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:

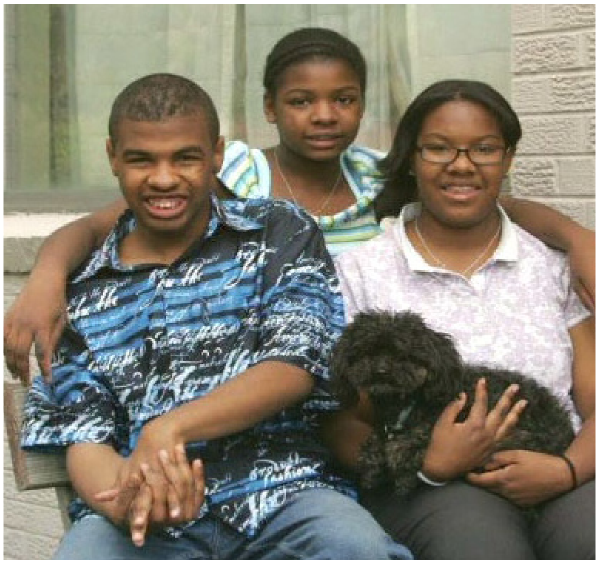
People with Autism Spectrum Disorders are valuable. People with Autism Spectrum Disorders are important members of their families, good employees, colleagues, classmates, and friends, and play important roles in the communities in which they live, play, and worship.

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

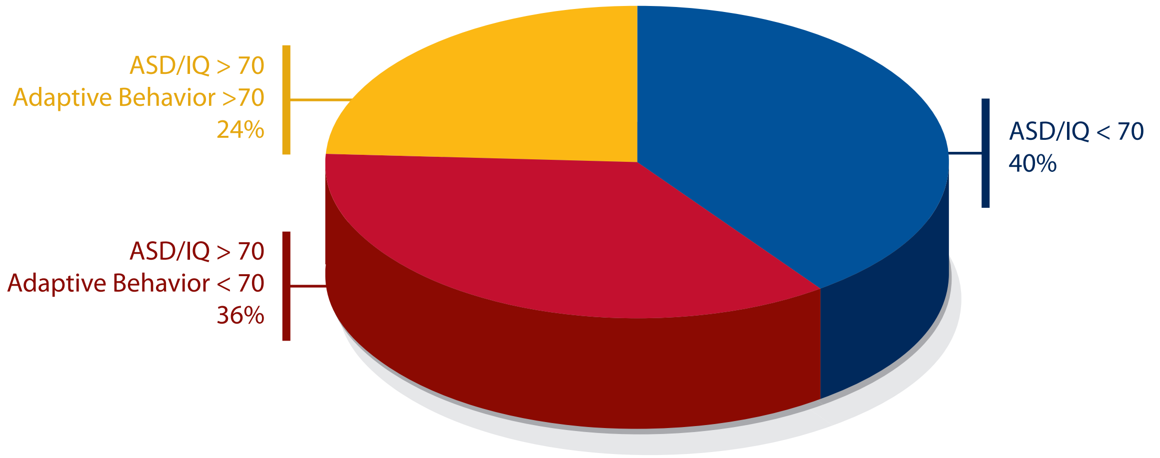
Task 1: Define Autism Spectrum Disorders

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 10-16-104.5, C.R.S. Senate Bill 93-113 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. • Specifies that autism is not a mental illness for insurance purposes.
2004 25.5-6-801 through 25.5-6-805, C.R.S.; rules 10 C.C.R. 2505-10, Section 8.519 Senate Bill 04-177 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. • 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). • Behavioral services were capped at $25,000 per year and the number of children enrolled at a given time was capped at 75.
2009 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. Senate Bill 09-244 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. • Requires health insurance to cover assessment, diagnosis, and, treatment of autism. • Prohibits carriers from denying issuance or renewal of policies due to autism diagnosis. • Delineates which health care professionals are eligible to provide treatment, and requires appropriate certification and credentialing. • Applies to small and large State of Colorado group plans, not individual or ERISA plans. • Provides parity with other medical illnesses. • States the annual cap on treatment payments for ABA therapies: 1. Birth – age 8: $34,000 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.

Colorado Autism Commission
Ten-Year Strategic Plan

"In 2008, the Colorado General Assembly created the 24 member Colorado Autism Commission (SB08-163) in order to obtain additional information on people with Autism Spectrum Disorders (ASD) in the State. The Colorado General Assembly charged the Commission with preparation of a Ten-Year Strategic Plan for the State of Colorado.

In response the Commission has developed a plan for improving the lives of Coloradoans affected by ASD. A formal and sustainable mechanism must be established for implementation of the plan."

Betty Lehman
Chair, Colorado Autism Commission

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. 9.2 Train multi-disciplinary teams to determine the Educational Identification of Autism Spectrum Disorders.	2012 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. 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.	2016 Ongoing 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

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Executive Director
The Arc of Arapahoe/Douglas
Commission Coordinator

Ellen Brilliant
Commission Facilitator

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Child Welfare; Family Preservation www.childwelfare.com/Family%20Preservation.htm.

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Colorado Department of Human Services; Family Support Services Program www.cdhs.state.co.us/ddd/FSSP_Main.htm.

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

Appendix

TABLE OF CONTENTS

Appendix A

Act Creating Commission

NOTE: This bill has been prepared for the signature of the appropriate legislative officers and the Governor. To determine whether the Governor has signed the bill or taken other action on it, please consult the legislative status sheet, the legislative history, or the Session Laws.

An Act

SENATE BILL 08-163

BY SENATOR(S) Shaffer, Gordon, Bacon, Groff, Isgar, Johnson, Schwartz, Tapia, Tupa, Veiga, Windels, Boyd, Gibbs, Keller, Morse, Tochtrop, and Williams;
also REPRESENTATIVE(S) Primavera, Benefield, Casso, Fischer, Frangas, Gagliardi, Gallegos, Gardner B., Green, Hodge, Kefalas, Kerr J., Labuda, Levy, McFadyen, McKinley, Stafford, Todd, Borodkin, Butcher, Carroll M., Carroll T., Curry, Ferrandino, Garza-Hicks, Kerr A., Looper, Marostica, Marshall, Massey, Merrifield, Peniston, Pommer, Rice, Riesberg, Romanoff, Scanlan, Solano, Stephens, Summers, Swalm, and White.

CONCERNING THE CREATION OF AN AUTISM COMMISSION.

Be it enacted by the General Assembly of the State of Colorado:

SECTION 1. Article 1 of title 26, Colorado Revised Statutes, is amended BY THE ADDITION OF A NEW PART to read:

PART 4
AUTISM COMMISSION

26-1-401. Colorado autism commission - purpose - creation. (1) THERE IS HEREBY ESTABLISHED IN THE DEPARTMENT THE COLORADO

Capital letters indicate new material added to existing statutes; dashes through words indicate deletions from existing statutes and such material not part of act.

AUTISM COMMISSION, REFERRED TO IN THIS PART 4 AS THE "COMMISSION". THE PURPOSE OF THE COMMISSION SHALL BE TO STUDY AUTISM ISSUES AND TO DEVELOP A TEN-YEAR STRATEGIC PLAN FOR THE STATE OF COLORADO TO ADDRESS THE GROWING NUMBER OF INDIVIDUALS WITH AUTISM IN COLORADO WHO NEED SERVICES FROM ONE OR MORE SYSTEMS.

(2) THE COMMISSION SHALL CONSIST OF TWENTY-FOUR MEMBERS, WHO ARE KNOWLEDGEABLE ABOUT AUTISM OR ABOUT SYSTEMS THAT SERVE PEOPLE WITH AUTISM SPECTRUM DISORDERS OR BOTH, APPOINTED BY THE GOVERNOR, AS FOLLOWS:

(a) TWO MEMBERS WHO ARE INDIVIDUALS WITH AUTISM WHO SHALL BE CONSIDERED SELF-ADVOCATES;

(b) ONE MEMBER WHO IS A PARENT OF A CHILD WITH AUTISM;

(c) ONE MEMBER WHO IS A PARENT OF AN ADULT CHILD WITH AUTISM;

(d) TWO MEMBERS WHO REPRESENT AUTISM OR DISABILITY ADVOCACY ORGANIZATIONS;

(e) ONE MEMBER WHO REPRESENTS AUTISM SERVICE PROVIDERS;

(f) ONE MEMBER WHO IS A PHYSICIAN LICENSED IN COLORADO;

(g) ONE MEMBER WHO REPRESENTS THE DEPARTMENT OF EDUCATION;

(h) ONE MEMBER WHO REPRESENTS THE DEPARTMENT OF PUBLIC HEALTH AND ENVIRONMENT;

(i) ONE MEMBER WHO REPRESENTS THE DEPARTMENT OF HEALTH CARE POLICY AND FINANCING;

(j) ONE MEMBER WHO REPRESENTS THE DEPARTMENT OF HUMAN SERVICES;

(k) ONE MEMBER WHO REPRESENTS THE DEPARTMENT OF LABOR AND EMPLOYMENT;

(l) ONE MEMBER WHO REPRESENTS THE DIVISION WITHIN THE DEPARTMENT OF HUMAN SERVICES THAT GOVERNS SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES;

(m) ONE MEMBER WHO REPRESENTS THE DIVISION WITHIN THE DEPARTMENT OF HUMAN SERVICES THAT GOVERNS VOCATIONAL REHABILITATION;

(n) ONE MEMBER WHO REPRESENTS THE DIVISION WITHIN THE DEPARTMENT OF HUMAN SERVICES THAT GOVERNS MENTAL HEALTH;

(o) ONE MEMBER WHO REPRESENTS THE COLORADO COMMISSION ON HIGHER EDUCATION;

(p) ONE MEMBER WHO REPRESENTS THE STATE COUNCIL ON DEVELOPMENTAL DISABILITIES CREATED IN SECTION 27-10.5-203, C.R.S.;

(q) ONE MEMBER WHO REPRESENTS THE CENTER SPECIALIZING IN DEVELOPMENTAL DISABILITIES AT THE UNIVERSITY OF COLORADO SCHOOL OF MEDICINE;

(r) ONE MEMBER WHO REPRESENTS A NONPROFIT LEGAL ORGANIZATION FOR PEOPLE WITH DISABILITIES AND OLDER PEOPLE THAT RECEIVES FUNDING THROUGH THE FEDERAL DEVELOPMENTAL DISABILITIES ACT;

(s) ONE MEMBER WHO IS A SCHOOL DISTRICT REPRESENTATIVE WITH EXPERTISE IN THE NEEDS OF CHILDREN WITH AUTISM IN THE PUBLIC SCHOOLS;

(t) ONE MEMBER WHO IS A REPRESENTATIVE OF A COMMUNITY MENTAL HEALTH CENTER AND WHO HAS EXPERIENCE TREATING INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS;

(u) ONE MEMBER WHO IS A MEMBER OF A COMMUNITY-CENTERED BOARD; AND

(v) ONE MEMBER WHO IS A REPRESENTATIVE OF THE BUSINESS COMMUNITY.

(3) THE GOVERNOR SHALL MAKE THE APPOINTMENTS TO THE COMMISSION ON OR BEFORE AUGUST 1, 2008.

(4) WHEN MAKING APPOINTMENTS TO THE COMMISSION, THE GOVERNOR SHALL ENSURE REPRESENTATION FROM THE VARIOUS GEOGRAPHIC AREAS OF THE STATE.

(5) THE GOVERNOR MAY, WITH OR WITHOUT CAUSE, REMOVE AND REPLACE A MEMBER OF THE COMMISSION. IF A VACANCY OCCURS OR A MEMBER IS REMOVED FROM THE COMMISSION, THE GOVERNOR SHALL APPOINT A NEW MEMBER IN ACCORDANCE WITH THE PROVISIONS OF SUBSECTION (2) OF THIS SECTION.

(6) THE MEMBER WHO REPRESENTS THE DEPARTMENT OF HUMAN SERVICES SHALL CONVENE THE FIRST MEETING OF THE COMMISSION NO LATER THAN SEPTEMBER 8, 2008. THE COMMISSION SHALL MEET AT LEAST SIX TIMES OVER THE FOLLOWING TWELVE MONTHS AND MORE OFTEN AS THE COMMISSION DETERMINES IS NECESSARY AND FUNDING WILL ALLOW.

(7) THE COMMISSION SHALL ELECT A CHAIR AND VICE-CHAIR FROM ITS MEMBERSHIP. THE COMMISSION MAY CREATE AS MANY SUBCOMMITTEES AS IT DEEMS NECESSARY TO CARRY OUT THE SCOPE AND MISSION OF THE COMMISSION. EACH SUBCOMMITTEE SHALL BE CHAIRED BY A COMMISSION MEMBER BUT MAY BE COMPOSED OF MEMBERS OUTSIDE OF THE COMMISSION. MEMBERS OF THE COMMISSION SHALL SERVE WITHOUT COMPENSATION BUT MAY BE REIMBURSED FOR EXPENSES INCURRED IN CONNECTION WITH THEIR SERVICE ON THE COMMISSION IF THE NONPROFIT ORGANIZATION THAT IS THE CUSTODIAN OF THE DONATED MONEYS COLLECTED PURSUANT TO SECTION 26-1-404 RECEIVES SUFFICIENT GIFTS, GRANTS, OR DONATIONS TO COVER THE COSTS OF THE REIMBURSEMENTS.

26-1-402. Commission - duties. (1) THE COMMISSION SHALL EXAMINE AUTISM IN THIS STATE AND SHALL:

(a) DEFINE THE AUTISM SPECTRUM FOR PURPOSES OF THE SCOPE OF THE COMMISSION AND IDENTIFY THE NUMBER OF INDIVIDUALS AFFECTED BY AUTISM IN THE STATE;

(b) IDENTIFY EXISTING SERVICES AND GAPS IN SERVICES IN COLORADO FOR PEOPLE WITH AUTISM SPECTRUM DISORDERS;

(c) REVIEW SERVICES PROVIDED BY OTHER STATES THAT BENEFIT PEOPLE WITH AUTISM SPECTRUM DISORDERS AND IDENTIFY PROMISING PRACTICES; AND

(d) EXAMINE ISSUES AFFECTING THE EFFICIENT DELIVERY AND COORDINATION OF SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDERS THAT THE COMMISSION DEEMS NECESSARY TO STUDY.

(2) AFTER STUDYING THE ISSUES OUTLINED IN SUBSECTION (1) OF THIS SECTION, THE COMMISSION SHALL DEVELOP A TEN-YEAR STRATEGIC PLAN DESIGNED TO:

(a) CLARIFY THE ARRAY OF NECESSARY SERVICES AND SUPPORTS THAT ENABLE PERSONS WITH AUTISM SPECTRUM DISORDERS TO FUNCTION TO THEIR INDIVIDUAL POTENTIALS ACROSS THEIR LIFESPANS;

(b) PROVIDE EFFECTIVELY COORDINATED SERVICES AND SUPPORTS TO PERSONS WITH AUTISM SPECTRUM DISORDERS IN THIS STATE;

(c) ESTIMATE THE FUNDING AND THE SOURCES OF FUNDING NEEDED TO PROVIDE THE NECESSARY SERVICES AND SUPPORTS DESCRIBED IN PARAGRAPH (a) OF THIS SUBSECTION (2) AND TO ACCOMPLISH THE COORDINATION OF SERVICES AS DESCRIBED IN PARAGRAPH (b) OF THIS SUBSECTION (2).

26-1-403. Report. (1) THE COMMISSION SHALL SUBMIT A FINAL REPORT TO THE GOVERNOR AND TO THE GENERAL ASSEMBLY NO LATER THAN OCTOBER 1, 2009. THE FINAL REPORT SHALL INCLUDE BUT NEED NOT BE LIMITED TO:

(a) THE COMMISSION'S FINDINGS AND RECOMMENDATIONS, INCLUDING CONSIDERATION OF EACH OF THE ISSUES DESCRIBED IN SECTION 26-1-402 (1);

(b) A TEN-YEAR STRATEGIC PLAN FOR PROVIDING SERVICES AND SUPPORTS TO PERSONS WITH AUTISM SPECTRUM DISORDERS IN COLORADO AS OUTLINED IN SECTION 26-1-402 (2);

(c) PROPOSALS FOR LEGISLATION TO IMPLEMENT THE STRATEGIC PLAN CONTAINED IN THE REPORT;

(d) RECOMMENDATIONS TO APPLICABLE PRINCIPAL DEPARTMENTS OF THE STATE CONCERNING POLICIES, PROCEDURES, AND RULES THAT MAY BE ALTERED OR ADOPTED TO IMPROVE SERVICES THAT BENEFIT PEOPLE WITH AUTISM SPECTRUM DISORDERS OR TO IMPROVE COORDINATION AMONG STATE AGENCIES THAT PROVIDE SERVICES THAT BENEFIT PEOPLE WITH AUTISM SPECTRUM DISORDERS.

26-1-404. Commission funding - staff support. (1) THE EXECUTIVE DIRECTOR OF THE DEPARTMENT OF HUMAN SERVICES SHALL DESIGNATE A NONPROFIT ORGANIZATION AS THE CUSTODIAN OF FUNDS FOR THE COMMISSION. THE ORGANIZATION IS AUTHORIZED TO RECEIVE AND EXPEND ANY FUNDS NECESSARY FOR THE OPERATION OF THE COMMISSION. THE ORGANIZATION SHALL PREPARE A BUDGET FOR THE OPERATION OF THE COMMISSION. PRIOR TO THE EXPENDITURE OF ANY MONEYS RECEIVED, THE ORGANIZATION SHALL TRANSMIT A COPY OF THE OPERATING BUDGET TO THE EXECUTIVE DIRECTOR OF THE DEPARTMENT OF HUMAN SERVICES AND SHALL CERTIFY THAT THERE IS ADEQUATE FUNDING AVAILABLE TO COVER THE EXPENSES IDENTIFIED IN THE OPERATING BUDGET.

(2) ANY STAFF NEEDED TO ASSIST THE COMMISSION IN CONDUCTING ITS DUTIES SHALL BE PROVIDED BY NONPROFIT AGENCIES OR PRIVATE GROUPS.

(3) ALL COSTS INCURRED BY THE COMMISSION IN CARRYING OUT ITS STUDY AND REPORT INCLUDING, BUT NOT LIMITED TO, THE DIRECT OR INDIRECT COSTS ASSOCIATED WITH THE DUTIES OF THE COMMISSION, THE REIMBURSEMENT OF REASONABLE EXPENSES FOR THE MEMBERS OF THE COMMISSION TO ATTEND MEETINGS, AND THE COSTS OF RESEARCH AND ANALYSIS SHALL BE PAID BY CONTRIBUTIONS, GRANTS, SERVICES, AND IN-KIND DONATIONS FROM PRIVATE SOURCES.

26-1-405. Repeal of part. THIS PART 4 IS REPEALED, EFFECTIVE JULY 1, 2010.

SECTION 2. Safety clause. The general assembly hereby finds, determines, and declares that this act is necessary for the immediate preservation of the public peace, health, and safety.

Peter C. Groff PRESIDENT OF THE SENATE	Andrew Romanoff SPEAKER OF THE HOUSE OF REPRESENTATIVES
Karen Goldman SECRETARY OF THE SENATE	Marilyn Eddins CHIEF CLERK OF THE HOUSE OF REPRESENTATIVES

APPROVED____

Bill Ritter, Jr.
GOVERNOR OF THE STATE OF COLORADO

STATE OF COLORADO

OFFICE OF THE GOVERNOR
136 State Capitol Building
Denver, Colorado 80203
(303) 866 - 2471
(303) 866 - 2003 fax

1876

Bill Ritter, Jr.
Governor

A 203 08

EXECUTIVE ORDER

MEMBERS

COLORADO AUTISM COMMISSION

ORDERED:

That the following named persons be and they are hereby appointed to the:

COLORADO AUTISM COMMISSION

for terms expiring October 1, 2009:

Kathy O. Grant of Denver, Colorado, an individual with Autism who shall be considered a self-advocate, appointed;

Nathan P. Johansen of Westminster, Colorado, an individual with Autism who shall be considered a self-advocate, appointed;

Jessica N. Frost of Parker, Colorado, a parent of a child with Autism, appointed;

Kathleen Leszcynski of Lafayette, Colorado, a parent of an adult child with Autism, appointed;

Elizabeth R. Lehman of Denver, Colorado, to serve as a representative of Autism or disability advocacy organizations, appointed;

Stephen D. Fretz of Vail, Colorado, to serve as a representative of Autism or disability Advocacy organizations, appointed;

David B. Hatfield of Monument, Colorado, to serve as a representative of Autism service providers, appointed;

Ann M. Reynolds, MD of Denver, Colorado, a physician licensed in Colorado, appointed;

Kathleen D. Watters of Englewood, Colorado, to serve as a representative of the Department of Public Health and Environment, appointed;

Michelle B. Cason of Westminster, Colorado, to serve as a representative of the Department of Health Care Policy and Financing, appointed;

Sharon S. Jacksi of Lyons, Colorado, to serve as a representative of the Department of Human Services, appointed;

Heidi Bimmerle of Golden, Colorado, to serve as a representative of the Department of Labor and Employment, appointed;

Barbara D. Ramsey of Denver, Colorado, a representative of the division within the Department of Human Services that governs services to persons with Developmental Disabilities, appointed;

Anne K. Kabigting of Denver, Colorado, a representative of the division within the Department of Human Services that governs vocational rehabilitation, appointed;

Chris M. Habgood of Lakewood, Colorado, a representative of the division within the Department of Human Services that governs mental health, appointed;

Larry B. Beckner of Grand Junction, Colorado, to serve as a representative of the Colorado Commission on Higher Education, appointed;

Bruce H. Cline of Littleton, Colorado, a representative of the State Council on Developmental Disabilities created in section 27-10.5-203, C.R.S., appointed;

Cordelia R. Rosenberg of Denver, Colorado, a representative of the Center specializing in Developmental Disabilities at the University of Colorado School of Medicine, appointed;

Liz C. Fuselier of Denver, Colorado, a representative of a non-profit legal organization for people with disabilities and older people that receives funding through the Federal Developmental Disabilities Act, appointed;

Christina H. Wu of Greenwood Village, Colorado, a school district representative with expertise in the needs of children with Autism in the public schools, appointed;

Peter J. Weinberg of Denver, Colorado, a representative of a community mental health center and who has experience treating individuals with Autism Spectrum Disorders, appointed;

Janet L. Rasmussen of Boulder, Colorado, a member of a community-centered board, appointed;

Barry L. Jackson of Highlands Ranch, Colorado, a representative of the business community, appointed.

GIVEN under my hand and the
Executive Seal of the State of
Colorado, this twelfth day
of August, 2008.

Bill Ritter, Jr.
Governor

Appendix B

Testimony Committee Report

Colorado Autism Commission

Testimony Committee Report

July 8, 2009

Colorado Autism Commission Mission:

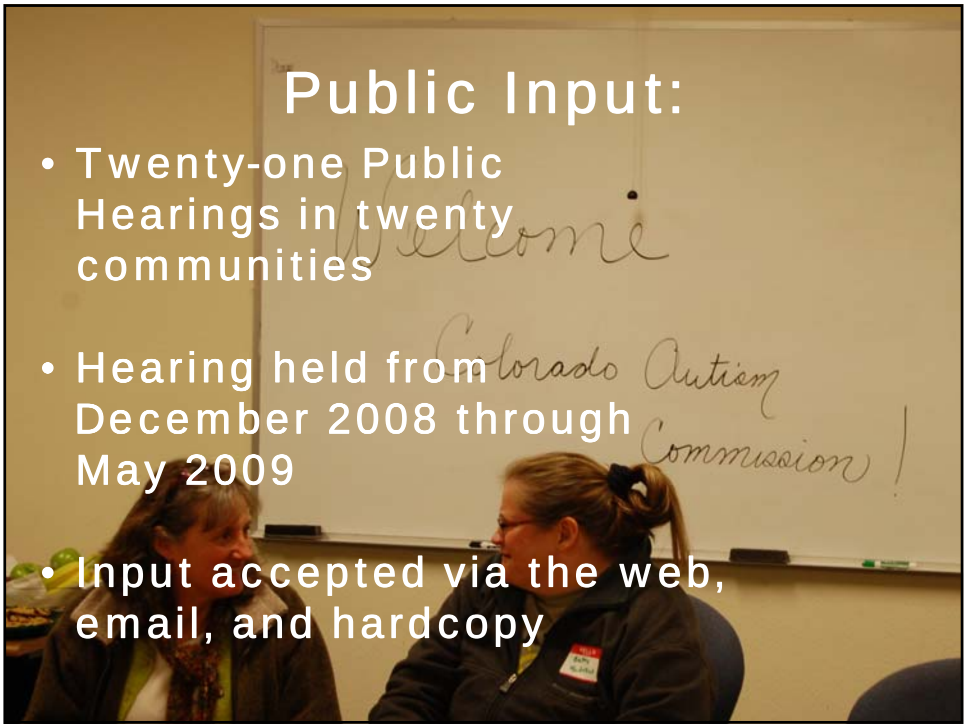
To develop and promote a 10 year strategic plan to integrate, coordinate, and expand services for all Coloradans affected by Autism Spectrum Disorders.

The Autism Commission held Public Hearings for the purpose of:

- Informing the work of the Commission;
- Ensuring widespread access to the Commission beyond those persons directly or indirectly represented by Commissioners;
- Eliciting stories of how Colorado's service system has impacted the lives and wellbeing of persons with autism and their families, especially what works and what needs improvement; and
- Promoting the work of the Autism Commission.

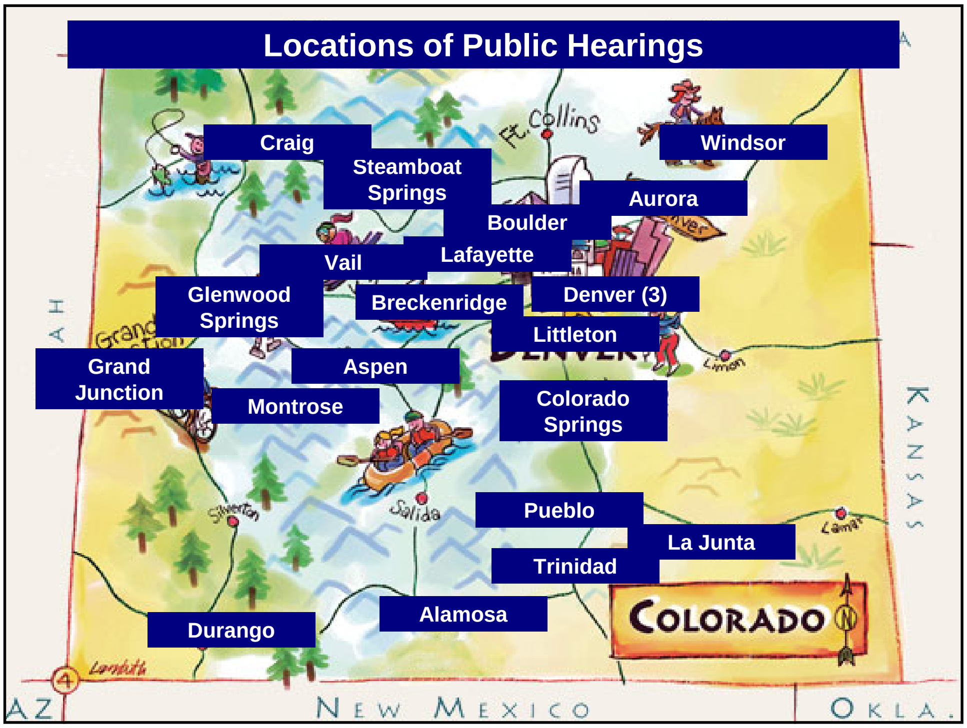
Testimony Committee

- Ann Reynolds
- Stephen Fretz
- David Hatfield
- Jan Rasmussen
- Ed Steinberg
- Cheryl Carver
- Barry Jackson
- Colleen McMilin
- Jonathan Schleifer
- Angela West
- Bruce Cline
- <u>And virtually everyone else at some point…</u>

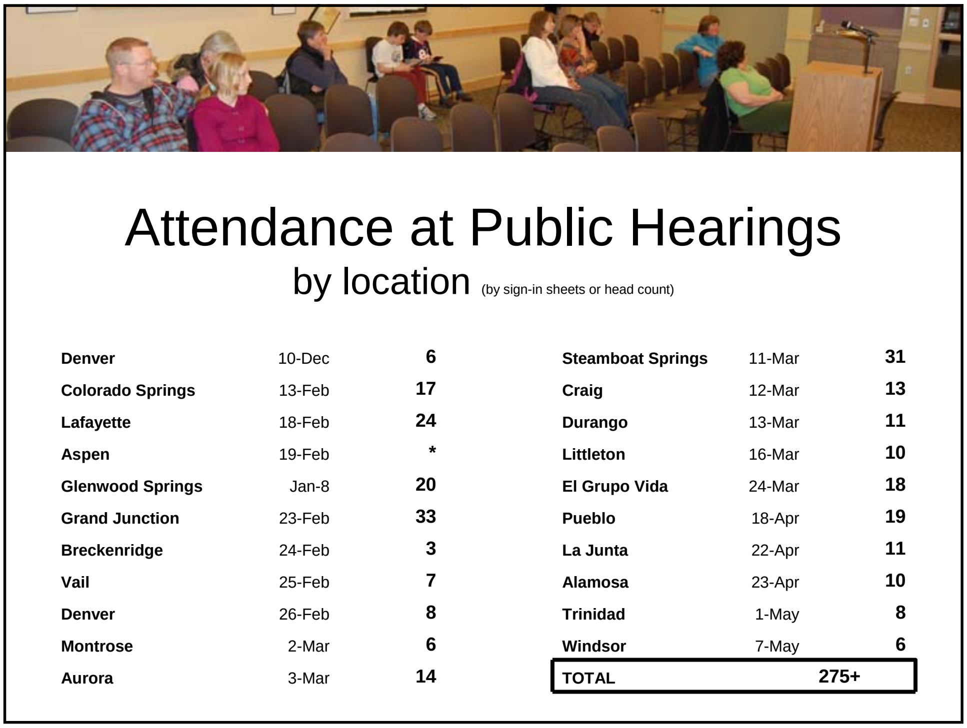


Public Input:

- Twenty-one Public Hearings in twenty communities
- Hearing held from December 2008 through May 2009
- Input accepted via the web, email, and hardcopy



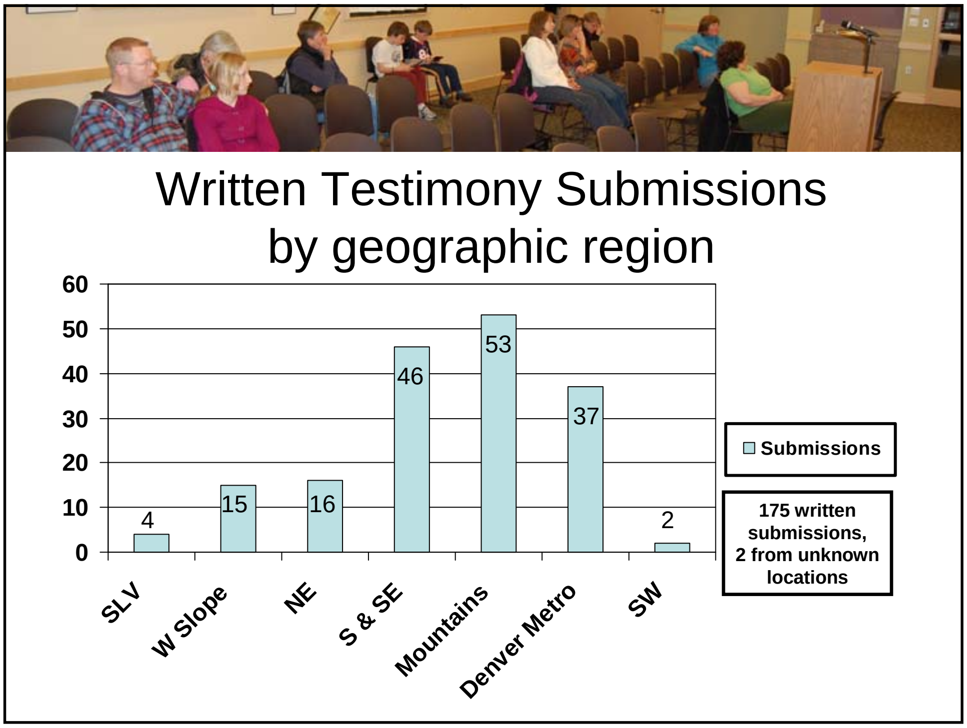
Locations of Public Hearings



Attendance at Public Hearings

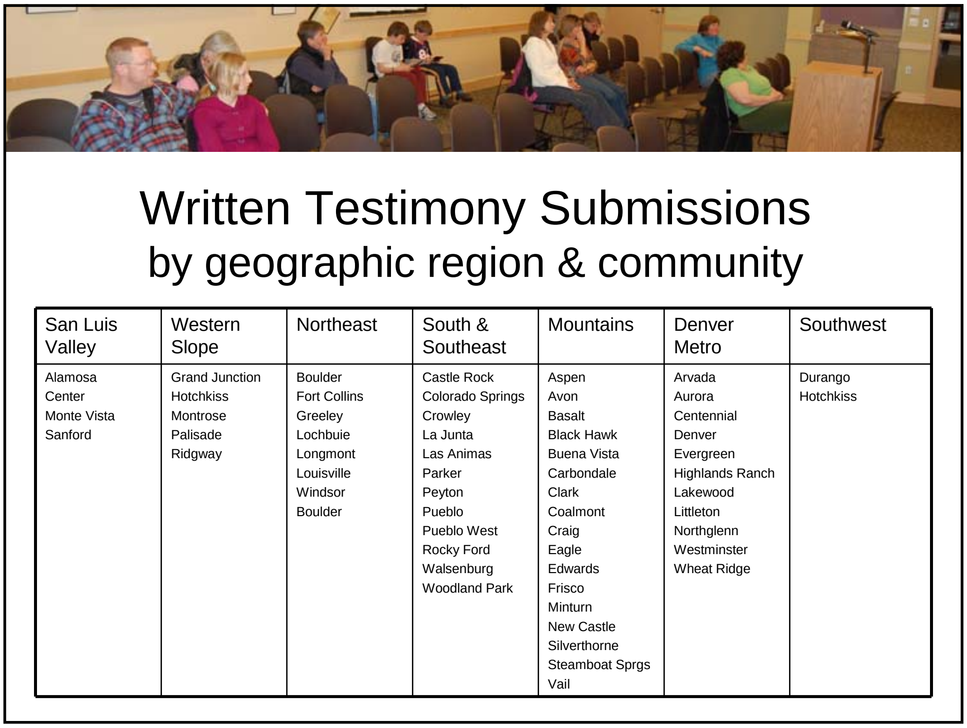
by location (by sign-in sheets or head count)

Denver	10-Dec	**6**	**Steamboat Springs**	11-Mar	**31**
Colorado Springs	13-Feb	**17**	**Craig**	12-Mar	**13**
Lafayette	18-Feb	**24**	**Durango**	13-Mar	**11**
Aspen	19-Feb	*****	**Littleton**	16-Mar	**10**
Glenwood Springs	Jan-8	**20**	**El Grupo Vida**	24-Mar	**18**
Grand Junction	23-Feb	**33**	**Pueblo**	18-Apr	**19**
Breckenridge	24-Feb	**3**	**La Junta**	22-Apr	**11**
Vail	25-Feb	**7**	**Alamosa**	23-Apr	**10**
Denver	26-Feb	**8**	**Trinidad**	1-May	**8**
Montrose	2-Mar	**6**	**Windsor**	7-May	**6**
Aurora	3-Mar	**14**	**TOTAL**		**275+**



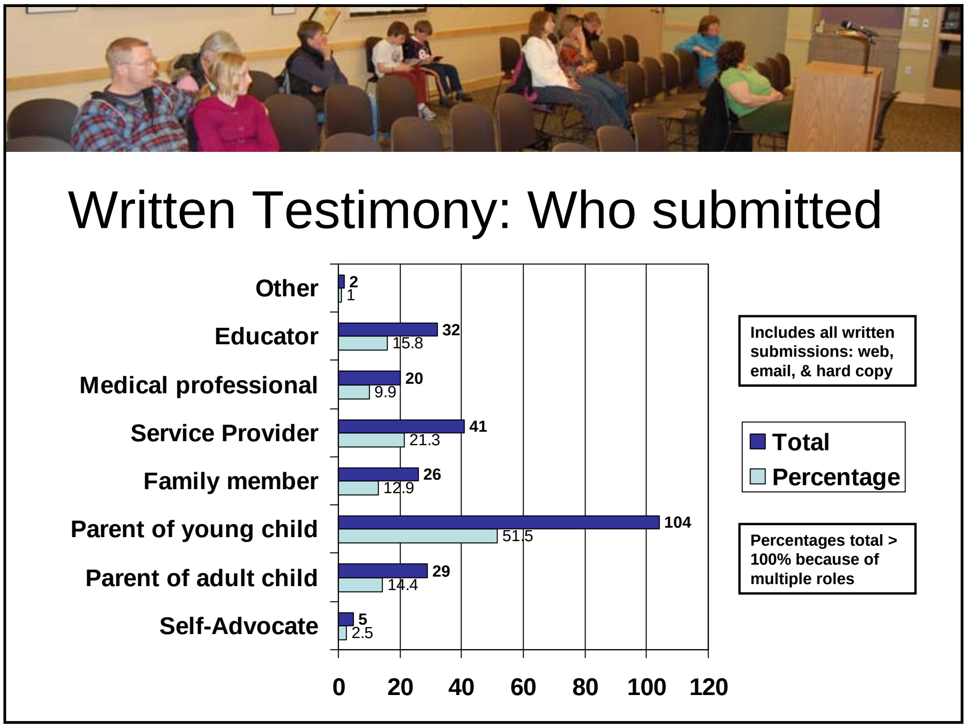
Written Testimony Submissions by geographic region

175 written submissions, 2 from unknown locations



Written Testimony Submissions
by geographic region & community

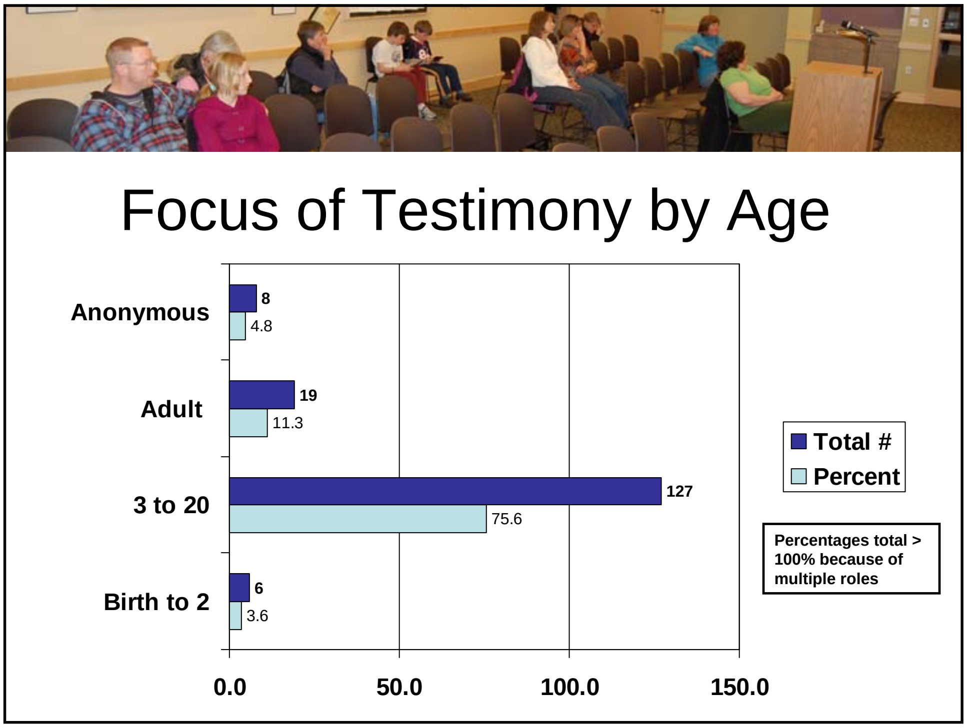
San Luis Valley	Western Slope	Northeast	South & Southeast	Mountains	Denver Metro	Southwest
Alamosa	Grand Junction	Boulder	Castle Rock	Aspen	Arvada	Durango
Center	Hotchkiss	Fort Collins	Colorado Springs	Avon	Aurora	Hotchkiss
Monte Vista	Montrose	Greeley	Crowley	Basalt	Centennial	
Sanford	Palisade	Lochbuie	La Junta	Black Hawk	Denver	
	Ridgway	Longmont	Las Animas	Buena Vista	Evergreen	
		Louisville	Parker	Carbondale	Highlands Ranch	
		Windsor	Peyton	Clark	Lakewood	
		Boulder	Pueblo	Coalmont	Littleton	
			Pueblo West	Craig	Northglenn	
			Rocky Ford	Eagle	Westminster	
			Walsenburg	Edwards	Wheat Ridge	
			Woodland Park	Frisco		
				Minturn		
				New Castle		
				Silverthorne		
				Steamboat Sprgs		
				Vail		



Written Testimony: Who submitted

Includes all written submissions: web, email, & hard copy

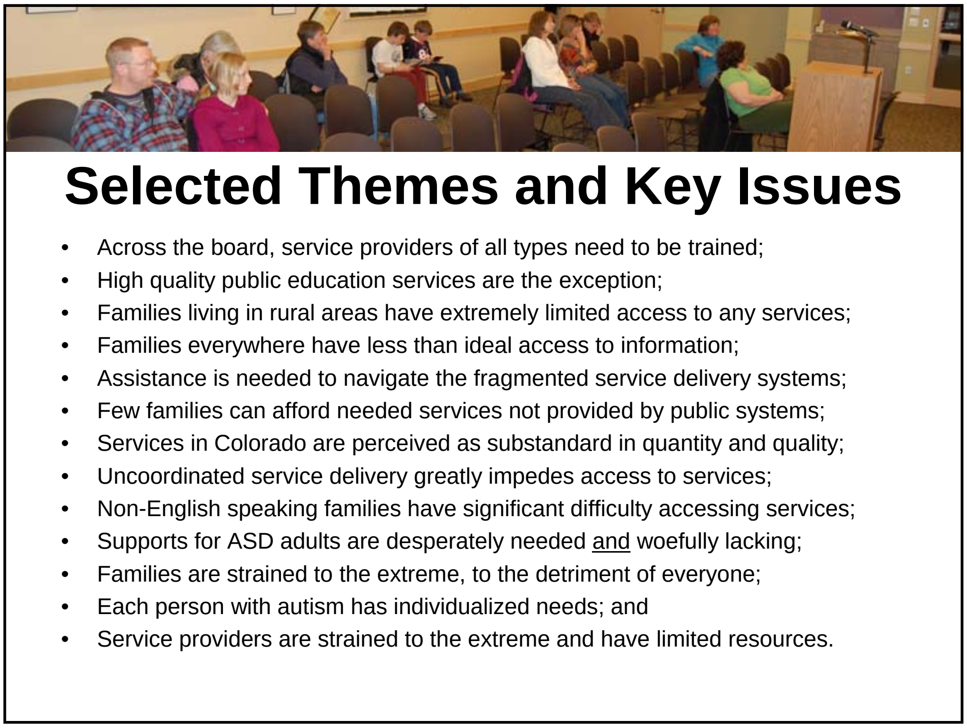
Percentages total > 100% because of multiple roles



Focus of Testimony by Age

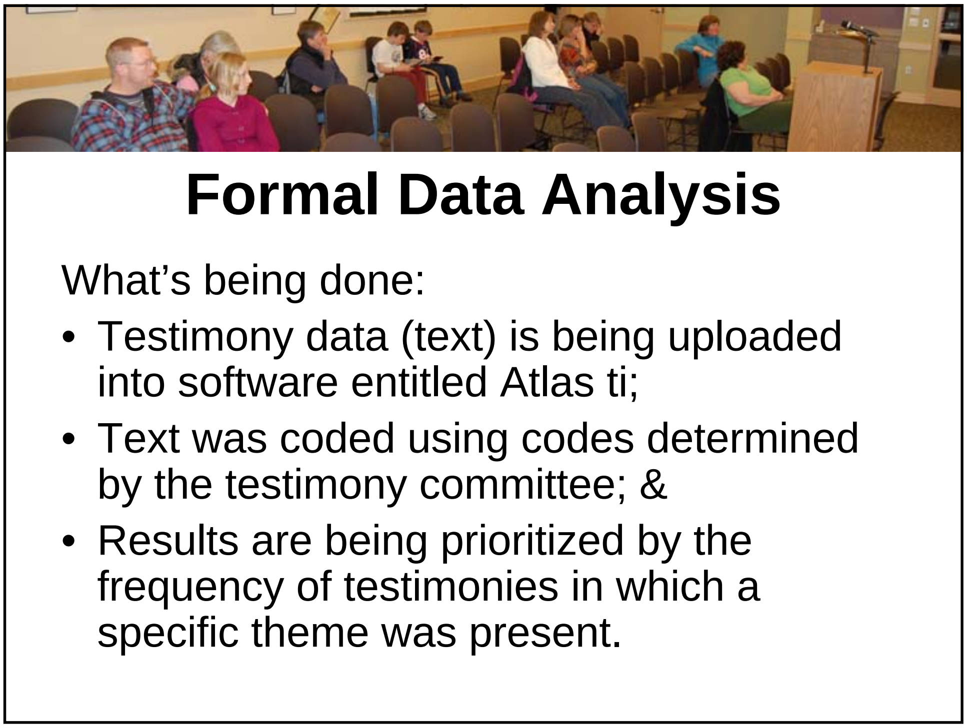
Percentages total > 100% because of multiple roles

What did we learn (hear)?



Selected Themes and Key Issues

- Across the board, service providers of all types need to be trained;
- High quality public education services are the exception;
- Families living in rural areas have extremely limited access to any services;
- Families everywhere have less than ideal access to information;
- Assistance is needed to navigate the fragmented service delivery systems;
- Few families can afford needed services not provided by public systems;
- Services in Colorado are perceived as substandard in quantity and quality;
- Uncoordinated service delivery greatly impedes access to services;
- Non-English speaking families have significant difficulty accessing services;
- Supports for ASD adults are desperately needed and woefully lacking;
- Families are strained to the extreme, to the detriment of everyone;
- Each person with autism has individualized needs; and
- Service providers are strained to the extreme and have limited resources.



Formal Data Analysis

What's being done:

- Testimony data (text) is being uploaded into software entitled Atlas ti;
- Text was coded using codes determined by the testimony committee; &
- Results are being prioritized by the frequency of testimonies in which a specific theme was present.

Data Analysis Code Examples

Basic Codes (each code is then categorized by group, i.e. Birth to 2, 3-20, Adults and then categorized as +, -, or solution):

Financing Services (code category)
- Health insurance
- Funding for programs
- Family support groups (funding of)

Treatment Services (code category)
- Inadequate treatment
- Behavioral therapy
- IQ as a limiting factor
- Access to care
- Training of service providers

Populations (of data sample to follow)

Age Group Represented		Testimonies Collected
Birth to 2 years		2
3-20 years		51
Adults		9
Unknown		2
Description of Submitter		Testimonies Collected
Parent		44
Service Provider		14
Educator		8
Family Member		4
Self-Advocate		1
Unknown		1

Partial Results*

What's working
Early intervention programs (16)
Behavioral, occupational and speech therapy (32)
Schools (caring teachers, specific school districts) (29)

What's not working
Health insurance (24)
Cost (27)
Access to services (number of providers, waitlist, lack of mental health services) (32)
Schools (lack of trained teachers, lack of paraprofessionals, classroom structure) (49)

Possible solutions
Public awareness (20)
Financial support (27)
Schools (training, funding) (34)

* This data is drawn from 64 completed testimonies; a code is counted only once per section of testimony even if it is mentioned multiple times.

How to use this Data?

Although the committee feels all of this information will be beneficial: A) In explaining how we collected public input and from whom we collected it; and B) The data analysis will provide us some useful statistical information that we can use to develop and support the Commission's recommendations; it's altogether clear that the **best use of this information will be derived by actually reading it in whole or in part.**

Appendix C

Estimate of number of Coloradoans with ASD

Working Hypothesis about the number of Coloradoans with Autism Spectrum Disorders

One of the charges to the Commission is to speak to the number of people with an Autism Spectrum Disorder in Colorado. In my opinion, accurately determining such a number is beyond the scope of the Commission, even considering the fact that most of the state agencies that offer relevant services and supports are part of the Commission. To the best of my knowledge, we have only two accessible sources to go to for numbers and each has significant limitations. These two sources are: (1) results of the Center for Disease Control funded ADDM project in which Colorado participated, and (2) the Annual Colorado Department of Education Child Count.

What the Colorado Department of Education Child Count Tells Us. Every state is required to report annually the number of children receiving special education (i.e. have an IEP). For children 6-21 years, they report that number in 13 categories of eligibility. In 1991, Autism and Traumatic Brain Injury were added as reporting categories. In Colorado in 2003, (it takes awhile for the feds to analyze all of the data and get their reports online) 879 children ages 6-21 served under IDEA Part B were reported as having Autism. Table 1 shows Colorado data for all 13 categories. This number is much smaller than the forecast based upon the ADDM results. We have reason to believe that the child count number is a depressed estimate. Two sources of information contribute to this statement. Paul Shattuck analyzed child count data from the late 1990's and rank ordered the states in terms of their counts of students with Autism. Colorado ranked 49th in its number of children reported in the Autism category. This finding of relatively low reporting of Autism is consistent with anecdotal reports we hear about reluctance in school systems to classify children as having Autism. The official reason given for not categorizing children as having Autism is that Autism is a medical diagnosis and school personnel are not qualified to make such a diagnosis. Parents are frequently told if they think their child may have Autism, Aspergers, etc. they should go to "JFK" or some other source. We at "JFK" have had multiple families tell us that they were advised by someone on the school evaluation team that if they want services to be paid for by their insurance, they need to get the medical diagnosis. Meanwhile, the Department of Education's position is that since Autism is defined by core deficits in communication, social interaction and repetitive behaviors and focused interest which interfere with learning. Education (CDE, school districts) argue that their responsibility is to address the educational implications of these "core deficits" of Autism. The issue of what education should/can address versus what health insurance should / can address is a point I expect we will return to as a Commission. For now, the issue I am trying to address is what the child count can tell us about the number of children and youth on the Autism Spectrum in Colorado. For me, the bottom line is that it offers us a number of students who are currently acknowledged in the schools but it is not a number that can be used to forecast the scope of the issue. Certainly there are some children and youth on the spectrum reflected in other categories. Likely categories are speech or language impairments, mental retardation and learning disabilities.

Table 1. Students ages 6 through 21 served under IDEA, Part B, by disability category from the 2003 Child Count

Specific learning disabilities	32,151
Speech or language impairments	14,492
Mental retardation	3,546
Emotional disturbance	9,187
Multiple disabilities	3,049
Hearing impairments	1,268
Orthopedic impairments	7,449
Other health impairments	0
Visual impairments	321
Autism	879
Deaf-blindness	64
Traumatic brain injury	368
Developmental delay	0
All Disabilities	**72,774**

Autism and Developmental Disabilities Monitoring Data. The other source of data we have is from the CDC ADDM data. This is the data that was released in the winter of 2007 that received wide national attention. Fifteen states contributed data that yielded the national estimate of 1 in 150 children had a disorder of Autism, Asperger's or PDD-NOS. For Colorado, the figure was 1 in 169; slightly less than the national figure but still a substantial number when we apply this number to Colorado's 2000 Census figures of 4,301,261 it yields a number of 25,451 Coloradoans who have an ASD.

This is a large number and presumably not everyone who has an ASD has a need for publicly funded supports and services. Within the ADDM data, there is information about the proportion of these people whose intelligence quotient is tested as less than 70. The data indicates that about 40 percent have IQs below 70. Given our current definition of eligibility for Developmental Disability services in Colorado, these individuals would unquestionably be eligible for service. Applying the ADDM figure this number would be 10,180.

However, as we know from testimony received on 10/2/08 regarding the developmental disabilities eligibility definition, there are a number of people who have a diagnosis on the spectrum who have IQ's above 70 and who have significant impairments in adaptive behavior such that they would meet the federal definition of developmental disability. However we have no reliable representative data source to inform us as to what percent of the remaining 60% of people with a diagnosis on the spectrum (who have IQ's greater than 70) have substantial deficits in three or more of the seven domains of daily functioning identified in the federal definition.

The only data I have found that speaks to this issue comes from data from colleague Susan Hepburn. Looking at participants in her research, she finds that 60 percent of children in her group with IQ's over 70 have composite Vineland Adaptive Behavior Composite scores below 70. I am arguing that a composite Vineland quotient below 70 is an appropriate way to operationalize significant impairment in adaptive behavior consistent with the intent of the federal definition of developmental disabilities. If Susan's data is applied to the balance of our Colorado number, there will be an additional 9163 people across the age span who need services and supports that are greater than what are generally available. I hesitate to say services and supports similar to those of a person with mental retardation because of the way our services and supports are currently configured. I do believe that these individuals and their families need supports and services if they are to achieve maximum independence and opportunities to contribute through employment and in many cases for their parents to continue gainful employment. Table 2 shows the Colorado 2000 census by age and also the number of people with ASD by age group and IQ level. Figure 1 presents this information in the form of a pie chart.

Table 2. Colorado 2000 census and expected numbers of people with ASD by age group.

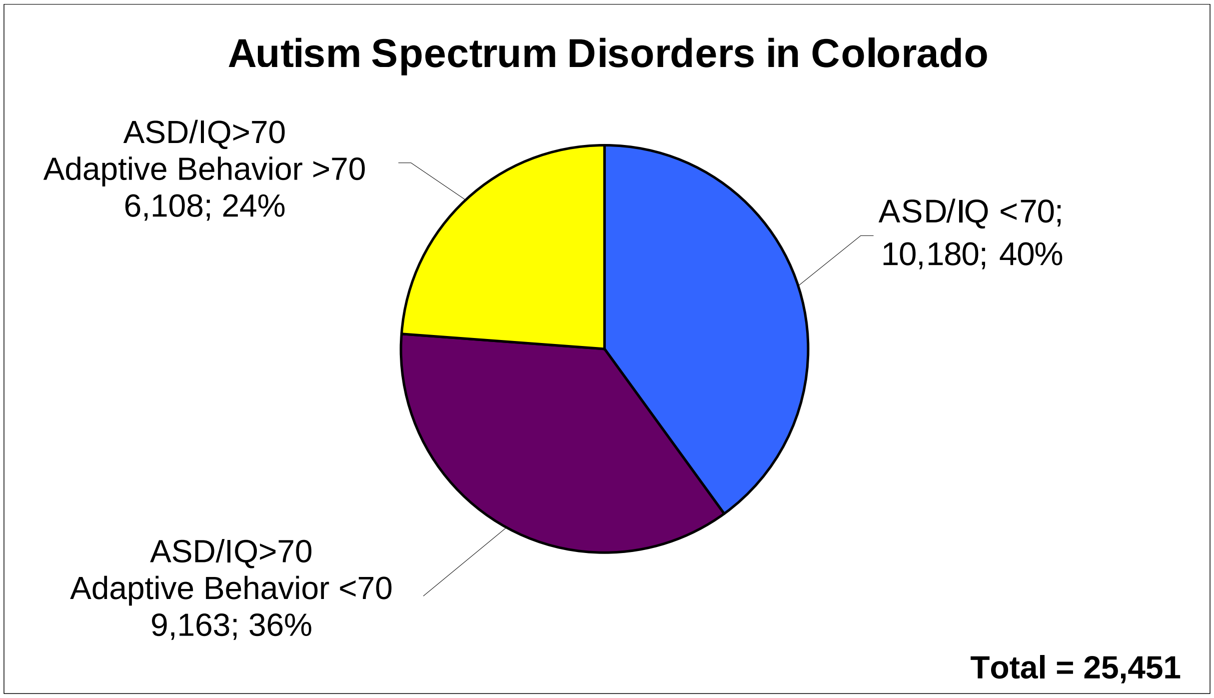
	ALL	ALL ASD	ASD/IQ <70	ASD/IQ <70 Adaptive Behavior <70	ASD/IQ >70 Adaptive Behavior >70
Birth-15 years	917,430	5,429	2,171	1,955	1,302
15-24 years	613,476	3,630	1,452	1,307	871
25-44 years	1,400,850	8,289	3,316	2,984	1,989
45-64 years	953,432	5,642	2,257	2,031	1,354
65+ years	416,073	2,462	985	886	591
TOTAL	**4,301,261**	**25,451**	**10,180**	**9,163**	**6,108**
Percent of Total		**100%**	**40%**	**36%**	**24%**

I offer these numbers as the best information I have been able to identify at this time to inform our efforts and answer the task assigned in the Commission legislation. I know of nothing on the near horizon (next 10 months) that would give us a number in which we can have greater confidence.

Developmental Disabilities Definition in Colorado. There is another factor that I believe needs to be considered as we outline the scope of our work. That factor will be the recommendations from the DD definition task group. The work of the group is to be accomplished by November 10, 2008. There is the possibility that the recommendation to come from the task group will be for a definition that will be fully inclusive of all people on the Autism Spectrum where IQ is over 70 but where adaptive behavior deficits are significant such that they need supports and services. If the recommendation is for a definition that is inclusive of those individuals, we will have common cause. If the recommendation is to maintain the current status of the way eligibility is determined then in our work we will need to address recommendations for this group of approximately 9163 Coloradoans and their families. The good news is we will at least know the recommendations by November 10th. By then, we will also know the results on Amendment 51. Figure 1 shows the total ASD Population in terms of the three groups identified.

Update September 2009: the Developmental Disabilities definition work group did recommend that any person having adaptive behavior scores below 70 should be eligible for service from their Community Centered Board regardless of Intelligence Quotient. The caveat to this eligibility is that they must also meet the criteria of documentation of developmental problems prior to age 22 and the person has a documented neurologic condition. A workgroup formed based upon the Definition groups recommendations has been meeting since late winter 2008 with the expectation that guidance regarding determining eligibility should be in place by early 2010.

Figure 1: Total ASD Population of the Three Groups Identified



Also new data is available from the CDE Child Count. The number of children ages 6 through 21 diagnosed with ASD receiving services under IDEA has dramatically increased over the past 15 years, from 22,664 in 1994 to 256,863 in 2007, according to data collected for the U.S. Department of Education. The current prevalence of young children with ASD, as reported by Centers for Disease Control and Prevention (CDC) is 1 in 150 nationwide and 1 in 169 in Colorado. Students identified as having an ASD in our public schools, ages 3-21 have increased from 505 in 2000 to 2,258 in 2007 (www.ideadata.org). it is believed that the population is much higher than this because many students with Asperger's Syndrome and PDD-NOS are identified and served under other disability categories.

Appendix D

Description of Oversight Committee and Task Force

Legislative Oversight Committee and a Taskforce for the Continuing Examination of the Treatment and Services Provided across the Life Span of Persons with Autism Spectrum Disorders

The Legislative Oversight Committee and Taskforce was modeled after Colorado's highly successful "Advisory Taskforce for the Continuing Examination of the Treatment of Persons with Mental Illness Who are Involved in the Justice System".

The Oversight Committee:

1. Will consist of six members consisting of three (3) senators and three (3) representatives.
    a. The senate president will appoint two (2) senators; the minority leader of the senate will appoint one (1) senator to serve on the committee.
    b. The speaker of the house of representatives will appoint three (3) representatives to serve on the committee and no more than two (2) will be from the same political party.

Duties of the Committee:

1. Meet at least 4 times per year and at such other times as it deems necessary.
2. The committee shall be responsible for the oversight of the task force and shall submit annual reports to the general assembly regarding the findings and recommendations of the task force. In addition, the committee may recommend legislative changes which shall be treated as bills recommended by an interim legislative committee for purposes of any introduction deadlines or bill limitations imposed by the joint rules of the general assembly.

The Task Force

1. The task force shall consist members involved with and representing organizations involved with all aspects of Autism Spectrum Disorders.
    a. The Colorado State Governor shall appoint a Chair and Vice-Chair whom shall have extensive experience with Autism Spectrum Disorder matters across the life span.
    b. The chair and vice-chair of the committee shall appoint members as follows:
        - *Autism Advocacy Organization*
        - *Autism Self Advocates*
        - *Autism Service Providers*
        - *Colorado Council on Developmental Disabilities*

- *Colorado Department of Education*
- *Colorado Department. of Health Care Policy & Finance*
- *Colorado Department of Human Services – Division of Developmental Disabilities*
- *Colorado Department of Human Services – Division of Mental Health*
- *Colorado Department. of Public Health & Environment*
- *Colorado Physicians*
- *Community Centered Boards*
- *Emergency Services*
- *Legal Center*
- *Mental Health Centers*
- *Parents of Children with Autism*

Duties of the Task Force:

1. The task force shall carry forth the recommendations outlined in the 10 year strategic plan developed by the Colorado Autism Commission.

2. The task force shall meet 8 times per year and at such other times as it deems necessary.

3. Create subcommittees as needed to carry out the duties of the task force. The subcommittees may consist, in part, of persons who are not members of the task force. Such persons may vote on issues before the subcommittee but shall not be entitled to a vote at meetings of the task force.

4. The task force shall adopt of a common framework for effectively addressing the various service needs of those coping with ASD.

5. The task force shall develop a plan to most effectively and collaboratively serve the ASD population their families/caregivers.

6. The task force shall orally provide guidance and make findings and recommendations to the committee for its development of reports and legislative recommendations for modification of systems providing across the life span services to individuals and families/caregivers affected by ASD.

7. Legislative proposals of the task force that identify the policy issues involved, the agencies responsible for the implementation of the changes, and the funding sources required for such implementation.

Compensation:

1. There will be not compensation for task force members.

Task force funding - staff support.

(1) The *Department of Public Health and Department of Human Services*, on behalf of the task force, is authorized to acquire, receive and expend contributions, grants, services, and in-kind donations from any public or private entity for any direct or indirect costs associated with the duties of the task force set forth in this article.

Cash fund.

(1) All private and public funds received through grants, contributions, and donations pursuant to this article shall be transmitted to the state treasurer, who shall credit the same to the examination of the treatment and services of persons with autism spectrum disorder cash fund, which fund is hereby created and referred to in this section as the "fund". The moneys in the fund shall be subject to annual appropriation by the general assembly for the direct and indirect costs associated with the implementation of this article. All moneys in the fund not expended for the purpose of this article may be invested by the state treasurer as provided by law. All interest and income derived from the investment and deposit of moneys in the fund shall be credited to the fund. Any unexpended and unencumbered moneys remaining in the fund at the end of a fiscal year shall remain in the fund and shall not be credited or transferred to the general fund or another fund.

Appendix E

Screening, Diagnosis, and Early Intervention Committee Report

Autism Commission
Where we are and where we need to be committee
Early Intervention, Screening and Diagnosis subcommittee

Members: Corry Robinson, Chair,
Jan Rasmussen
Liz Fuzelier
Norbert Soke

Sources of Information:

The work of this subcommittee was supported by information obtained from different sources: Part C, state of the state and state plan documents produced by the Colorado team at the Region 8 summit, the Assuring Better Child Development initiative data, recommendations from the American Academy of Pediatrics, Kaiser state health facts and other national data, recommendations from the National Research Council (NRC) and numerous peer-reviewed articles, Testimony committee and others (see attachment).

Final document:

After numerous meetings and discussion, the subcommittee elaborated a final document that was presented to the full commission focusing on what were and where we want to be in the areas of early intervention; screening and diagnosis (see power point presentation).

Screening, Diagnosis and Early Intervention
Themes

Screening, Diagnosis and Early Intervention
Themes

- Lack of data regarding current capacity in terms of qualified personnel for all activities.
- Lack of clarity regarding implications of Diagnosis using DSM criteria (medical/psychological diagnosis versus educational identification).
- Lack of data regarding numbers of children with diagnosis or educational identification as having an ASD.

Screening, Diagnosis and Early Intervention Themes

- Lack of personnel capacity for screening, diagnosis and early intervention.
- Lack of data regarding specific diagnoses and services currently provided for children serviced in Part C.
- Lack of uniform access statewide.

What We Have-National

- Recommendations and standards for Screening, Diagnosis and Early Intervention that have been endorsed by Professional Organizations and Federal Agencies.

Specific Recommendations

- Screening – AAP recommendations
- Diagnosis – Should be established with gold standard assessment – Autism Diagnostic Observation Schedule
- Early Intervention – Recommended characteristics of Early Intervention Services from Nation Research (Standard needs to go beyond recommended number of hours.)

Screening
What We Have-Colorado

- ABCD initiative for developmental screening
- Kaiser Permanente Colorado implementing screening for autism

What We Need

- Increased personnel capacity for screening
- Infrastructure to support screening
- Better insurance reimbursement for screening
- Uniform system for tracking screening results

Diagnosis
What We Have

- Some capacity to teach providers in reliable administration of the ADOS

What We Need

- Collaboration among clinical providers, ChildFind, Part C in approach to be used in identification and diagnosis state wide
- Clarification with insurers regarding role for insurance in supporting gold standard diagnostic procedures

Early Intervention Services
What We Have

- Part C (children birth to three) early intervention services and supports
- Children with autism waiver, only 75 slots
- New insurance legislation effective 7/1/2010 which will fund early intervention services for children with insurance policies governed under Colorado Insurance Commission

What We Need

- Increased personnel capacity to deliver services consistent with NRC recommended standards
- Vastly increased capacity in terms of provides with skills in Applied Behavioral Analysis
- Consensus at the state level regarding standards for services to be supported with public dollars

What We Need

- Enforceable standards for services paid by insurance
- Evaluation of the Children with Autism Waiver
- Educational materials for parents regarding criteria for evaluating effective services

Summary

- Meeting national standards for screening and diagnosis for children birth to five are probably a feasible objective for a 10 year state wide strategic plan
- There is an immediate need for a coordinated plan (among Part C, CDE, IHE) to build personnel capacity

Summary

- Priority should be given to convening a forum with representation from Part C (state level) CDE (ChildFind and Autism Services) and Colorado Chapter of Academy of Pediatrics to create a consensus statement regarding ASD, screening, diagnosis, and early intervention services and supports. (Current membership of subcommittee not adequate in this regard).

LOGIC MODEL TEMPLATE – ACT EARLY SUMMIT - Colorado

The focus of state plans should be on enhancing state wide early identification and intervention efforts and service provision and coordination for children and families with autism spectrum disorder (ASD) and related disabilities.

Resources	Activities	Outputs	Short & Long-Term Outcomes	Impact
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
1. Colorado Autism Commission (established by statute to create 10 year strategic plan) 2. LEND grant 3. Autism Treatment Network 4. Autism Society: Speaker series, support groups, childcare for families to attend this events (information and referral) 5. Autism Society information and referral program: phone calls, emails, website, newsletter, listserv 6. Autism Society respite training to providers and families – working with local colleges & community enrichment	**CARE COORDINATION** 1. Develop care coordinator associated with evaluation team – a person to walk parents through system (ie., Kaiser) 2. Provide appropriate training and resources for care coordinators 3. Utilize telemedicine to increase network of care coordinators, physicians, CCB-CM, professional services, parents, ChildFind (work with ABCD, database for all to input) 4. Add to Part C – IFSP data fields on diagnosis and transition 5. Assess prospects for a common identifier across birth – 21 (evaluation perspective) 6. Community groups to educate parents to be care coordinators 7. Training efforts addressing long term planning to providers, case managers, educators	**CARE COORDINATION** 1. Well-informed families able to seek care and advocate 2. Communication between collaterals evidenced by inputs in database 3. Data to generate specific reports 4. Linked data systems 5. Quarterly trainings to provider case managers statewide as evidenced by trainings published in central website **DIAGNOSIS** 6. Well-informed families able to seek care and advocate 7. Decreased time between diagnosis and service to 45 days 8. Communication between collaterals evidenced by	**CARE COORDINATION** 1. Training and on-going professional support to create a well educated pool of professionals. 2. Develop system for diagnosis and delivery of services 3. There will be a centralized source of information regarding ASD and best practices 4. Knowing age of diagnosis of ASD (data systems) 5. Knowing prevalence of ASD in younger age group (data systems) 6. Know geographic distribution of children with ASD (data systems) 7. Know what services children with ASD are receiving (data systems) 8. Know outcomes for	**CARE COORDINATION** 1. Children and families receive high quality evidence-based services in a timely manner. 2. Global awareness by systems of care to focus on long-term planning at the beginning. Parents will have a roadmap. 3. Comprehensive and coordinated interagency system of care with a single point of entry. 4. Comprehensive and coordinated financial system to support the services. 5. Increased state-wide consistency in service provision 6. Have capacity to make data-driven decisions regarding service

*Evaluation Logic Model Template, adapted from the W.K. Kellogg Foundation Evaluation Handbook (1998)

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In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
program that brings providers and families together 7. CCMS – Community Contract managements Data System 8. MMIS – Medicaid data system 9. Results Matter – EI 10. ADDM surveillance data 11. 619 child count 12. 619 Results Matter 13. CDPHE newborn hearing and metabolic disease datasets	8. Utilize medical home trainings to educate providers regarding resources for long term planning 9. Create a CO ASD online resource to assemble all materials being disseminated and provide one consistent message 10. Find funding for CO ASD online resource **DIAGNOSIS** 11. Develop database for tracking outcomes 12. Add to Part C – IFSP data fields on diagnosis and transition 13. Assess prospects for a common identifier across birth – 21 (evaluation perspective) 14. Explore feasibility of positive reporting of ASD diagnosis by clinical source 15. Develop training activities to	inputs in database 9. Data to generate specific reports 10. Linked data systems 11. Younger children are accessing services for ASD **DATA** 12. Communication between collaterals evidenced by inputs in database 13. Data to generate specific reports 14. Linked data systems **INTERVENTION** 15. Well-informed families able to seek care and advocate 16. Communication between collaterals evidenced by inputs in database 17. Data to generate specific reports 18. Linked data systems	children with ASD in Results Matters (data systems) 9. Centralized source of information regarding ASD / best practices **DIAGNOSIS** 10. Training and on-going professional support to create a well educated pool of professionals. 11. Develop system for diagnosis and delivery of services 12. At time of positive screen, children will be referred for diagnostic assessment to be completed within 30 days 13. Positive screen for ASD results in evidence-based early intervention within 45 days 14. At the time of a positive	provision 7. Have information about cost-effectiveness of EI 8. Families and all citizens in CO have access to well-maintained and consistently updated resources for ASD **DIAGNOSIS** 9. Decreased age at which children with ASD are identified (currently 4.5 years). 10. ChildFind teams are knowledgeable and skilled and have the necessary resources to assess children who may be on the spectrum. 11. Comprehensive and coordinated interagency system of care with a single point of entry. 12. Comprehensive and

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Resources	Activities	Outputs	Short & Long-Term Outcomes	Impact
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
	increase ability to diagnose, so time from screening to diagnosis is shorter) 16. Develop training programs to increase the # people ADOS trained 17. Increase collaboration between PCP, ChildFind, and dx centers 18. One-day course in ASD screening, billing, telephone follow-up 19. Explore STAT training 20. Implement screening in resident training programs Lectures to trainees in Medicare, PNPs, Pas **DATA** 21. Develop database for tracking outcomes 22. Add to Part C – IFSP data fields on diagnosis and transition 23. Assess prospects for a common identifier across birth – 21 (evaluation perspective)	19. Younger children are accessing services for ASD 20. Expand waiver services to cover all children on waiting list 21. Determine a plan to evaluate effectiveness / look at existing methods of evaluation (Results Matter data) 22. Providers will be more supported, have a higher skill level, fewer referrals to outside sources or children will experience more inclusive opportunities **SCREENING** 23. Well-informed families able to seek care and advocate 24. Decreased time between diagnosis and service to 45 days 25. Communication between collaterals evidenced by	screen, children will be referred for diagnostic assessments, and these assessments will be completed within 30 days 15. There will be a centralized source of information regarding ASD and best practices 16. Knowing age of diagnosis of ASD (data systems) 17. Knowing prevalence of ASD in younger age group (data systems) 18. Know geographic distribution of children with ASD (data systems) 19. Know what services children with ASD are receiving (data systems) 20. Know outcomes for children with ASD in Results Matters (data systems) 21. Centralized source of information regarding	coordinated financial system to support the services. 13. Increased state-wide consistency in service provision 14. Have capacity to make data-driven decisions regarding service provision 15. Have information about cost-effectiveness of EI Ensure accuracy and fidelity of ASD diagnosis **DATA** 16. Comprehensive and coordinated interagency system of care with a single point of entry. 17. Comprehensive and coordinated financial system to support the services. 18. Increased state-wide

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Resources	Activities	Outputs	Short & Long-Term Outcomes	Impact
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
	INTERVENTION 24. Legislation for insurance carriers to cover ASD 25. Explore stimulus funding opportunities to support these outcomes 26. Develop revisions to Autism Waiver 27. Coordinate agreement regarding critical features that should be part of early intervention – “endorsement” of core principles, reasonable standards of wholistic goal- and outcome-driven treatment 28. Coordinate collaboration between health and education approaches to ASD intervention – articulate position and principles of how these systems can work together 29. Coordinate support and advocacy for consistent inclusion of specialized	inputs in database 26. Data to generate specific reports 27. Linked data systems 28. Younger children are accessing services for ASD 29. Track how often 96110 is used to bill for screening 30. Track how many individuals visit dissemination booths 31. Track how many attend ABCD trainings 32. Track how many attend one-day trainings (activity #4)	ASD / best practices ASD diagnosis made by age 2.5 years **DATA** 22. Knowing age of diagnosis of ASD (data systems) 23. Knowing prevalence of ASD in younger age group (data systems) 24. Know geographic distribution of children with ASD (data systems) 25. Know what services children with ASD are receiving (data systems) 26. Know outcomes for children with ASD in Results Matters (data systems) 27. Centralized source of information regarding ASD / best practices **INTERVENTION**	consistency in service provision 19. Have capacity to make data-driven decisions regarding service provision 20. Have information about cost-effectiveness of EI **INTERVENTION** 21. Children and families receive high quality evidence-based services in a timely manner. 22. Comprehensive and coordinated interagency system of care with a single point of entry. 23. Comprehensive and coordinated financial system to support the services. 24. Informed decision-making regarding appropriate levels of

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Resources	**Activities**	**Outputs**	**Short & Long-Term Outcomes**	**Impact**
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
	intervention and treatment services in natural and inclusive educational settings – articulate position and principles of how this can work 30. Explore funding for Hanen model of parent education for 0-3 31. Develop database for tracking outcomes 32. Add to Part C – IFSP data fields on diagnosis and transition 33. Assess prospects for a common identifier across birth – 21 (evaluation perspective) 34. Explore stimulus funding opportunities to support outcomes 35. Expand the pyramid model for 0-3, infant-toddler training 36. Provide more information to providers regarding evidence-based practices **SCREENING**		28. Training and on-going professional support to create a well educated pool of professionals. 29. Develop system for diagnosis and delivery of services 30. Positive screen for ASD results in evidence-based early intervention within 45 days 31. Funding will no longer be a barrier to diagnosis and early intervention 32. Evidence-based interventions will be available throughout Colorado 33. There will be a centralized source of information regarding ASD and best practices 34. Knowing age of diagnosis of ASD (data systems) 35. Knowing prevalence of	service 25. Increased state-wide consistency in service provision 26. Have capacity to make data-driven decisions regarding service provision 27. Have information about cost-effectiveness of EI 28. Early intensive intervention occurs before age 3 **SCREENING** 29. Decreased age at which children with ASD are identified (currently 4.5 years). 30. Children and families ChildFind teams are knowledgeable and skilled and have the necessary resources to assess children who may

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Resources	**Activities**	**Outputs**	**Short & Long-Term Outcomes**	**Impact**
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
	37. Outreach to pediatricians and family practice physicians re: early identification 38. Develop physician mentors for Assuring Better Child Health & Development (ABCD) initiative to improve early screening and identification 39. One or two day symposium teaching physicians about autism, how to screen, teaching necessary skills. Target one staff member at each practice. Target AAP spring conference in 2010 to focus on this. CME's to be offered. 40. Utilize medial home trainings currently in place to teach the above. 41. Booth at Pueblo State Fair, Cinqo de Mayo Fair, health fairs, livestock shows, other fairs to disseminate CDC materials/ChildFind/other info. ABCD initiative may support some funding for this.		ASD in younger age group (data systems) 36. Know geographic distribution of children with ASD (data systems) 37. Know what services children with ASD are receiving (data systems) 38. Know outcomes for children with ASD in Results Matters (data systems) 39. Centralized source of information regarding ASD / best practices 40. Families have provider for behavioral & professional in-home services despite payment from multiple sources 41. 40 EI (infant-toddler) providers trained in the pyramid model in collaboration with division of child care center on social	be on the spectrum. 31. Comprehensive and coordinated interagency system of care with a single point of entry. 32. Comprehensive and coordinated financial system to support the services. 33. Increased state-wide consistency in service provision 34. Have capacity to make data-driven decisions regarding service provision 35. Have information about cost-effectiveness of EI

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The focus of state plans should be on enhancing state wide early identification and intervention efforts and service provision and coordination for children and families with autism spectrum disorder (ASD) and related disabilities.

Resources	Activities	Outputs	Short & Long-Term Outcomes	Impact
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
	42. Look at all materials available in the state, including ABCD, to ensure consistency of information in materials prior to dissemination at fairs and other events. 43. Work on dissemination to Spanish-speaking populations via radio, other venues 44. Outreach to FQHC's regarding their needs to adequately serve ASD population, as well as physicians who go out to rural areas, physicians who use telemedicine 45. Outreach to licensed and unlicensed child care, day care, preschools, other early educators 46. Support pediatric practice with information & referrals to provide parents when screening indicates further evaluation is recommended 47. Develop database for tracking outcomes		emotional competence and inclusion within one year **SCREENING** 42. Extend SB 4 to include services for children as they get older 43. All primary health care settings will implement AAP recommended developmental screening including screening for autism and maternal depression, and collateral effects on other family members/family dynamics 44. At time of positive screen, children will be referred for diagnostic assessment to be completed within 30 days 45. Positive screen for ASD results in evidence-based	

*Evaluation Logic Model Template, adapted from the W.K. Kellogg Foundation Evaluation Handbook (1998)

LOGIC MODEL TEMPLATE – ACT EARLY SUMMIT - Colorado

The focus of state plans should be on enhancing state wide early identification and intervention efforts and service provision and coordination for children and families with autism spectrum disorder (ASD) and related disabilities.

Resources	Activities	Outputs	Short & Long-Term Outcomes	Impact
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
	48. Create a CO ASD online resource to assemble all materials being disseminated and provide one consistent message 49. Find funding for CO ASD online resource 50. Increase collaboration between PCP, ChildFind, and dx centers 51. Promote screening (CDC, LTSAE, ABCD)with booth at state AAF, AAP, AAFP meetings, health fair squad 52. One-day course in ASD screening, billing, telephone follow-up 53. Explore STAT training 54. Implement screening in resident training programs 55. Lectures to trainees in Medicare, PNPs, PAs		early intervention within 45 days 46. All children will receive optimal developmental surveillance 47. Developmental screenings will take place as recommended by the CDC and AAP 48. At the time of a positive screen, children will be referred for diagnostic assessments, and these assessments will be completed within 30 days 49. There will be a centralized source of information regarding ASD and best practices 50. Knowing age of diagnosis of ASD (data systems) 51. Knowing prevalence of ASD in younger age group (data systems) 52. Know geographic distribution of children	

*Evaluation Logic Model Template, adapted from the W.K. Kellogg Foundation Evaluation Handbook (1998)

LOGIC MODEL TEMPLATE – ACT EARLY SUMMIT - Colorado

The focus of state plans should be on enhancing state wide early identification and intervention efforts and service provision and coordination for children and families with autism spectrum disorder (ASD) and related disabilities.

Resources	**Activities**	**Outputs**	**Short & Long-Term Outcomes**	**Impact**
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
			with ASD (data systems) 53. Know what services children with ASD are receiving (data systems) 54. Know outcomes for children with ASD in Results Matters (data systems) 55. Centralized source of information regarding ASD / best practices 56. Families have provider for behavioral & professional in-home services despite payment for multiple sources 57. Screening for ASD will occur at 18 & 24 months in primary care practices – 50% compliance in 1-3 years, 90% compliance in 4-6 years	

*Evaluation Logic Model Template, adapted from the W.K. Kellogg Foundation Evaluation Handbook (1998)

Resources	**Activities**	**Outputs**	**Short & Long-Term Outcomes**	**Impact**
In order to accomplish our set of activities we will need the following:	In order to address our problem or asset we will accomplish the following activities:	We expect that once accomplished these activities will produce the following evidence of service delivery:	We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:	We expect that if accomplished these activities will lead to the following changes in 7-10 years:
14. Advocacy 15. Established Collaborative Efforts: JFK Partners to advise parents about Autism Society of Colorado, referral to diagnostic centers, joint work on public policy 16. Autism treatment fund – funding source for Children with Autism waiver (from tobacco settlement) 17. Additional places where people are ADOS trained 18. www.chadis.com	56. Explore opportunities to further fund to Autism Treatment Fund 57. 10-year plan from Autism Commission to coordinate funding, outreach, education, identification, trainings	33. Possible collaboration with insurance for single payer	58. Extend SB 4 to include services for children as they get older	36. Capacity of provider pool will be increased, building on existing providers 37. Children with ASD will reach their maximum potential.

*Evaluation Logic Model Template, adapted from the W.K. Kellogg Foundation Evaluation Handbook (1998)

RESOURCES

In order to accomplish our set of activities we will need the following:

ACTIVITIES

In order to address our problem or asset we will accomplish the following activities:

OUTPUTS

We expect that once accomplished these activities will produce the following evidence of service delivery:

OUTCOMES

We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:

IMPACTS

We expect that if accomplished these activities will lead to the following changes in 7-10 years:

*Evaluation Logic Model Template, adapted from the W.K. Kellogg Foundation Evaluation Handbook (1998)

Appendix F

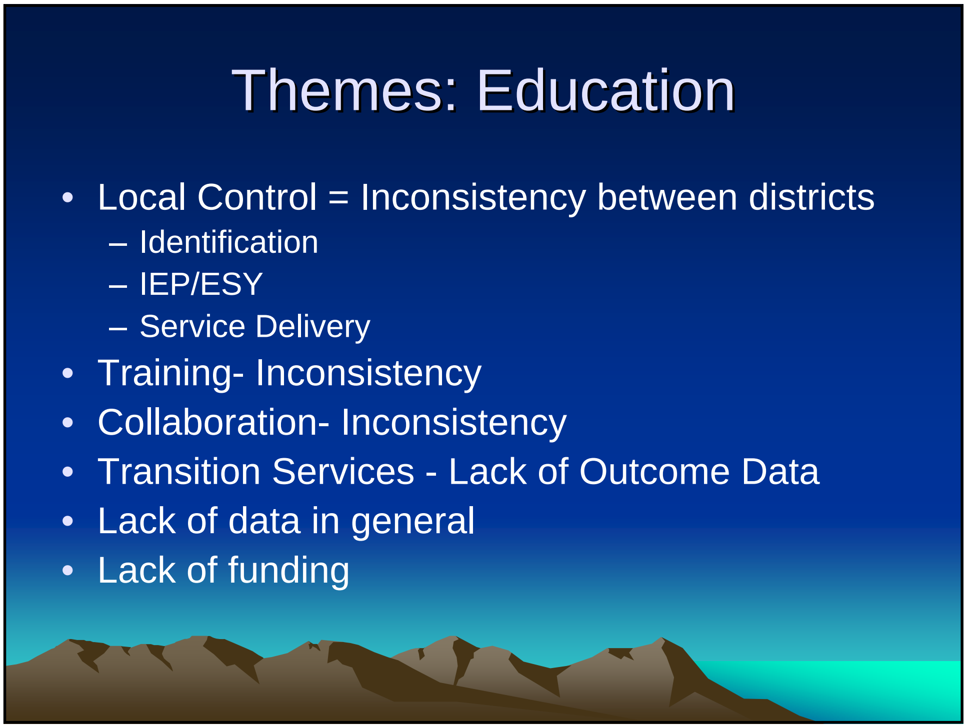
Education
Committee Report

Education
Ages 5-21

Christina Wu
Melinda Graham
Jason Gruhl
Dixie Periman
Cora Nash
Kristen Kaiser
Meghan Norman

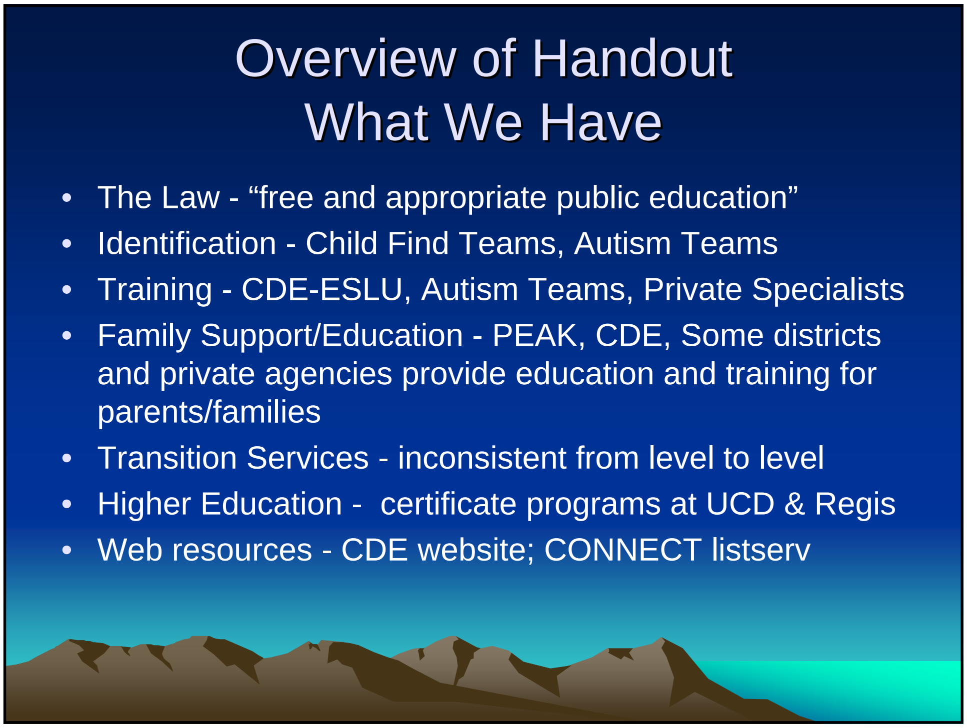
EDUCATION: AGES 5-21

- RESEARCH AREAS
  - INFRASTRUCTURE: Federal, State, Local rules and regulations
  - PROFESSIONAL DEVELOPMENT: Teachers, related service providers, paraeducators, security, bus drivers, other school employees
  - COLLABORATION: families, outside professionals, medical, universities, adult service agencies.



Themes: Education

- Local Control = Inconsistency between districts
  - Identification
  - IEP/ESY
  - Service Delivery
- Training- Inconsistency
- Collaboration- Inconsistency
- Transition Services - Lack of Outcome Data
- Lack of data in general
- Lack of funding



Overview of Handout What We Have

- The Law - “free and appropriate public education”
- Identification - Child Find Teams, Autism Teams
- Training - CDE-ESLU, Autism Teams, Private Specialists
- Family Support/Education - PEAK, CDE, Some districts and private agencies provide education and training for parents/families
- Transition Services - inconsistent from level to level
- Higher Education - certificate programs at UCD & Regis
- Web resources - CDE website; CONNECT listserv

Immediate vs Future Goals

- Short Term Goals

  -Systematic Statewide Training
  -Guiding Principles
  -Teacher Competencies
  -Dissemination of Information
  -Research & Collaboration
  -Educational Identification
  -Regional Resources

- Long Term Outcomes

  -Trained Professionals across the state
  -Consistent Delivery of Service
  -Collaboration between families, schools, and other professionals

Issues to be Explored in the Future

- Higher Education:
  Autism Degree/Certification

- Private School/Provider Regulations

The Law

The Individuals with Disabilities Education Act (IDEA) on the federal level and the Rules for the Administration of the Exceptional Children's Education Act (ECEA) at the state level provide the governing laws that create the foundation for a free and appropriate public education to all students with disabilities including ASD. The agency that monitors the compliance of these laws is the Colorado Department of Education – Exceptional Student Leadership Unit (CDE-ESLU). The Individualized Education Program (IEP) is created to for each student with disabilities needing additional supports and services to meet their educational needs. While the IEP is based on student needs, it can be created and interpreted differently across the school districts in the state of Colorado. It is important to note that IDEA and ECEA have no specific rules and regulations specific to Autism and there is insufficient federal and state funding to support programming for all students with disabilities, including those with ASD.

Child Find Teams

Under the governance of IDEA and ECEA, the Child Find Teams' purpose is to identify, locate, and evaluate children with disabilities from birth – age 21 who are in need of early intervention and Special Education services. These teams may determine the educational identification of children with ASD through the evaluation process. However, not all school districts choose to make an educational identification of Autism. Many school districts are not adequately trained on assessments for determining an educational identification of Autism. Furthermore, some school districts require a medical diagnosis of Autism before providing additional services and some will only consider their own evaluations and determination, not an outside assessment or diagnosis. The Autism disability label is not used according to the same guidelines in school districts and thus, there is no accurate count as to the number of students with ASD being educated in Colorado or the cost to the districts to educate these students.

School Districts & Board of Cooperative Educational Services (BOCES)

All school districts have or have access to (through a BOCES) all Special Education services required by IDEA. These include services provided by Special Education teachers, Speech Language Pathologists, Occupational Therapists, Physical Therapists, Psychologists, Social Workers, etc. Students with ASD may need one or more services in these areas.

Colorado Department of Education (CDE)

CDE offers several resources for school districts and families. There is a CDE Autism webpage which contains many documents on Autism topics and it also lists upcoming trainings and workshops. In addition, the consultants with CDE-ESLU manage a listserv (CONNECT listserv) which provides information on trainings and workshops and members can post questions to get information from others in the field. Finally, CDE has recently published a set of "Quality Program Indicators" which is a set of guidelines to be used by educators and administrators to evaluate current programs or assist in setting up new programs for students with ASD. These guidelines are currently being piloted.

Trainings/Workshops/Technical Assistance

CDE-ESLU provides training and technical assistance to school districts and BOCES in a variety of ways, including providing training in the area of ASD. Some school districts have Autism teams who provide training and technical assistance within their own school district. Some school districts contract with private specialists or agencies for training and technical assistance. There is a persistent need for more professional development across the state, in particular to educational identification and educational support of students with ASD. Training needs to be comprehensive and provided for both service providers and parents. Training should utilize a variety of methodologies and instructional approaches, involve all individuals who are part of the educational program for the child, including - but not necessarily limited to - school district personnel, administrators, teachers, academic professionals, service providers, parents, advocates, etc., use a variety of training strategies to reach people with different learning styles, contain designs to incorporate different levels of expertise, be implemented in a responsive and timely manner, include a team approach to training, and be monitored for effectiveness through periodic evaluations.

Institutions of Higher Education/Autism Certificate Programs

Several colleges and universities in the state offer Special Education teacher preparation programs and continuing education courses. Usually these programs lead to a generalist license, are limited to approximately 32 credit hours for the degree, and offer very little coursework that is specific to Autism. At this time the University of Denver and Regis University (Denver metro area) have Autism certificate programs. However, these programs are new and have not certified many people.

Autism Task Force

The Colorado Autism Task Force is comprised of individuals from CDE, school administrators and teachers, academic professionals, service providers, parents of children with Autism, advocates for children with Autism, and individuals who have Autism. The task force has been in existence since 1999 and its purpose has been to advise CDE in the needs of its constituents and provide workgroups to develop new policy and documents.

Transition

The area of transition includes when students move from one school level to another and also programming for those students 15-22 years of age. CDE provides transition teams with trainings throughout the year on transition-related topics, provides technical assistance to districts specifically in the area of transition, and collaborates with agencies such as Voc Rehab and SWAP. However, school districts vary in transition services from level to level as the programming is often very specific to the district. There is very little training regarding the needs of students with Autism in post-school settings and how we are preparing them. High functioning students with Autism are leaving schools without the skills needed to succeed in employment, students are struggling in higher education settings, and there is little data regarding post-school outcomes on these students 1-5 years out.

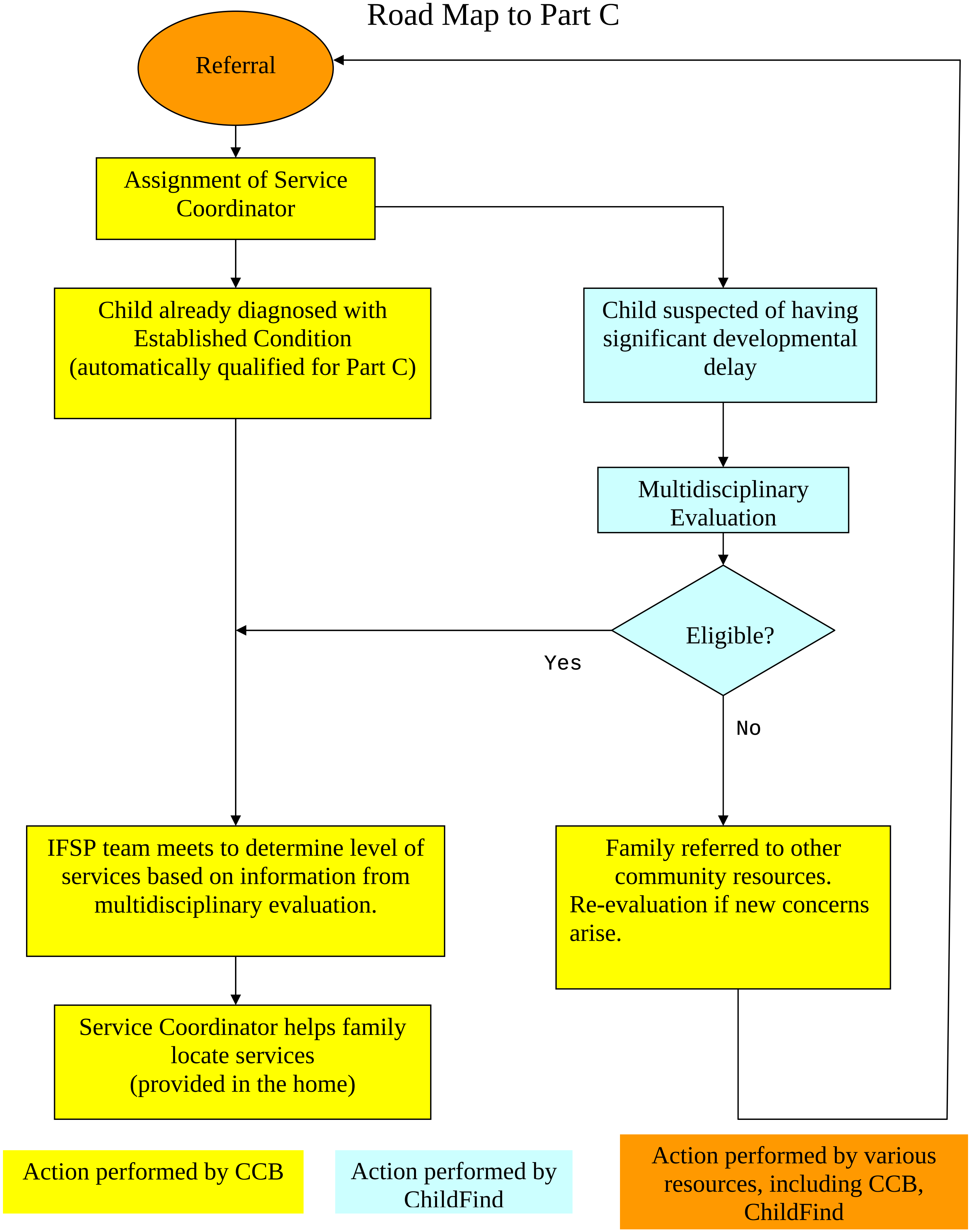
Family Involvement

This area continues to be a growing need for school districts to work collaboratively and effectively with families. School districts that are involved with Response to Intervention (RTI) and Positive Behavior Support (PBS) usually incorporate a parent piece to increase their family involvement. Groups such as PEAK (parent training and information center) and CDE offer workshops to train families on the IEP process. School districts using CDE's Quality Program Indicators will notice a section on Family Involvement and Support. There are programs and resources for schools and families but the quality of family involvement still varies from district to district.

Road Map to Part C

Part C **0-3 Years Old** **Individual Family Services Plan** **(IFSP)**	Part B **3-21 Years Old** **Individual Education Plan** **(IEP)**
Established Condition or significant delay in development.	Specific category of disability or significant developmental delay (3 & 4 years old).
Recipient is **child and family.**	Recipient is **child only.**
Services based on **developmental** needs of child as determined**.** The IFSP Team is made up of the therapist or evaluators, family members, and the Service Coordinator. The IFSP team determines the duration, and frequency of the services based on a multidisciplinary evaluation.	Services based on **educational** needs of child. The IEP team is made up of special educators, general educators, related service providers and parents or caregivers. The IEP team determines the student's services based on the multidisciplinary team's evaluation.
Services provided in **"natural environments"**, typically in the home and within the family's daily routines and activities using a consultative model.	Services provided in the **"least restrictive environment"**, typically **tried first** in the same environment as their peers to the greatest extent beneficial to the individual student**, and then may become more restrictive as needs intensify**.
Eligibility determined by CCB with the support of the local Child Find office through multidisciplinary evaluation.	Eligibility determined by the individual student's multidisciplinary IEP team through evaluation, observation and record review.
Service Coordinator required, and is assigned to family shortly after referral is made.	Service coordination is required by the **Case Manager** assigned to the student on the IEP.
Services coordinated by **local Community Center Boards (CCB's)** utilizing internal providers and/or independent contractors.	Services provided by special education staff and therapists contracted by the **local school district or Board of Cooperative Educational Services (BOCES).**
Services might include: Occupational Therapy Physical Therapy Speech Therapy Psychological Services Developmental Intervention See 14 allowable EI services	**Services Might Include**: Early Childhood Special Education Specialist Special Education Teacher Speech Therapist Occupational Therapist Physical Therapist School Psychologist School Social Worker Autism or Behavior Specialist **School Nurse**

Road Map to Part C



Appendix G

Medical and Mental Health Committee Report

Autism in Colorado

Where We Are Now
Where We Should Be

Governor's Autism Commission

June 2009

Medical/Mental Health: Diagnosis and Management

Medical/Mental Health: Diagnosis and Management

- Medical Priorities
  - – Management of Co-occuring medical issues
  - – Adult Care
- Mental Health Priorities
  - – Crisis Intervention
  - – Coordination of ongoing care=Avoid need for crisis intervention

Medical/Mental Health: Diagnosis and Management

- Themes
  - –Guidelines
  - –Training
  - –Funding
  - –Coordination
  - –Transition To Adult Services

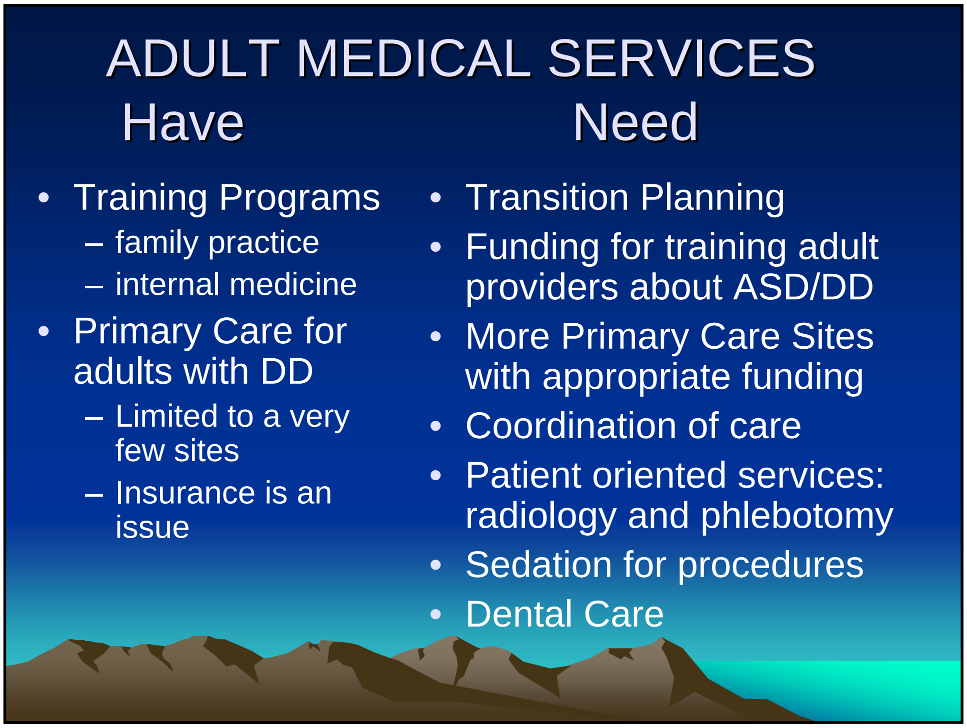
MEDICAL SERVICES

Have

- ATN Site working on developing guidelines for managing co-occuring medical conditions
- Medical Home Initiative
- Family Voices Provider Hotline

Need

- “Autism center” to coordinate awareness/training/dissemination of guidelines once available
- Quality improvement initiatives
- Extend Medical Home Initiative to include ASD
- Tele-health Services
- Adequate reimbursement for time
- Parent Liaison Program



ADULT MEDICAL SERVICES

Have

- Training Programs
  - family practice
  - internal medicine
- Primary Care for adults with DD
  - Limited to a very few sites
  - Insurance is an issue

Need

- Transition Planning
- Funding for training adult providers about ASD/DD
- More Primary Care Sites with appropriate funding
- Coordination of care
- Patient oriented services: radiology and phlebotomy
- Sedation for procedures
- Dental Care

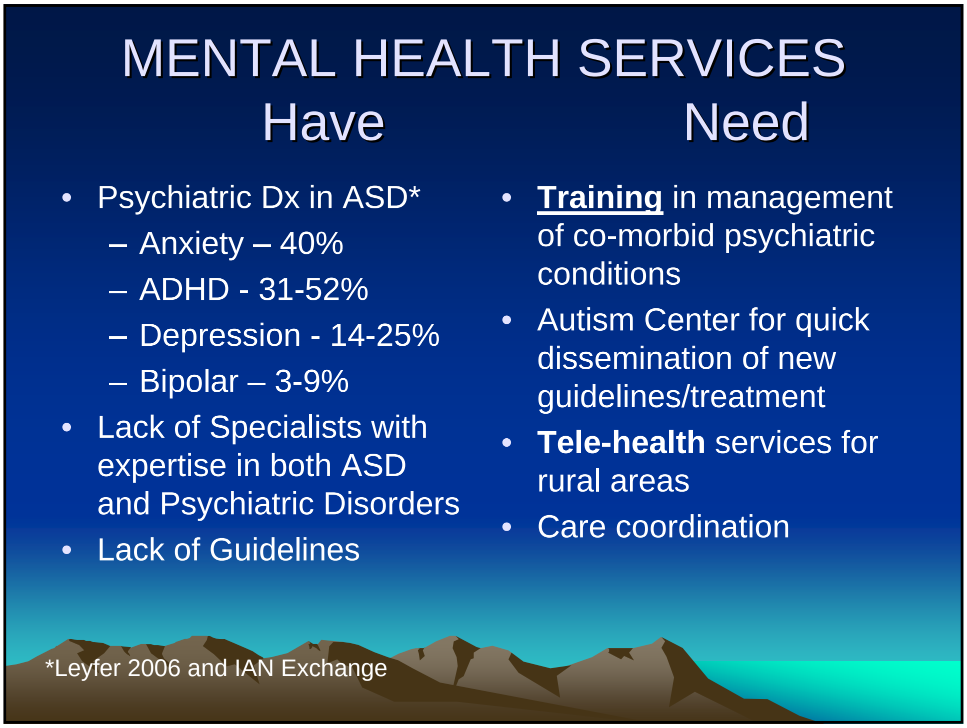
FQHC-Federally Qualified Health Center

- Metro Community Provider Network-Center for Exceptional Health Care
  - Better Medicaid and Medicare reimbursement, sliding scale for uninsured
  - Primary Care for adults with cognitive impairment
  - Resource coordination is provided by Developmental Pathways – Local CCB
  - No funding for medications

Emergency Services

- Excellent specialists and ER services

- Training of first responders and ER personnel in how to work with individuals with ASD
- Mechanisms for sedation and coordination of procedures
- ER management/DX of co-existing medical issues



MENTAL HEALTH SERVICES

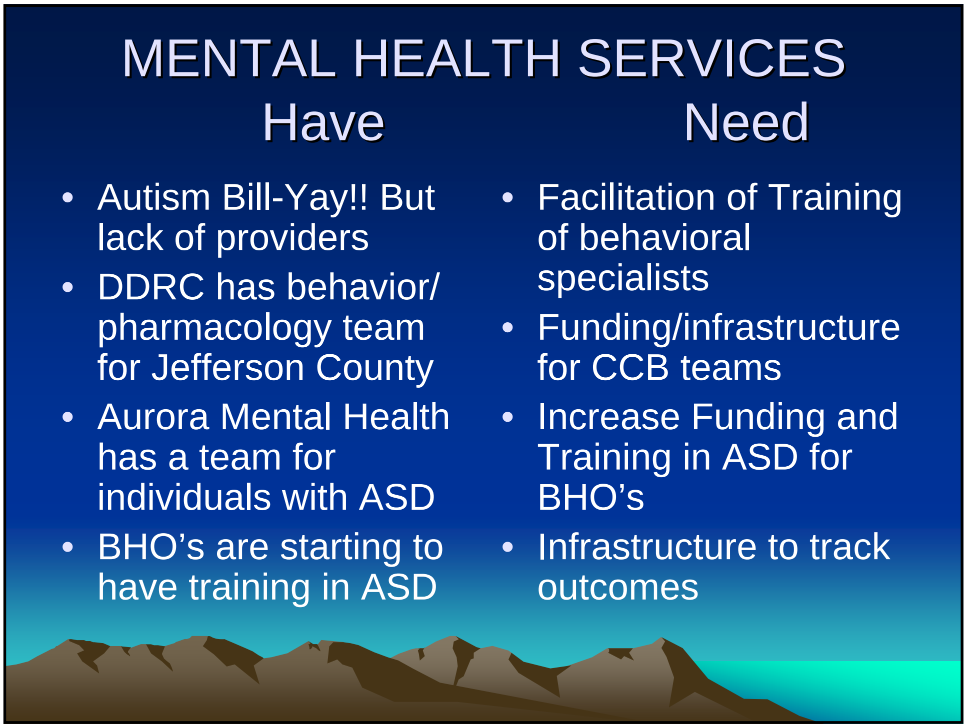
Have

- Psychiatric Dx in ASD*
  - – Anxiety – 40%
  - – ADHD - 31-52%
  - – Depression - 14-25%
  - – Bipolar – 3-9%
- Lack of Specialists with expertise in both ASD and Psychiatric Disorders
- Lack of Guidelines

Need

- **Training** in management of co-morbid psychiatric conditions
- Autism Center for quick dissemination of new guidelines/treatment
- **Tele-health** services for rural areas
- Care coordination

*Leyfer 2006 and IAN Exchange



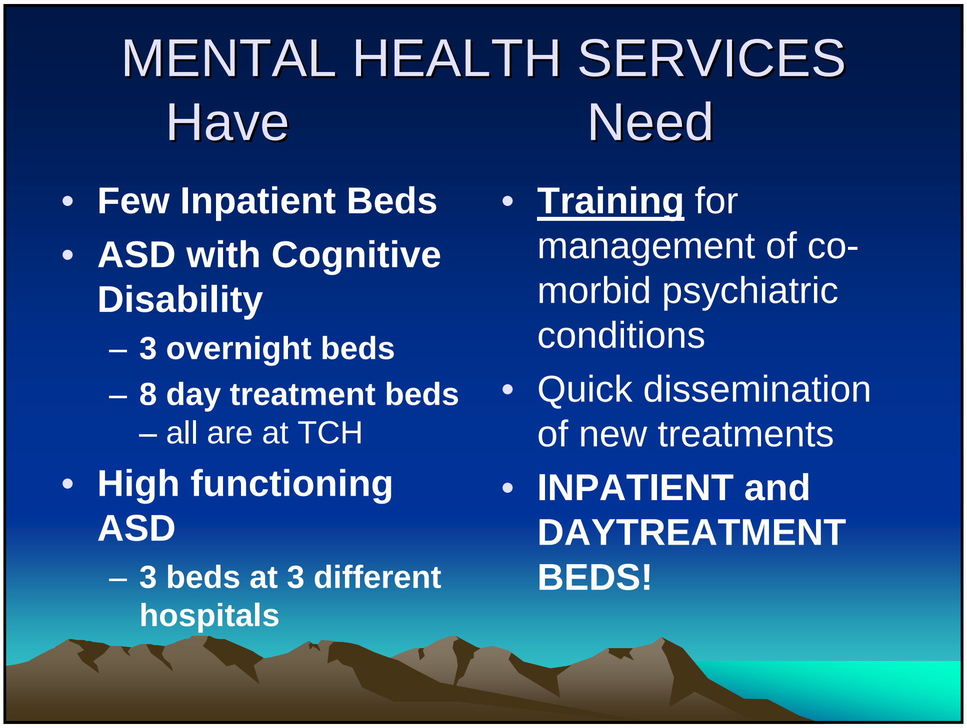
MENTAL HEALTH SERVICES

Have

- Autism Bill-Yay!! But lack of providers
- DDRC has behavior/ pharmacology team for Jefferson County
- Aurora Mental Health has a team for individuals with ASD
- BHO’s are starting to have training in ASD

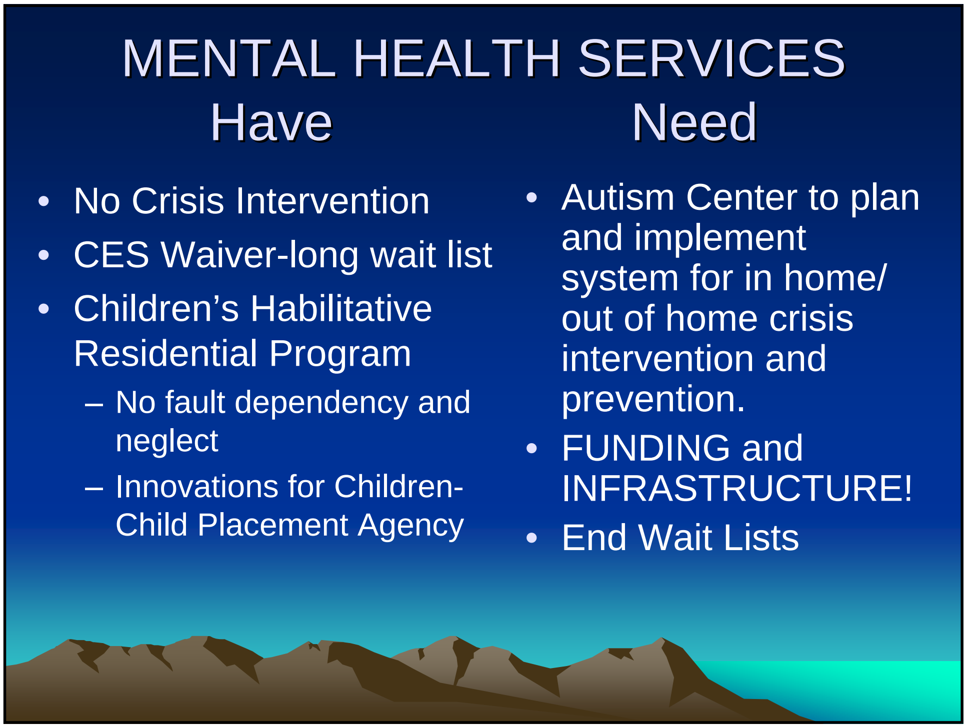
Need

- Facilitation of Training of behavioral specialists
- Funding/infrastructure for CCB teams
- Increase Funding and Training in ASD for BHO’s
- Infrastructure to track outcomes



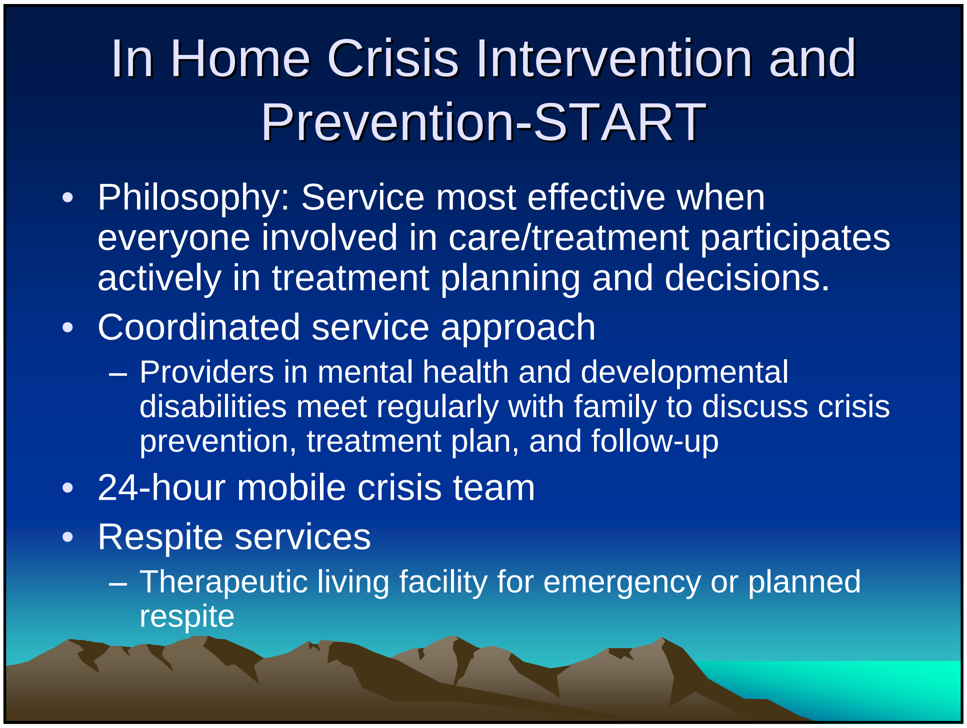
MENTAL HEALTH SERVICES

Have	Need
Few Inpatient Beds **ASD with Cognitive Disability** – **3 overnight beds** – **8 day treatment beds** – all are at TCH **High functioning ASD** – **3 beds at 3 different hospitals**	**Training** for management of co-morbid psychiatric conditions Quick dissemination of new treatments **INPATIENT and DAYTREATMENT BEDS!**



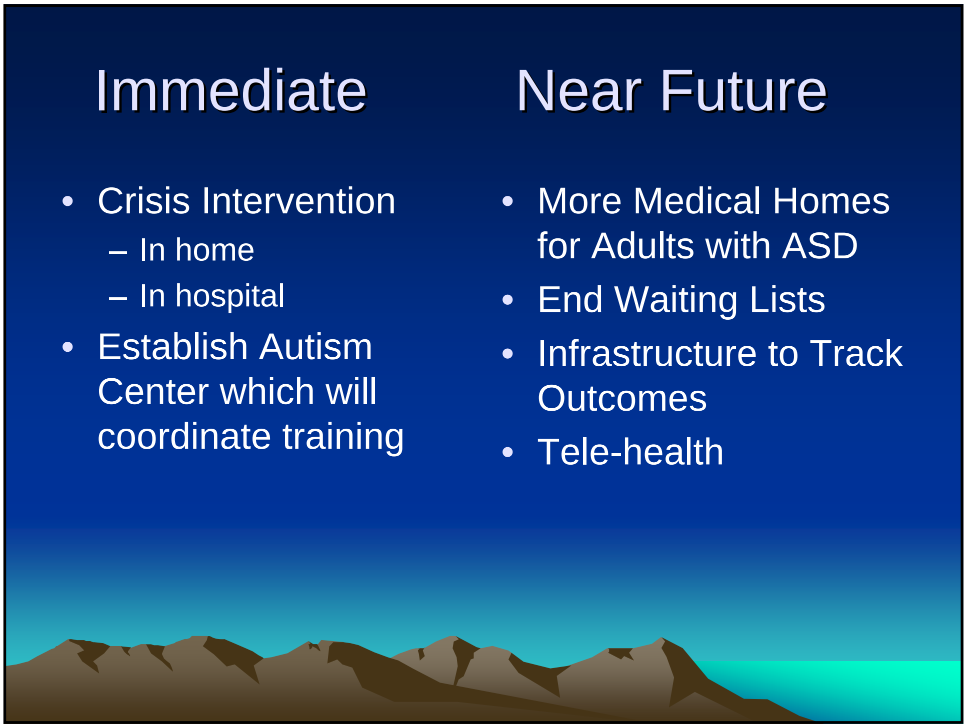
MENTAL HEALTH SERVICES

Have	Need
No Crisis Intervention CES Waiver-long wait list Children's Habilitative Residential Program – No fault dependency and neglect – Innovations for Children-Child Placement Agency	Autism Center to plan and implement system for in home/ out of home crisis intervention and prevention. FUNDING and INFRASTRUCTURE! End Wait Lists



In Home Crisis Intervention and Prevention-START

- Philosophy: Service most effective when everyone involved in care/treatment participates actively in treatment planning and decisions.
- Coordinated service approach
  - Providers in mental health and developmental disabilities meet regularly with family to discuss crisis prevention, treatment plan, and follow-up
- 24-hour mobile crisis team
- Respite services
  - Therapeutic living facility for emergency or planned respite



Immediate

- Crisis Intervention
  - In home
  - In hospital
- Establish Autism Center which will coordinate training

Near Future

- More Medical Homes for Adults with ASD
- End Waiting Lists
- Infrastructure to Track Outcomes
- Tele-health

MEDICAL AND MENTAL HEALTH ISSUES IN INDIVIDUALS WITH ASD

THEMES: GUIDELINES, TRAINING, FUNDING, COORDINATION, TRANSITION TO ADULT SERVICES

DIAGNOSIS AND MANAGEMENT:
MEDICAL ISSUES IN INDIVIDUALS WITH ASD

What CO is doing	What We Should be Doing and/or Research Supported Practice	What We Need
Autism Treatment Network Site (ATN)- ATN is developing guidelines for medical management of children with ASD.	Dissemination of guidelines once completed. Training. Improve awareness of co-occuring medical conditions in children with ASD.	Autism center to coordinate awareness training and dissemination once guidelines are ready. Quality improvement initiatives.
Excellent community of pediatric primary care providers who desire training about ASD. Special Care Clinic at TCH-provides primary care management for children with special health care needs including ASD. Medical Home Initiative (Not focused on ASD) Medicaid Webinars on Medical Home - Early Intervention (not ASD specific)	Refer to the Wisconsin Plan for a medical home for children with ASD as a model for care in Colorado. Refer to Colorado Revised Statue 25.5-1-103 (2008) for definition of Medical Home.	Training for PCP's regarding management of children with ASD. Centralized support for PCP's to manage children with ASD in the medical home. Adequate reimbursement for time to examine children/phone consultation with specialists, therapists, and school personnel to coordinate care.
Provider Hotline – Family Voices	Better awareness of this service.	Dissemination of information about the hotline.
Excellent Emergency Medical Care	Emergency Medical Care that is sensitive to the needs of children with ASD.	Training for Emergency Medical providers and first responders about the needs of children with ASD.

		Funding for space that is sensitive to the needs of children with ASD.
Excellent Specialty Care	Specialty Care that is sensitive to the needs of children with ASD.	Access to sedation and coordination of procedures for children with ASD. Adequate reimbursement for time to examine children. Funding for space that is sensitive to the needs of children with ASD.
University based training programs in Internal Medicine and Family Practice. (No ASD specific training for adults) Metro Community Provider Network - Center for Exceptional Health Care (FQHC-Federally Qualified Health Center-better reimbursement for Medicaid and Medicare, and funding for sliding scale for uninsured) This clinic provides Primary Care for individuals with Cognitive Impairment over age 18. Resource coordination managed through Developmental Pathways so coordination only available to individuals in that catchment area. Any type of insurance is accepted and there is a sliding scale if no insurance. There is no funding for medications. See www.cms.hhs.gov/center/fqhc.asp Physician trained in both internal medicine and pediatrics at Kaiser sees individuals with disabilities. There is a clinic at AF Williams Family Medicine Clinic for adults with developmental disabilities. Consultation is provided one afternoon a month. Any insurance accepted except Medicaid and	Transition Services and PCP's for adults with ASD. Incorporate training in management of individuals with ASD into training programs for Internal Medicine and Family Practice. Support for clinics for adults with ASD. Need coordinators and social workers. Need for access to specialists. Need for access to patient oriented hospital services such as radiology and phlebotomy. This is a huge issue for adults. Coordination of care under anesthesia. Dental Care for adults with ASD. There are fewer providers for adults than for children.	Funding for transition services. Funding for training programs to address medical needs of adults with ASD. Funding for clinics for adults with ASD. Most have Medicaid, at least as backup, but some may be underinsured. Address need for specialists who take Medicaid. Training in patient centered/family centered care and funding for coordination of care. Funding for space and time to work with individuals with ASD.

Medicare.		
Dental Training Program and excellent dental practices. Funding for sedation for dental procedures for children with developmental disabilities.	Greater attention and awareness of dental issues in individuals with ASD.	Awareness of need for and support of routine dental care in children with ASD.
Parent Liaison Program for other special health care needs	Parent Liaison Program for ASD	

DIAGNOSIS AND MANAGEMENT: PSYCHIATRIC DIAGNOSES IN INDIVIDUALS WITH ASD

What CO is doing	**What We Should be Doing and/or Research Supported Practice**	**What We Need**
Co-occurring Psychiatric Diagnoses in Children with ASD is common and often under recognized and inadequately addressed. Rates of Psychiatric Dx in ASD* Anxiety – 40% ADHD - 31-52% Depression - 14-25% Bipolar – 3-9% *Leyfer 2006 and IAN Exchange https://www.ianexchange.org For the purposes of this document, Dual Diagnosis refers to ASD plus a co-morbid psychiatric diagnosis.	Coordinated care between primary care, developmental disabilities professionals, and mental health professionals. Training to increase comfort level of providers to manage individuals with "dual diagnosis." It should be noted that research regarding management is critical and NEEDED. Resource: NADD website (www.thenadd.org) National Association for persons with a Developmental Disability and Mental Health Needs	Research regarding guidelines for identification and management of mental health issues in individuals with ASD. Autism Center to disseminate guidelines once available. Training on recognition, diagnosis, and management of psychiatric co-morbidities. Support for Tele-health/ Oregon Model
ATN is developing guidelines for use of psychopharmacologic medication in individuals with ASD.	Implementation of guidelines once available.	Training around Psychopharmacologic management. Better re-imbursement for medication management.
Insurance Coverage for Behavioral Intervention!!! But not until July 2010 and only until age 18.		More providers, more funding, and a system to track outcomes based on different models of care.

		More coordination between providers of behavioral intervention and providers who prescribe medication.
JFK Research on CBT to manage anxiety.		Funding and training to disseminate and fund the treatment.
At least 5 children with DD are seen in Denver area Emergency Departments weekly for CRISIS intervention. There are very few services in the community for these individuals and many leave before an inpatient bed is available. There is no system for follow up. Adams County has an in home crisis intervention program. DDRC has a behavior/ pharmacology team that is funded by Mill Levy money in Jefferson County.	Crisis Intervention: Hospital Based and Pre-Hospital/In Home START – Philosophy “Services will be most effective when everyone involved in care and treatment is allowed to participate actively in treatment planning and service decisions.” Emphasizes a coordinated service approach. Service providers in mental health and developmental disabilities meet regularly with the individual’s support network (usually family) to discuss crisis prevention and treatment planning, consultation, and follow-up. START also includes a 24-hour mobile crisis team as well as respite services that address the need for a therapeutic living facility that can be used in an emergency or as planned respite. Respite can last as long as a month, whereas community hospitals provide more intensive in-patient, psychiatric services for very short periods. Please see attachments 1, 2, and 3 for START Brochure and for an overview of Programs in Massachusetts and New Hampshire	An Autism Center to plan and implement a system for in home/and out of home crisis intervention and ongoing management and prevention. FUNDING and INFRASTRUCTURE! Awareness, training, funding for evaluation of possible medical/dental issues impacting behavior.
Inpatient Beds for Psychiatric Hospitalization in Colorado for Children with ASD **ASD with Cognitive Disability – 3 overnight beds and 8 day treatment beds** – all are at TCH **High functioning ASD– 2 beds**, 1 bed each at any given time at	Adequate number of inpatient and day treatment slots for children and adults with ASD in Colorado. These programs must include treatments that are appropriate for individuals with ASD.	More Inpatient and Day treatment beds for children with high and low functioning autism with appropriate intervention services for a child with ASD. Many programs only take children with ASD if they can benefit from “talk therapy” which is often

Cedar Springs and Denver Health		inappropriate for a child with ASD. **This requires funding and training.**
Inpatient Beds for Psychiatric Hospitalization in Colorado for Adults with ASD **None specifically for ASD.**		**Inpatient Psychiatric Beds for Adults with ASD**
Behavioral Health Organizations (BHO) are required to treat individuals with ASD if there is also a psychiatric diagnosis. The BHO's are currently funding 3 trainings on ASD which will take place in different parts of the state. BHO has a Standards Committee that will be meeting to discuss current status, vision, and resources needed for management of individuals with ASD	Programs appropriate for individuals with ASD.	Training, Infrastructure for Coordination, Funding for appropriate programs.
Two systems of insurance coverage – Medical vs. Behavioral Health. Many Psychiatrists are fee for service only.		System for addressing medical vs psychiatric coverage for individuals with ASD. Adequate Re-imbursement.
Long Term School Programs for Dual Diagnosis. Example: Joshua School – Excellent private school for children with ASD which often serves children with dual diagnosis. Laradon - Alternative School offers a specialized curriculum, designed to meet the needs of students with a dual diagnosis, from the ages of 5 to 21 years old, in a highly structured environment. Generally IQ is under 70. No crisis intervention.	Adequate number of high quality, specialized school programs when least restrictive environment has not been adequate to meet child's needs.	
Residential Placement/Host Home/Group Home	Residential settings that work for adults with a dual diagnosis.	Appropriate host homes for adults with dual diagnosis –

CHRP – Children’s Habilitative Residential Program. Parents must apply for “No fault dependency and neglect” Developmental Disabilities Apartment Program through Residential Waiver	System changes that address the need without using the term “neglect”	similar to what occurs in Vermont with the Vermont Crisis Intervention Network that includes ongoing intervention support for host families from an autism team.
SIED School Placement-often not appropriate for children with ASD	School Programs appropriate for children with dual diagnosis in all districts.	Funding and Training See Education Documents
CES Waiver – wait list		End the Wait List.

START –
Philosophy “Services will be most effective when everyone involved in care and treatment is allowed to participate actively in treatment planning and service decisions”

Emphasizes a coordinated service approach. Service providers in mental health and developmental disabilities meet regularly with the individual’s support network (usually family) to discuss crisis prevention and treatment planning, consultation, and follow-up. START also includes a 24-hour mobile crisis team as well as respite services that address the need for a therapeutic living facility that can be used in an emergency or as planned respite. Respite can last as long as a month, whereas community hospitals provide more intensive in-patient, psychiatric services for very short periods (up to 7 days).

Collaborative Services in Massachusetts: The START/Sovner Center Program

by Joan B. Beasley

START – an acronym for Systemic, Therapeutic, Assessment, Respite and Treatment – has been providing clinical, emergency, and respite services since 1989. The Massachusetts Department of Mental Retardation (DMR) funds the START program in order to provide community-based crisis intervention and prevention services to individuals with developmental disabilities and behavioral (mental) health care needs in the northeast part of the state. START and the Robert D. Sovner Behavioral Health Resource Center of which it is a part serve a region of approximately 750 square miles and 1.1 million total residents. Over 1200 individuals have used Sovner Center and START services.

The program's underlying philosophy is that services will be most effective when everyone involved in care and treatment is allowed to participate actively in treatment planning and service decisions. In order for this to occur, collaboration between service providers and with service users is necessary, and an integral part of the program.

START Services

In order to access appropriate mental health services and to facilitate a coordinated service approach and foster service linkages, START provides a number of opportunities for consultation, education, and individualized treatment planning. START also provides a number of services to coordinate care and fill in service gaps. The services include collaborative contacts, after-hour contacts, emergency team meetings, planned respite, and emergency respite services:

- **Collaborative Contacts:** Collaborative contacts are made up of crisis prevention planning meetings, consultation visits, treatment planning meetings, and follow-up meetings. START clinicians are required to facilitate individual crisis prevention planning meeting at least once a year. Whenever possible, the START clinician, the service user, members of the mental health service team (i.e., the outpatient therapist, a representative from the mental health crisis team, the psychiatrist), members of the developmental disabilities service team (i.e., the service coordinator, residential and day program providers), and the individual's informal or social supports (family members, friends, and other interested parties) meet to develop a plan to assist the individual and his or her caregivers during times of difficulty. START clinicians are also required to maintain ongoing contact with family members and other caregivers. Follow-up meetings are scheduled to evaluate the effects of treatment strategies, update crisis prevention plans and to foster active communication among providers and with direct caregivers.
- **After Hours Contacts:** START provides 24-hour mobile crisis services. After hours (5 p.m. – 9 a.m. Monday through Friday and all weekend), START clinicians rotate on-call responsibilities and are available to provide assistance to families, DMR, psychiatric pre-screening teams, and residential providers 24 hours a day, 7 days a week. After-hours contacts may include phone calls to assist during a time of crisis, clinicians providing mobile evaluation services and assisting a mental health crisis team to determine whether or not a psychiatric inpatient admission is needed, assistance locating an available inpatient bed, or pre-screening the individual for an emergency respite admission.
- **Emergency Meetings:** Emergency meetings are team meetings facilitated by START clinicians on a psychiatric inpatient unit or at the emergency respite facility following an admission. The meetings are scheduled within 24 hours of the admission or the next business day whenever possible. The purpose of the meeting is to allow the START clinician and other members of the team to provide information to the inpatient unit in order to assist with treatment and disposition planning. Family members and residential providers are strongly encouraged to participate in the meeting. In addition, the START clinician attempts to facilitate phone contact between the individual's outpatient and inpatient psychiatrists, and encourages ongoing contact between the family and residential provider throughout the admission. Whenever possible, a discharge planning meeting is also scheduled to ensure a smooth transition back home.
- **START Respite:** START respite is a place where people can live for short periods of time when they are in distress or in need of support and assistance. The START respite facility is staffed with a full-time director, a weekend coordinator, direct care specialists, and awake overnight staff. The staffing pattern is 3:4 during "awake hours" (8 a.m.– 10 p.m.) and 2:4 during "sleep hours"(10 p.m.– 8 a.m.). However, one-to-one staffing is provided as needed. The respite center has private bedrooms, and one bedroom has a private bath. It is divided into two wings so those individuals who have more severe difficulties do not disturb or become disturbed by other guests. Additional facility-based emergency respite is provided by independent affiliates of START. They maintain the same staff to guest ratio, and work closely with START personnel.

Citation: Hanson, R., Wieseler, N., & Lakin, C. (2000). Impact: Feature Issue on Behavior Support for Crisis Prevention and Response, 14(1) [online]. Minneapolis: University of Minnesota, Institute on Community Integration. Available from http://ici.umn.edu/products/impact/141/.

- **Planned Respite Services:** Two of the beds in the four-bed respite home are designated as "planned respite beds." Planned respite beds at START are intended to serve individuals who have not been able to use respite in more traditional settings due to their ongoing mental health and/or behavioral issues. Families participating in the program must be approved by DMR as eligible for these services, but once approved, they schedule visits as needed and as space is available. Planned respite visits are provided to any START service recipient and are not restricted to people living with their family. An individual can visit respite for dinner, a recreational activity, or to just "check in" for a few hours. Some families visit respite with the guest to become familiar with the facility and staff prior to scheduling overnights.
- **Emergency Respite Services:** Emergency respite services are provided at the START respite facility. Two beds in the four-bed respite facility operated by START are designated for emergency respite purposes. Emergency respite is designed to provide out-of-home housing and services to individuals who for a short period of time (suggested 30 days or less) cannot be managed at home or their residential program. Additional emergency respite services are purchased on an as-needed basis from START affiliates.
- **Psychiatric Inpatient Services:** Community mental health hospitals and general community hospitals provide psychiatric inpatient mental health services. Inpatient psychiatric services are expected to be very short term (seven days or less). Inpatient psychiatric services are primarily provided by three hospitals in the region. The hospitals have affiliation agreements to coordinate services with START and DMR representatives. The affiliation agreements are with the hospitals that provide the bulk of the inpatient services to people with developmental disabilities in the region. However, other hospitals also provide some psychiatric inpatient services. START clinicians offer the same services at these times. In order to access needed services, START relies upon the use of affiliation agreements and linkages with the developmental disabilities and mental health service systems, and the individual's natural support system.

Nearly, 20 years ago, the late Frank Menolascino recommended a "systematic" approach to the management of behavioral health needs of persons with developmental disabilities, including the provision of comprehensive diagnostic evaluations, active family involvement and education, early diagnosis and treatment, vocational services, residential services, and family support with short-term crisis care facilities to provide back-up support when needed. He stressed that "Coordination of the many services needed for individuals with dual diagnoses requires awareness of the various services available in a given community and a professional attitude that permits active collaboration. It necessitates sharing of the overall treatment plan with the individual, the family, and with community resources. Close attention to the clarity and continuity of communication is essential" (Menolascino et al. 1983). START is one model of a "systematic approach" to care as described by Menolascino and others to assist people with developmental disabilities and behavioral health care needs in the community. The guiding premise of START is that the individual's needs and wishes drive all services and supports, while the coordinated linkages fill service gaps and allow for the use of multiple services and service systems through proactive communication and collaboration. Jimmy's story, below, helps to demonstrate how START works with individuals who have developmental disabilities and behavioral support needs.

Jimmy's Experience

Jimmy* is in his early 20's and has moderate cognitive impairments and autism. He has lived with his family all of his life, and they would like to continue to have him with them. They have tried to access family support for many years, but Jimmy has not been able to use traditional out-of-home respite services available to other DMR service recipients because of ongoing severe self-injury and major property destruction.

Prior to Jimmy's referral to START, his family was in constant crisis. His behavior problems were severe and out of control. He was hospitalized in psychiatric facilities on numerous occasions, and after each admission seemed worse. He was referred to the START team and Sovner Center clinic, and upon arrival the family expressed doubts that they could continue to manage the situation.

Jimmy and his family received services from START, and since working with the START team, he has been diagnosed and successfully treated for obsessive-compulsive and bipolar disorders, and his behavior has improved dramatically. He continues to receive support staffing through a DMR provider agency in the family home, and members of the START team provide ongoing training and support to his direct service staff. A START clinician attends Jimmy's psychiatric appointments to assist in communicating with his psychiatrist, and also talks with his day program provider to ensure that everyone on his team is in communication with regard to Jimmy and his mental health care needs.

Jimmy continues to have ongoing challenges, however, he and his family are no longer in constant distress. The system is linked, communication is active, and everyone continues to benefit from this approach – especially Jimmy.

References

Menolascino, Frank J. & McCann, Brian M. Eds. (1983) *Mental health and mental retardation: Bridging the gap.* Baltimore: University Park Press

*Pseudonym

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Citation: Hanson, R., Wieseler, N., & Lakin, C. (2000). Impact: Feature Issue on Behavior Support for Crisis Prevention and Response, 14(1) [online]. Minneapolis: University of Minnesota, Institute on Community Integration. Available from http://ici.umn.edu/products/impact/141/.

Program Description

THE CENTER FOR START SERVICES

Consultation and Training in Crisis Prevention, Management, and Support for Individuals with Intellectual Disabilities and Behavioral Health Needs

Mission: To enhance local capacity and provide collaborative, cost-effective support to individuals and their families through exemplary clinical services, education and training, with close attention to service outcomes.

The **START** program model which was first developed in 1988, presents a least restrictive model of care/support that offers provision of multi-modal clinical assessment and support, training and empowerment for families and caregivers including effective behavior management and therapeutic tools, a residential therapeutic respite facility, and optimal utilization of existing resources through:

- System linkages
- Used throughout the United States to enhance the service system though active collaboration
- Provides professional and logistic "linkages" between service providers in multiple disciplines
- Improves expertise across systems of care
- Promotes the use of "generic" services whenever possible
- "Special" services provided for those who need them
- Sustainable blended funding
- Services designed to fill service gaps **START** is an evidence based program model. Research outcomes include:
- Reduction of emergency service use
- High rates of satisfaction by families and care recipients
- Cost effective service delivery

START was cited as a program model in the 2002 US Surgeon General's Report on mental health disparities for persons with developmental disabilities.

back to top...

History of START

START has been providing clinical, emergency and respite services since 1989 (Beasley et. al, 1992). The Massachusetts Department of Mental Retardation funds the **START** program in order to provide community based crisis intervention and prevention services to individuals with developmental disabilities and behavioral (mental) health care needs. The underlying philosophy o f **START** is that services will be most effective when everyone involved in care and treatment is allowed to participate actively in treatment planning and service decisions. In order for this to occur, collaboration between service providers and with service users is needed.

START is a part of the Robert D. Sovner Behavioral Health Resource Center. Services at the Center include **START** and outpatient mental health services that specialize in treating individuals with developmental disabilities. The services are provided region-wide, and over 1200 individuals have used Sovner Center and **START** services since they began in 1989.

back to top...

START Services

The following services are available from a range of experts in **START** model concepts and implementation:

- CONSULTATION SERVICES

- TRAINING

- TECHNICAL ASSISTANCE & SUPPORT

- RESEARCH & EVALUATION

- MH/ID COMMUNITY SERVICE ELEMENTS
    - Service planning/coordination
    - Cross systems/interdisciplinary training
    - Outpatient mental health – counseling/psychiatry
    - Health care and dentistry
    - Crisis prevention and crisis intervention planning
    - Residential/Housing/Day/Vocational: Habilitation
    - Respite
    - Inpatient hospitalization
    - Hospital diversion/mobile crisis support
    - Psychology/behavioral support planning
    - Family support/education/outreach

back to top...

START Locations

States in which services have been developed based on the **START** Model:

- California
- Connecticut
- Maine
- Massachusetts*
- Minnesota
- Missouri
- New Hampshire*
- North Carolina*
- Ohio
- Oregon
- Pennsylvania
- South Carolina
- Tennessee*
- Texas
- Washington

**States with full implementation*

back to top...

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Survey of Pediatricians regarding their care of patients with Autism Spectrum Disorders.

In order to obtain feedback from pediatricians in the state for the Autism Commission, a survey was sent to all members of the Colorado Chapter of the AAP on September 17, 2009.

The most common barriers to care sited by the respondents to the survey were as follows.

Lack of well trained behavior therapists	93%
Lack of coverage for behavioral interventions	83%
Lack of training in psychopharmacology	83%
Lack of time for an office visit	66%
Lack of access to a timely diagnostic evaluation	66%
Lack of reimbursement	63%
Lack of care coordination	60%
Lack of school resources	58%

The most common problems that pediatricians report hearing from families of the children with ASD are as follows:

Behavior management	93%
Lack of school support	83%
Access to resources	74%
Financial concerns	71%

71% of pediatricians responding to this survey reported that they are screening for ASD per the guidelines established by the AAP in 2007. 80% reported that improved reimbursement would make screening more possible and 73% reported that they need more time to do ASD screening.

60% of respondents reported an interest in further training in the management of children with ASD.

Appendix H

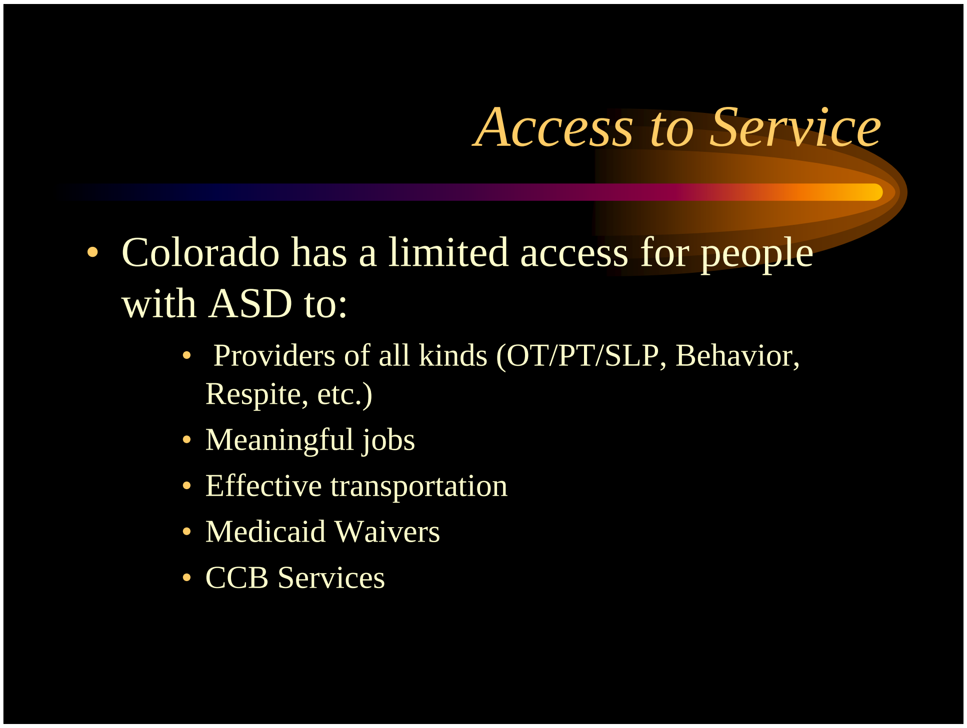
Community Services Committee Report

Where are we now?
Where we should be?

Community

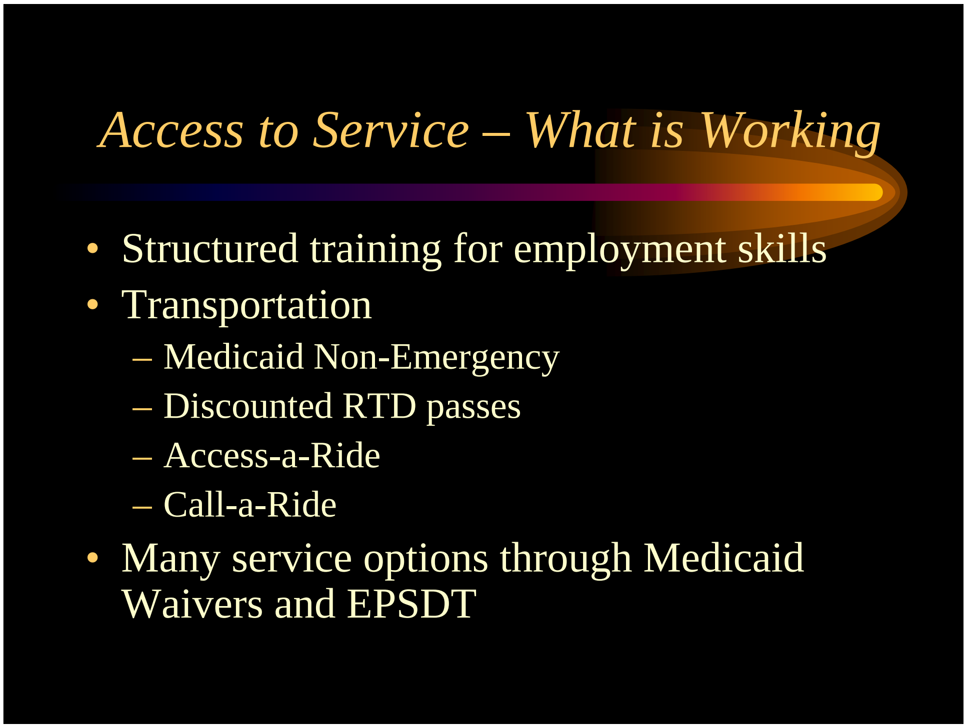
Themes

- People with ASD require a coordinated support system across the lifespan. Autism is complicated beyond any other diagnosis due to the diversity of need across the spectrum, statewide systems, and community.
  - Access to Service
  - Safety
  - Communication
  - Care Coordination
  - Activities of Daily Living
  - Needs of the Caregiver
  - Life in Common



Access to Service

- Colorado has a limited access for people with ASD to:
    - Providers of all kinds (OT/PT/SLP, Behavior, Respite, etc.)
    - Meaningful jobs
    - Effective transportation
    - Medicaid Waivers
    - CCB Services



Access to Service – What is Working

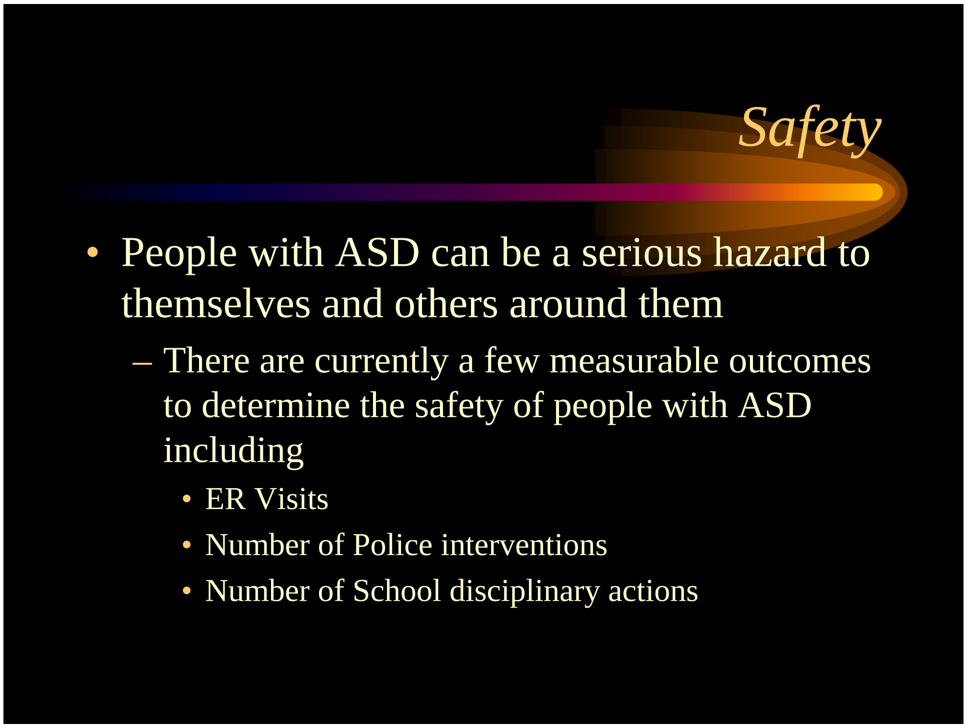
- Structured training for employment skills
- Transportation
    - Medicaid Non-Emergency
    - Discounted RTD passes
    - Access-a-Ride
    - Call-a-Ride
- Many service options through Medicaid Waivers and EPSDT

Access to Services – What we need

- Employment Opportunities
  - Increased capacity with Dept. Vocational Rehab
  - Vocational Counselors with ASD knowledge
  - Jobsite assistance with environmental adaptations and family input
  - Initial and ongoing coaching/mentoring
- Affordable and Effective Transportation
  - Easy to use transportation routes and schedules
  - Transportation staff with knowledge of how to support people with ASD
  - More transportation options for people in rural CO

Access to Services – What we need

- Medicaid and Waivers
  - Fully fund waivers to eliminate waitlists
  - Increase the pool of qualified providers
  - Increase the age and capacity on the CWA waiver
  - Increase services available through Medicaid State Plan benefits to better suit the needs of people with ASD
- Definitions
  - Change the definition of Developmental Disability to include all Autism Spectrum Disorder so CCB’s can better serve all people with ASD



Safety

- People with ASD can be a serious hazard to themselves and others around them
  - There are currently a few measurable outcomes to determine the safety of people with ASD including
    - ER Visits
    - Number of Police interventions
    - Number of School disciplinary actions

Safety – What we Have Now?

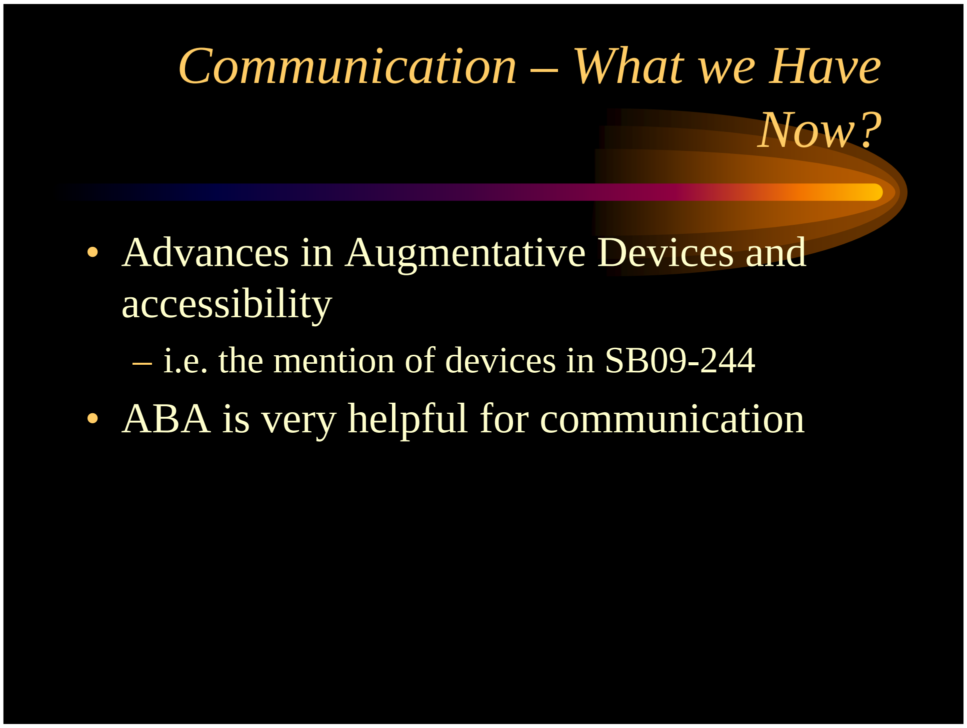
- Life Trak
  - tracking system for people with disabilities, partnership with emergency responders
- Service Animals for assistance
- Community Safety Skills Training
  - Example: Safety First, Boulder, CO

Safety – What we Need?

- More opportunities for line of sight supervision
- More opportunities for initial and ongoing community safety training:
  - emergency responders, schools, rec centers, etc.
- Available home/safety modification
- Training for all law enforcement on ASD

Communication

- A core deficit for people with ASD
- People with ASD have a unique form of communication that others may not understand
- Every behavior may be a mechanism for communication even if misunderstood
- People with ASD may have trouble understanding verbal communication used by others
- Fluent speech and pragmatics may be at varied skill levels



Communication – What we Have Now?

- Advances in Augmentative Devices and accessibility
  - i.e. the mention of devices in SB09-244
- ABA is very helpful for communication

Communication – What we Need?

- Increased access to augmentative communication
- Research funding for effective augmentative communication systems
- Autism specific training for SLP professionals
- Increased pool of SLP/Behavioral professionals
- Have insurance companies pay for augmented communication systems and training
  - encourage out of state companies to become Colorado Medicaid Providers
- Increase emphasis on research and testing for pragmatics

Care Coordination

- Individuals with ASD and supports have very complex care coordination needs
  - Coordination of medical, mental health, behavioral, educational, vocational, and long term care services
- Life transitions are so difficult, seamless care coordination is critical for consistency
- This is the largest issue for people with ASD

Care Coordination – What we Have Now?

- Family members and supports are the ones left to manage care coordination across all silos of care.
- Medical Home concepts are a positive start to care coordination.
- CCB as Case Management

Care Coordination – What we Need?

- Increase the access and capacity of existing care coordination systems.
- Combine functions of CCB’s, SEPs, Social Services, Mental Health etc. for all people in a true single entry agency accessible to all regions of the state.
- Regional Single Entry Agencies should have adequate information resources including comprehensive information for people with ASD.
- Adequate funding for Coordination services

Activities of Daily Living

- ADLs and IADLs are used for functional assessments to determine Eligibility for Waivers
- Activities of Daily Living – bathing, toileting, eating, dressing, mobility, transfers, behavior
- Independent Activities of Daily Living – hygiene, meal preparation, housework, laundry, shopping, medication management, money management, Accessing resources, Transportation
- IQ is still an eligibility component for DD programs and the test does not adequately address the issues people with ASD face.

Activities of Daily Living – What we Have Now?

- Needs based assessments with consistent standards using Supports Intensity Scale (SIS)
- Need for interrater reliability standard is recognized
- Newly passed SB09-244 will provide more access to therapies to enhance ADLs and IADLs

Activities of Daily Living – What we Need?

- More availability for assistance with ADLs and IADLs
- Interrater reliability standards need to be improved
- Remove the IQ component from functional assessments or change the scoring to focus more on adaptive skills
- With Research develop measurable ways to include sensory issues, communication, and social skills to better determine need in ADLs for assistance

Needs of the Caregiver

- Respite
- Support Groups
- Family Preservation
- Training and Education
- Financial
- Guardianship

Needs of the Caregiver – What we Have Now?

- Respite
  - Available under CES Wavier
  - Give Me a Break – Autism Society
  - *Competent Care for Challenging Children Program* – Autism Society
- Support Groups
  - Many community support groups in place
    - Example: Parent 2 Parent, Moms on the Spectrum, ABC's of ASD through the Autism Society
- Family Preservation
  - With documentation of significant need, families may access

Needs of the Caregiver – What we Have Now?

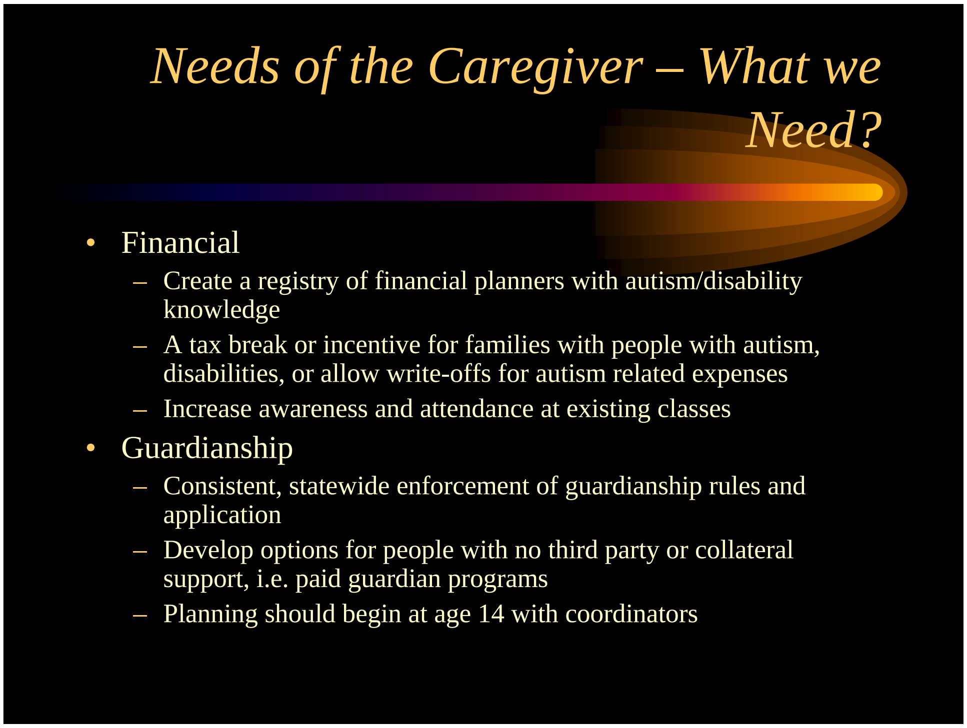
- Training and Education
  - RDI Certification
  - Start Here Book
  - Caregiver 360 – Web based
  - Peak Parents Training Calendar, Autism Society’s *The Source*
  - Part C, Mobilizing Families through Metro Arc’s
  - Give Me a Break Program Provider/Parent Training
- Financial
  - Many classes being taught at disability and financial organizations

Needs of the Caregiver – What we Need?

- Respite
  - Have Respite available through Medicaid State Plan
  - Provide Respite options for people not eligible for DD
  - Increase education for caregivers on respite options
  - Training for respite providers
  - License/certify respite providers
  - Adequate rates for respite providers
  - Fully fund Family Support at the CCBs
- Support Groups
  - Have a maintained database of all groups statewide

Needs of the Caregiver – What we Need?

- Family Preservation
  - Provide options for Therapy and counseling
  - Services for siblings
  - Increase Access to Expressive therapy i.e. Hopeful Waiver Services
  - Increased awareness of Family Preservation model
  - Have more appropriately trained and affordable child care options
- Training and Education
  - Increase affordable training opportunities for families and caregivers



Needs of the Caregiver – What we Need?

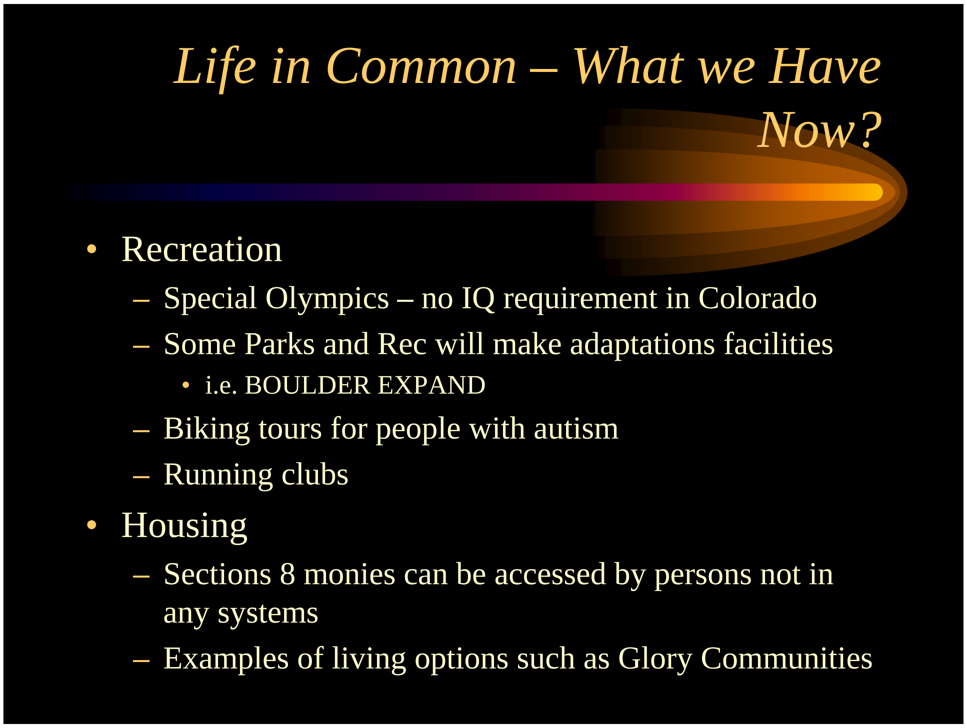
- Financial
  - Create a registry of financial planners with autism/disability knowledge
  - A tax break or incentive for families with people with autism, disabilities, or allow write-offs for autism related expenses
  - Increase awareness and attendance at existing classes
- Guardianship
  - Consistent, statewide enforcement of guardianship rules and application
  - Develop options for people with no third party or collateral support, i.e. paid guardian programs
  - Planning should begin at age 14 with coordinators

Life in Common

- Environmental Adaptations
  - People with ASD process sensory information differently and environmental adaptations are critical to reduce stress and anxiety
- Executive Functioning
  - core deficit for people with ASD
  - Cognitive abilities that control and regulate other abilities and behaviors. Executive functions are necessary for goal-directed behavior. They include the ability to initiate and stop actions, to monitor and change behavior as needed, and to plan future behavior when faced with novel tasks and situations
- Recreation
- Housing
- Social

Life in Common – What we Have Now?

- Environmental Adaptations
  - Educational systems and community are beginning to understand ASD and people with ASD and family members are beginning to communicate the need for environmental accommodation
- Executive Functioning
  - Assistive Technology advances i.e. Coleman Institute
  - Visual Schedules
  - Limited Distractions
  - Preferential seating
  - Sensory diet
  - Home modification opportunities



Life in Common – What we Have Now?

- Recreation
  - Special Olympics – no IQ requirement in Colorado
  - Some Parks and Rec will make adaptations facilities
    - i.e. BOULDER EXPAND
  - Biking tours for people with autism
  - Running clubs
- Housing
  - Sections 8 monies can be accessed by persons not in any systems
  - Examples of living options such as Glory Communities

Life in Common – What we Have Now?

- Social
  - Grasp
  - Circle of Friends
  - University led Groups
  - Downing Group
  - DAAM I
  - Social online networking, i.e. Facebook
  - Faith based organizations
  - Autism Society of Colorado Community Enrichment program, i.e. Pizza Night

Life in Common – What we Need?

- Environmental Adaptations
  - People with severe reactions to environment, need services to follow the person. Ex: Online applications, in home applications and services
  - New construction should have an environmental analysis for people with Disabilities including ASD
- Executive Functioning
  - Have more training opportunities for executive functioning including schedules and options for assistive technology
  - More evidence based research for executive functioning and people with ASD

Life in Common – What we Need?

- Recreation
  - Available and affordable recreation statewide
  - Increase training to Recreation staff to understand the ASD
- Housing
  - Increase availability
  - Increase awareness
  - Increased Options
- Social
  - Have a contact listing for all informal social groups statewide
  - Have a mentor and friend searching service

Where we are now narrative:
Community

People with Autism require a coordinated support system across the lifespan; including: the person, family, and the community. This is due to the general characteristics of autism itself. Autism is complicated beyond other diagnoses due to the diversity of need across the lifelong spectrum and across statewide systems. Per Betty Lehman, “Once you have met one person with Autism, you have met only with one person with autism.”

The Colorado ASD community has limited access to services including providers across all therapeutic needs including Mental Health, jobs and employment assistance services, adequate functional transportation for everyone in the state, Medicaid and Medicaid waiver waitlists and CCB services are not available for everyone. There are inconsistencies across the state with what is available and what can be accessed. Rural areas especially are not able to provide the same level of services that sometimes can be accessed in the urban areas.

Safety is a serious issue to the ASD community for both the person with ASD and others. There are few consistent ways to actually measure outcomes. We can only look at ED visits, PD interactions and school disciplinary actions and based on the way the encounters are coded, they may not be captured as an ‘autism‘ event.

Communication is a core deficit for all persons with ASD and often the person is not understood and may even have a unique way of communicating needs and wants. Every behavior a person with ASD uses is a means of communication, even if misunderstood or looked at by the typical person as inappropriate. The person with ASD has problems understanding typical verbal and body language communication. Scattered fluent speech and pragmatics problems are found in varied levels across the spectrum.

Care coordination seems to be a large issue for the person with ASD and their family/caregivers. The availability is inconsistent across the state. Coordinating care among medical, mental health, behavioral health, vocational and long term services is a life long ever changing task that really is not owned by any one entity.

ADL and IADL assessments provide functional assessments of the issues a person with ASD faces and will show the varied skills a person with ASD possess. But the IQ test (many, many persons with ASD score above the 70 score necessary for receipt of services) result continues to be used as the eligibility requirement for DD services which leaves many without services to assist with these very basic human needs which a person with autism with struggle to maintain across the lifespan. The person with autism will typically have many scattered skills within the ADL and IADL test results, making it difficult to interpret their true needs to maintain.
Needs of the caregivers are diverse, but have a similar theme: lack of timely respite, need for timely support groups, need for family preservation, timely training and education, financial education and assistance, guardianship knowledge and timely future planning skills. The availability of these needs are scattered across the state and family members or caregivers just plain do not have time or energy to access the services.

Persons with ASD all survive their environmental situations differently by processing sensory information differently than those without ASD. Executive functioning involves goal directed behavior and the person with ASD has problems processing the behavior. Cognitive abilities show scattered skills. Recreation choices are available to some, but are not readily available to all across the state. Even those who can find some choices have monetary issues which do not allow them to participate. Other safe social opportunities like dating and hang-outs are not available to all. Housing outside the family home is available to some, but not all equitably across the state. Waitlists are long. Comprehensive services through the CCB involves finding adequate service providers who may not have the knowledge of interpreting the world of autism, so many persons continue to live in the family home with aging parents.

People with autism need accommodations and support to access life-long learning because disability support teams are not available at all state colleges and universities or vocational and trade schools . There is inconsistent awareness among HS counselors, parents and the young adult about resources and accommodations in the higher education setting. Higher education options are not consistently discussed in transition training for parents and high school age students with autism

Even though these are not consistent across the state, there is VocRehab services to assist with job skills, urban RTD discount fares and Access-a-Ride, Medicaid for non-emergent transportation and Medicaid waivers like CES (until age 18 yrs, SLS and Comprehensive). Safety services that do exist include: LifeTrak, service animals, community safety training classes and PD and first responder training classes. While these are available, it is unclear why they are not accessed by all. While there have been many advances in communication teaching techniques as evidenced by ABA training, services are not available to all either because of lack of providers, lack of time and energy for caregivers to access services or lack of funding.

Augmentative devices are becoming more advanced and mention of their funding coverage in SB09-244 may make them more available to all. However, navigating the medical system to obtain their funding can be a many year process. Total person care coordination is the responsibility of the family member. The Medical Home Model concept offers a positive start to coordinate care. CCB's offer case management, but access to this service is not consistent across the state and does not include management into medical and mental health issues. Some PCP offices do offer some coordination of care, but this will typically be restricted to the health care issues. The SIS is used in CO to determine level of need for ADL and IADL skills and subsequently level of reimbursement for services through the CCB system. Interpretation of these scores is based on the subjective skill of the interviewer which can mean more access to services or less. There is no standard objective tool to assess needs. SB09-244 will require health insurers to provide standard therapy to improve ADL and IADL skills, but you will have to have a private health insurance policy. There is some respite available through the waiver services, but some ends at age 18 years and often falls onto the family to find and secure the providers. ASC does offer the Give Me a Break program and has a list of skilled providers. Use of respite programs and knowledge of them is inconsistent. While there are many support groups all over the state, knowledge of them, respite care and time to attend are deterrents to families. The family preservation waiver is available upon meeting the criteria, but knowledge of its services is inconsistent. Basic training and education classes and financial training classes are offered through many agencies and sites across the state. Attending the classes is a time zed respite issue for families. Environmental adaptations are showing up in the education system, but not consistently across the state. Executive functioning improvements are available through use of improved assistive technology, visual schedules, limiting distractions, preferential seating, sensory diets and home modification opportunities. Knowledge of these and how to access them limits their use making them an inconsistent tool to assist the person with ASD. Recreation and social opportunities are available, such and Special Olympics, Parks and Rec classes and GRASP and face book, but again their use in inconsistent because of time needs of the family and knowledge of their existence. For the family that does not speak English, all of the above issues pertain, but getting the information to the families and helping them access and use the knowledge is another challenge.