neglect" or requiring the curtailing of parental rights. | 2012 |

## Community

| Recommendation | Strategy | When |
|---|---|---|
| 15. Increase the availability of supports for community living for children and adults with Autism Spectrum Disorders living in Colorado. | 15.1 Ensure individuals with ASD have access to habilitative services to address activities of daily living. | 2016 |
| | 15.2 Require training for all first responders including: law enforcement, fire, and medical personnel to increase safe interactions in the community. | 2016 |
| 16. Increase employment, transportation, and housing for adults with Autism Spectrum Disorders. | 16.1 Assure ongoing coaching and mentoring for employment. | 2016 |
| | 16.2 ncrease transportation in urban and rural areas and simplify routes and schedules for people who cannot drive. | 2016 |
| 17. Provide support for families and caregivers of individuals with Autism Spectrum Disorders. | 17.1 Prioritize "family preservation" by increasing access to counseling and therapy for parents, siblings, and other family members. | 2012 |
| | 17.2 Ensure adequately trained child care is accessible and affordable for family caregivers. | 2016 |
| | 17.3 Increase the frequency and duration of respite for all caregivers of persons with ASD. | 2016 |
| 18. Increase support for communication, recreation, and social development for individuals with Autism Spectrum Disorders. | 18.1 Research and create access to technologies needed by persons with ASD. | 2016 |
| | 18.2 Ensure public recreational staff have adequate training to support the inclusion of persons with ASD. | 2020 |
| | 18.3 Increase training for communication professionals to provide effective interventions for persons with ASD. | Ongoing |

## Colorado Autism Commission
# Commissioners

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**Carol Meredith**
Executive Director
The Arc of Arapahoe/Douglas
Commission Coordinator

**Ellen Brilliant**
Commission Facilitator

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Angela West

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