

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

**TABLE OF CONTENTS**

<b>APPENDIX A: ACT CREATING COMMISSION .....</b>	<b>A1</b>
<b>APPENDIX B: TESTIMONY COMMITTEE REPORT.....</b>	<b>B1</b>
<b>APPENDIX C: ESTIMATE OF NUMBER OF COLORADOANS WITH ASD.....</b>	<b>C1</b>
<b>APPENDIX D: DESCRIPTION OF OVERSIGHT COMMITTEE AND TASK FORCE .....</b>	<b>D1</b>
<b>APPENDIX E: SCREENING, DIAGNOSIS, AND EARLY INTERVENTION COMMITTEE REPORT .....</b>	<b>E1</b>
<b>APPENDIX F: EDUCATION COMMITTEE REPORT .....</b>	<b>F1</b>
<b>APPENDIX G: MEDICAL AND MENTAL HEALTH COMMITTEE REPORT .....</b>	<b>G1</b>
<b>APPENDIX H: COMMUNITY SERVICES COMMITTEE REPORT .....</b>	<b>H1</b>

# **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.**



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

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



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;

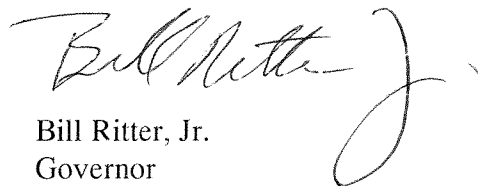
Peter J. Weinberg of Denver, Colorado, a representative of a community mental health center and who has experience treating individuals with Autism Spectrum Disorders, appointed;

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 Mission:**

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



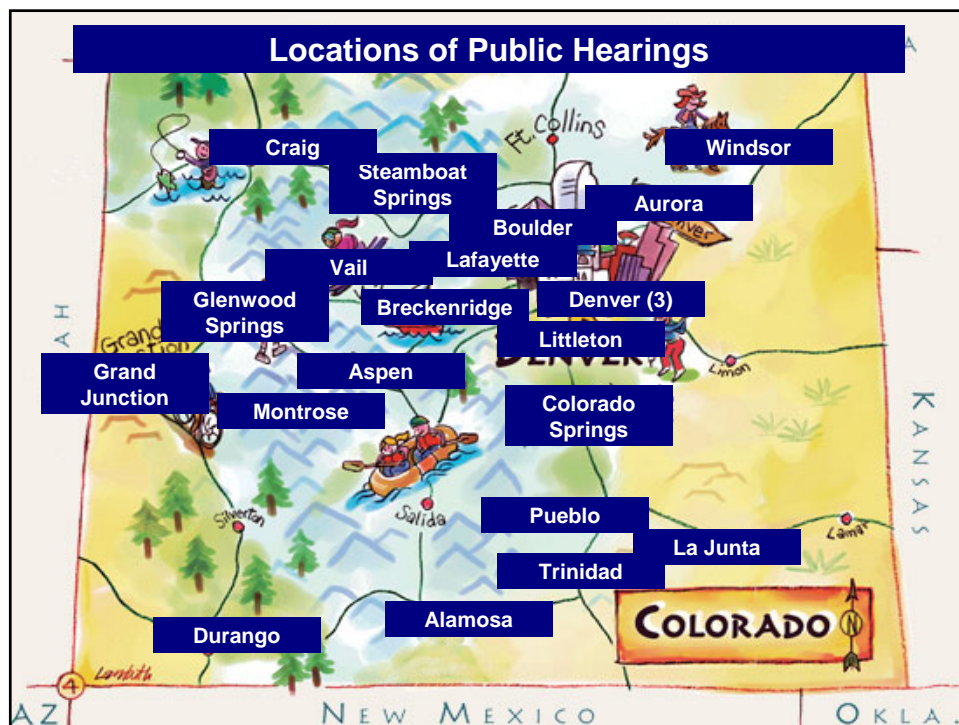
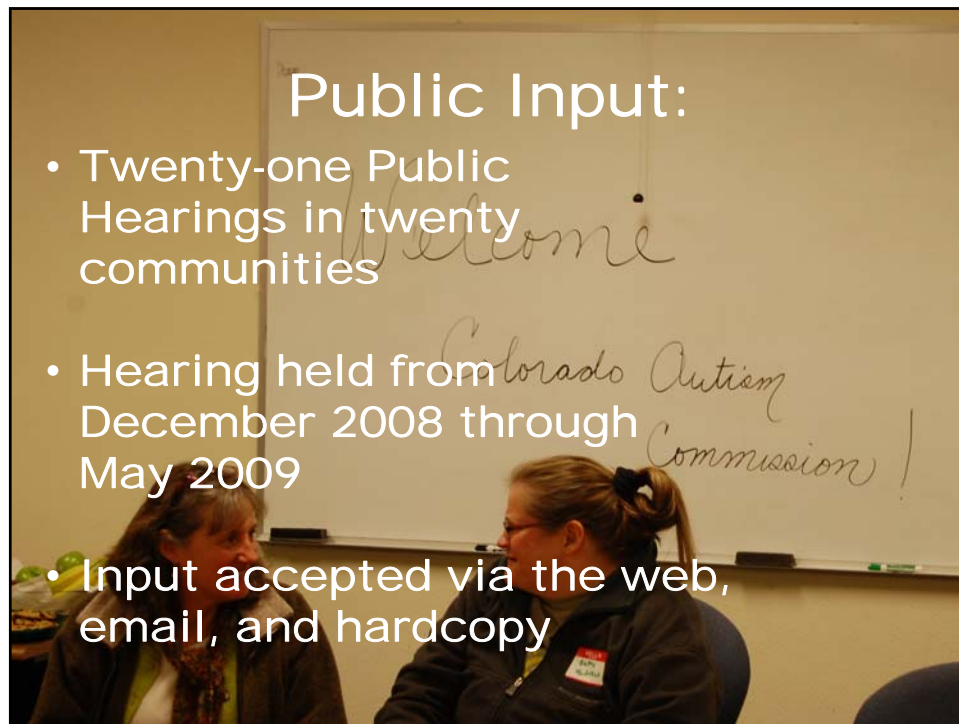
### **The Autism Commission held Public Hearings for the purpose of:**

- 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.

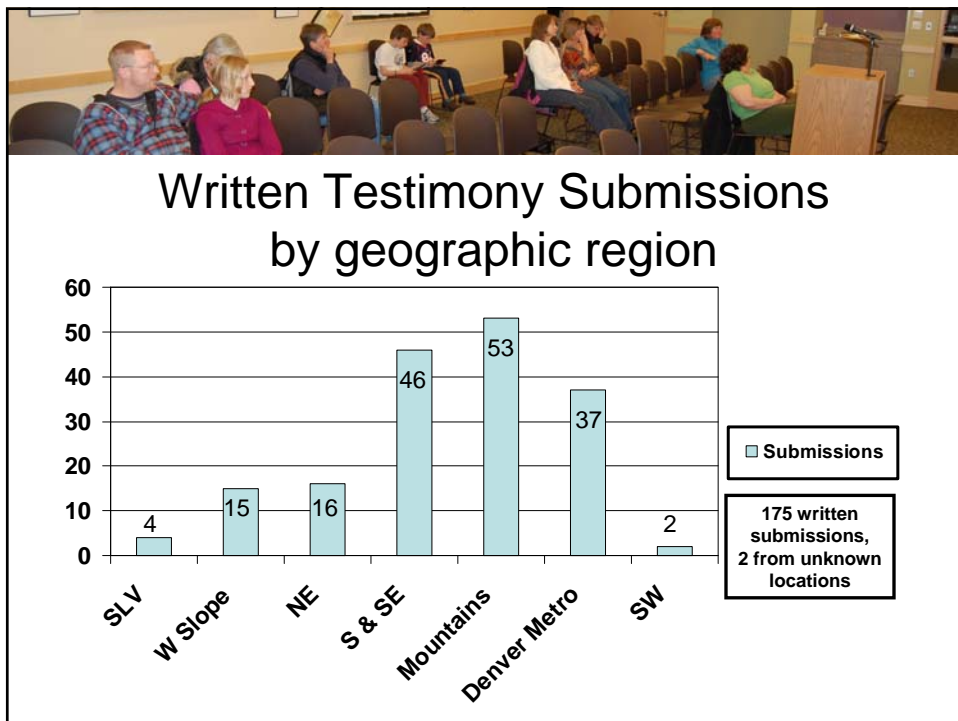
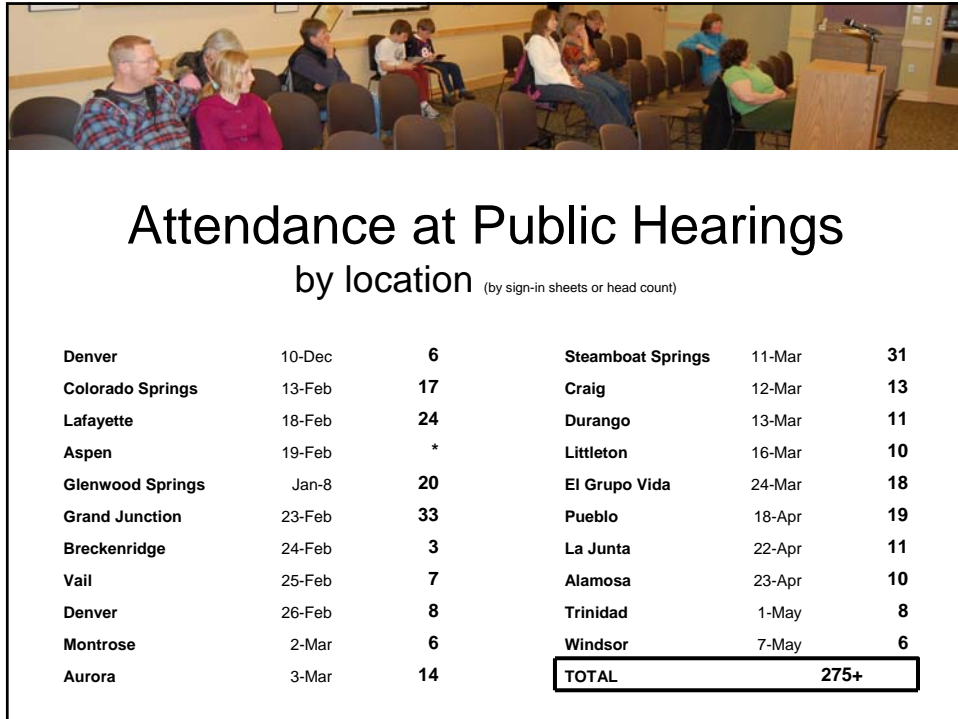
## **Testimony Committee**

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









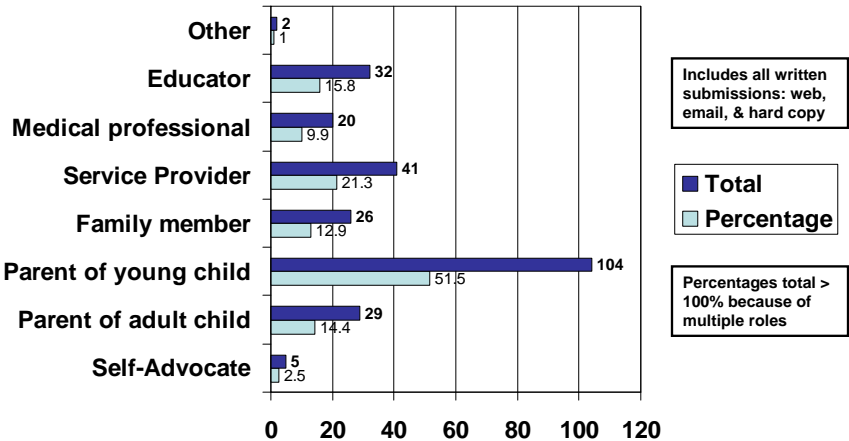


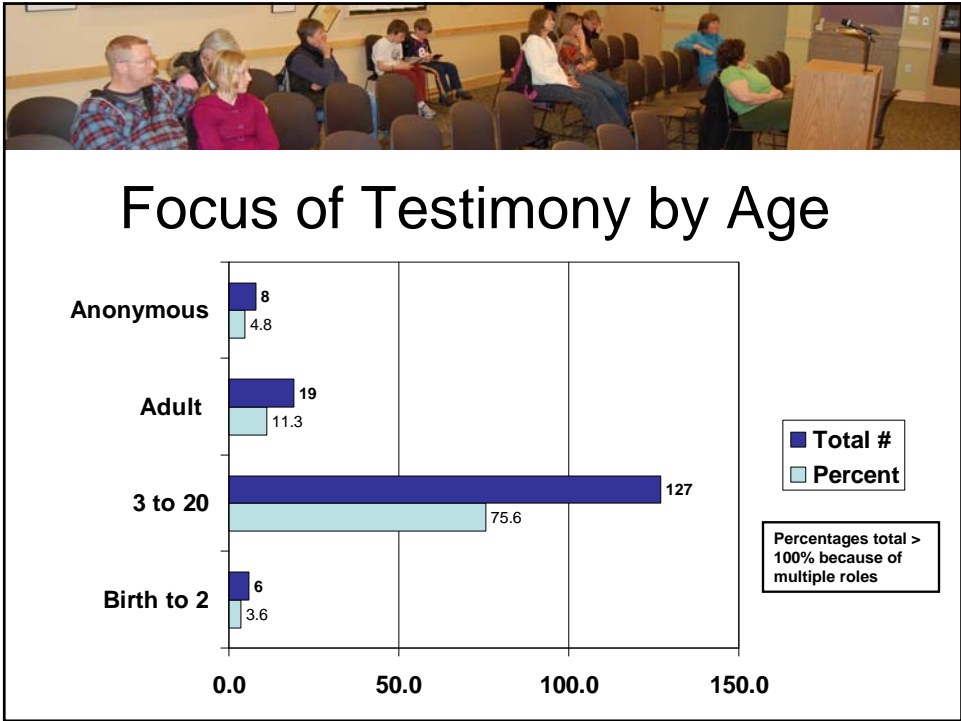
### Written Testimony Submissions by geographic region & community

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



### Written Testimony: Who submitted







## 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 49<sup>th</sup> 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
<b>All Disabilities</b>	<b>72,774</b>

**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.**

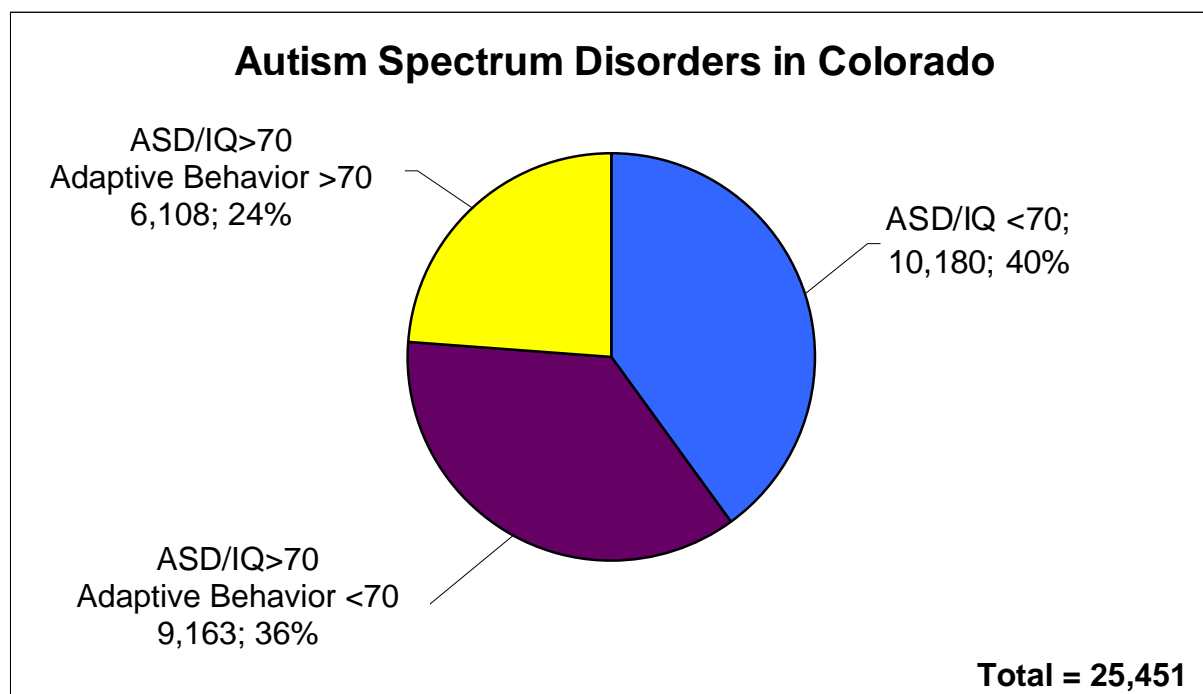
	ALL	ALL ASD	ASD/IQ <70	ASD/IQ <70 Adaptive Behavior <70	ASD/IQ >70 Adaptive Behavior >70
Birth-15 years	917,430	5,429	2,171	1,955	1,302
15-24 years	613,476	3,630	1,452	1,307	871
25-44 years	1,400,850	8,289	3,316	2,984	1,989
45-64 years	953,432	5,642	2,257	2,031	1,354
65+ years	416,073	2,462	985	886	591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

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 Coloradans and their families. The good news is we will at least know the recommendations by November 10<sup>th</sup>. 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](http://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 providers 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:
<ol style="list-style-type: none"> <li>1. Colorado Autism Commission (established by statute to create 10 year strategic plan)</li> <li>2. LEND grant</li> <li>3. Autism Treatment Network</li> <li>4. Autism Society: Speaker series, support groups, childcare for families to attend this events (information and referral)</li> <li>5. Autism Society information and referral program: phone calls, emails, website, newsletter, listserv</li> <li>6. Autism Society respite training to providers and families – working with local colleges &amp; community enrichment</li> </ol>	<p style="text-align: center;"><b>CARE COORDINATION</b></p> <ol style="list-style-type: none"> <li>1. Develop care coordinator associated with evaluation team – a person to walk parents through system (ie., Kaiser)</li> <li>2. Provide appropriate training and resources for care coordinators</li> <li>3. Utilize telemedicine to increase network of care coordinators, physicians, CCB-CM, professional services, parents, ChildFind (work with ABCD, database for all to input)</li> <li>4. Add to Part C – IFSP data fields on diagnosis and transition</li> <li>5. Assess prospects for a common identifier across birth – 21 (evaluation perspective)</li> <li>6. Community groups to educate parents to be care coordinators</li> <li>7. Training efforts addressing long term planning to providers, case managers, educators</li> </ol>	<p style="text-align: center;"><b>CARE COORDINATION</b></p> <ol style="list-style-type: none"> <li>1. Well-informed families able to seek care and advocate</li> <li>2. Communication between collaterals evidenced by inputs in database</li> <li>3. Data to generate specific reports</li> <li>4. Linked data systems</li> <li>5. Quarterly trainings to provider case managers statewide as evidenced by trainings published in central website</li> </ol> <p style="text-align: center;"><b>DIAGNOSIS</b></p> <ol style="list-style-type: none"> <li>6. Well-informed families able to seek care and advocate</li> <li>7. Decreased time between diagnosis and service to 45 days</li> <li>8. Communication between collaterals evidenced by</li> </ol>	<p style="text-align: center;"><b>CARE COORDINATION</b></p> <ol style="list-style-type: none"> <li>1. Training and on-going professional support to create a well educated pool of professionals.</li> <li>2. Develop system for diagnosis and delivery of services</li> <li>3. There will be a centralized source of information regarding ASD and best practices</li> <li>4. Knowing age of diagnosis of ASD (data systems)</li> <li>5. Knowing prevalence of ASD in younger age group (data systems)</li> <li>6. Know geographic distribution of children with ASD (data systems)</li> <li>7. Know what services children with ASD are receiving (data systems)</li> <li>8. Know outcomes for</li> </ol>	<p style="text-align: center;"><b>CARE COORDINATION</b></p> <ol style="list-style-type: none"> <li>1. Children and families receive high quality evidence-based services in a timely manner.</li> <li>2. Global awareness by systems of care to focus on long-term planning at the beginning. Parents will have a roadmap.</li> <li>3. Comprehensive and coordinated interagency system of care with a single point of entry.</li> <li>4. Comprehensive and coordinated financial system to support the services.</li> <li>5. Increased state-wide consistency in service provision</li> <li>6. Have capacity to make data-driven decisions regarding service</li> </ol>

### 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:
<ul style="list-style-type: none"> <li>program that brings providers and families together</li> <li>7. CCMS – Community Contract managements Data System</li> <li>8. MMIS – Medicaid data system</li> <li>9. Results Matter – EI</li> <li>10. ADDM surveillance data</li> <li>11. 619 child count</li> <li>12. 619 Results Matter</li> <li>13. CDPHE newborn hearing and metabolic disease datasets</li> </ul>	<ul style="list-style-type: none"> <li>8. Utilize medical home trainings to educate providers regarding resources for long term planning</li> <li>9. Create a CO ASD online resource to assemble all materials being disseminated and provide one consistent message</li> <li>10. Find funding for CO ASD online resource</li> </ul> <p style="text-align: center;"><b>DIAGNOSIS</b></p> <ul style="list-style-type: none"> <li>11. Develop database for tracking outcomes</li> <li>12. Add to Part C – IFSP data fields on diagnosis and transition</li> <li>13. Assess prospects for a common identifier across birth – 21 (evaluation perspective)</li> <li>14. Explore feasibility of positive reporting of ASD diagnosis by clinical source</li> <li>15. Develop training activities to</li> </ul>	<ul style="list-style-type: none"> <li>inputs in database</li> <li>9. Data to generate specific reports</li> <li>10. Linked data systems</li> <li>11. Younger children are accessing services for ASD</li> </ul> <p style="text-align: center;"><b>DATA</b></p> <ul style="list-style-type: none"> <li>12. Communication between collaterals evidenced by inputs in database</li> <li>13. Data to generate specific reports</li> <li>14. Linked data systems</li> </ul> <p style="text-align: center;"><b>INTERVENTION</b></p> <ul style="list-style-type: none"> <li>15. Well-informed families able to seek care and advocate</li> <li>16. Communication between collaterals evidenced by inputs in database</li> <li>17. Data to generate specific reports</li> <li>18. Linked data systems</li> </ul>	<ul style="list-style-type: none"> <li>children with ASD in Results Matters (data systems)</li> <li>9. Centralized source of information regarding ASD / best practices</li> </ul> <p style="text-align: center;"><b>DIAGNOSIS</b></p> <ul style="list-style-type: none"> <li>10. Training and on-going professional support to create a well educated pool of professionals.</li> <li>11. Develop system for diagnosis and delivery of services</li> <li>12. At time of positive screen, children will be referred for diagnostic assessment to be completed within 30 days</li> <li>13. Positive screen for ASD results in evidence-based early intervention within 45 days</li> <li>14. At the time of a positive</li> </ul>	<ul style="list-style-type: none"> <li>provision</li> <li>7. Have information about cost-effectiveness of EI</li> <li>8. Families and all citizens in CO have access to well-maintained and consistently updated resources for ASD</li> </ul> <p style="text-align: center;"><b>DIAGNOSIS</b></p> <ul style="list-style-type: none"> <li>9. Decreased age at which children with ASD are identified (currently 4.5 years).</li> <li>10. ChildFind teams are knowledgeable and skilled and have the necessary resources to assess children who may be on the spectrum.</li> <li>11. Comprehensive and coordinated interagency system of care with a single point of entry.</li> <li>12. Comprehensive and</li> </ul>

### 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:
	<p>increase ability to diagnose, so time from screening to diagnosis is shorter)</p> <p>16. Develop training programs to increase the # people ADOS trained</p> <p>17. Increase collaboration between PCP, ChildFind, and dx centers</p> <p>18. One-day course in ASD screening, billing, telephone follow-up</p> <p>19. Explore STAT training</p> <p>20. Implement screening in resident training programs</p> <p>Lectures to trainees in Medicare, PNP's, Pas</p> <p style="text-align: center;"><b>DATA</b></p> <p>21. Develop database for tracking outcomes</p> <p>22. Add to Part C – IFSP data fields on diagnosis and transition</p> <p>23. Assess prospects for a common identifier across birth – 21 (evaluation perspective)</p>	<p>19. Younger children are accessing services for ASD</p> <p>20. Expand waiver services to cover all children on waiting list</p> <p>21. Determine a plan to evaluate effectiveness / look at existing methods of evaluation (Results Matter data)</p> <p>22. Providers will be more supported, have a higher skill level, fewer referrals to outside sources or children will experience more inclusive opportunities</p> <p style="text-align: center;"><b>SCREENING</b></p> <p>23. Well-informed families able to seek care and advocate</p> <p>24. Decreased time between diagnosis and service to 45 days</p> <p>25. Communication between collaterals evidenced by</p>	<p>screen, children will be referred for diagnostic assessments, and these assessments will be completed within 30 days</p> <p>15. There will be a centralized source of information regarding ASD and best practices</p> <p>16. Knowing age of diagnosis of ASD (data systems)</p> <p>17. Knowing prevalence of ASD in younger age group (data systems)</p> <p>18. Know geographic distribution of children with ASD (data systems)</p> <p>19. Know what services children with ASD are receiving (data systems)</p> <p>20. Know outcomes for children with ASD in Results Matters (data systems)</p> <p>21. Centralized source of information regarding</p>	<p>coordinated financial system to support the services.</p> <p>13. Increased state-wide consistency in service provision</p> <p>14. Have capacity to make data-driven decisions regarding service provision</p> <p>15. Have information about cost-effectiveness of EI</p> <p>Ensure accuracy and fidelity of ASD diagnosis</p> <p style="text-align: center;"><b>DATA</b></p> <p>16. Comprehensive and coordinated interagency system of care with a single point of entry.</p> <p>17. Comprehensive and coordinated financial system to support the services.</p> <p>18. Increased state-wide</p>

### 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:
	<p style="text-align: center;"><b>INTERVENTION</b></p> <p>24. Legislation for insurance carriers to cover ASD</p> <p>25. Explore stimulus funding opportunities to support these outcomes</p> <p>26. Develop revisions to Autism Waiver</p> <p>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</p> <p>28. Coordinate collaboration between health and education approaches to ASD intervention – articulate position and principles of how these systems can work together</p> <p>29. Coordinate support and advocacy for consistent inclusion of specialized</p>	<p>inputs in database</p> <p>26. Data to generate specific reports</p> <p>27. Linked data systems</p> <p>28. Younger children are accessing services for ASD</p> <p>29. Track how often 96110 is used to bill for screening</p> <p>30. Track how many individuals visit dissemination booths</p> <p>31. Track how many attend ABCD trainings</p> <p>32. Track how many attend one-day trainings (activity #4)</p>	<p>ASD / best practices</p> <p>ASD diagnosis made by age 2.5 years</p> <p style="text-align: center;"><b>DATA</b></p> <p>22. Knowing age of diagnosis of ASD (data systems)</p> <p>23. Knowing prevalence of ASD in younger age group (data systems)</p> <p>24. Know geographic distribution of children with ASD (data systems)</p> <p>25. Know what services children with ASD are receiving (data systems)</p> <p>26. Know outcomes for children with ASD in Results Matters (data systems)</p> <p>27. Centralized source of information regarding ASD / best practices</p> <p style="text-align: center;"><b>INTERVENTION</b></p>	<p>consistency in service provision</p> <p>19. Have capacity to make data-driven decisions regarding service provision</p> <p>20. Have information about cost-effectiveness of EI</p> <p style="text-align: center;"><b>INTERVENTION</b></p> <p>21. Children and families receive high quality evidence-based services in a timely manner.</p> <p>22. Comprehensive and coordinated interagency system of care with a single point of entry.</p> <p>23. Comprehensive and coordinated financial system to support the services.</p> <p>24. Informed decision-making regarding appropriate levels of</p>

**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.**

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

**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.**

<b>Resources</b>	<b>Activities</b>	<b>Outputs</b>	<b>Short &amp; Long-Term Outcomes</b>	<b>Impact</b>
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, Cinco 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

**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.**

<b>Resources</b>	<b>Activities</b>	<b>Outputs</b>	<b>Short &amp; Long-Term Outcomes</b>	<b>Impact</b>
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:
	<p>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.</p> <p>43. Work on dissemination to Spanish-speaking populations via radio, other venues</p> <p>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</p> <p>45. Outreach to licensed and unlicensed child care, day care, preschools, other early educators</p> <p>46. Support pediatric practice with information &amp; referrals to provide parents when screening indicates further evaluation is recommended</p> <p>47. Develop database for tracking outcomes</p>		<p>emotional competence and inclusion within one year</p> <p align="center"><b>SCREENING</b></p> <p>42. Extend SB 4 to include services for children as they get older</p> <p>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</p> <p>44. At time of positive screen, children will be referred for diagnostic assessment to be completed within 30 days</p> <p>45. Positive screen for ASD results in evidence-based</p>	

### 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	



**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.**

<b>Resources</b>	<b>Activities</b>	<b>Outputs</b>	<b>Short &amp; Long-Term Outcomes</b>	<b>Impact</b>
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	

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. <a href="http://www.chadis.com">www.chadis.com</a>	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.

## **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:

# **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.

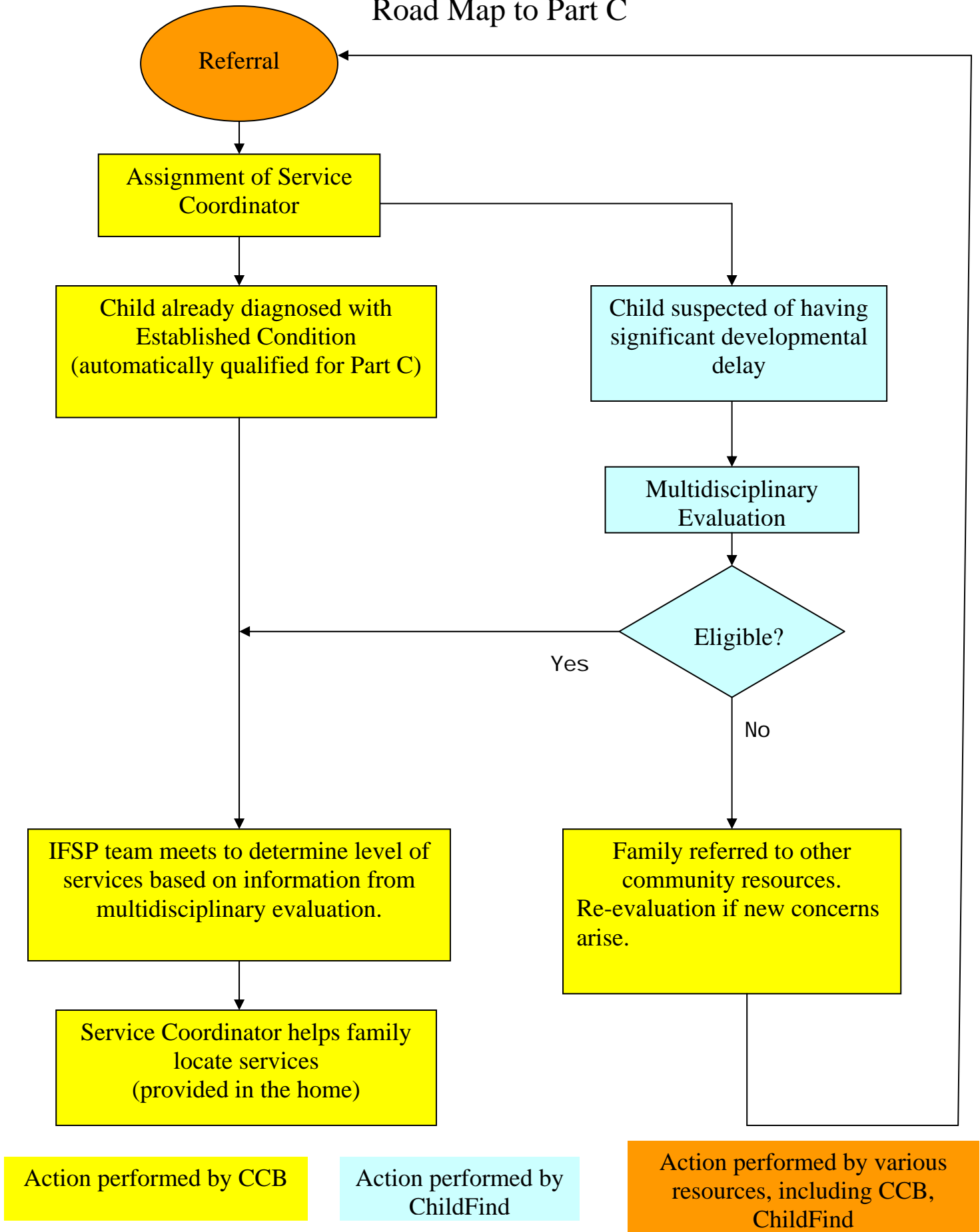
### **Family Involvement**

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

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

## 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-occurring 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-occurring 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	Need
------	------

- |  |   |
|--|---|
| <ul style="list-style-type: none"><li>• Psychiatric Dx in ASD*<ul style="list-style-type: none"><li>– Anxiety – 40%</li><li>– ADHD - 31-52%</li><li>– Depression - 14-25%</li><li>– Bipolar – 3-9%</li></ul></li><li>• Lack of Specialists with expertise in both ASD and Psychiatric Disorders</li><li>• Lack of Guidelines</li></ul> | <ul style="list-style-type: none"><li>• <b>Training</b> in management of co-morbid psychiatric conditions</li><li>• Autism Center for quick dissemination of new guidelines/treatment</li><li>• <b>Tele-health</b> services for rural areas</li><li>• Care coordination</li></ul> |
|--|---|

\*Leyfer 2006 and IAN Exchange

## MENTAL HEALTH SERVICES

Have	Need
------	------

- |   |   |
|---|---|
| <ul style="list-style-type: none"><li>• Autism Bill-Yay!! But lack of providers</li><li>• DDRC has behavior/ pharmacology team for Jefferson County</li><li>• Aurora Mental Health has a team for individuals with ASD</li><li>• BHO's are starting to have training in ASD</li></ul> | <ul style="list-style-type: none"><li>• Facilitation of Training of behavioral specialists</li><li>• Funding/infrastructure for CCB teams</li><li>• Increase Funding and Training in ASD for BHO's</li><li>• Infrastructure to track outcomes</li></ul> |
|---|---|

## MENTAL HEALTH SERVICES

Have	Need
------	------

- |   |   |
|---|---|
| <ul style="list-style-type: none"><li>• <b>Few Inpatient Beds</b></li><li>• <b>ASD with Cognitive Disability</b><ul style="list-style-type: none"><li>– 3 overnight beds</li><li>– 8 day treatment beds</li><li>– all are at TCH</li></ul></li><li>• <b>High functioning ASD</b><ul style="list-style-type: none"><li>– 3 beds at 3 different hospitals</li></ul></li></ul> | <ul style="list-style-type: none"><li>• <b><u>Training</u></b> for management of co-morbid psychiatric conditions</li><li>• Quick dissemination of new treatments</li><li>• <b>INPATIENT and DAYTREATMENT BEDS!</b></li></ul> |
|---|---|

## MENTAL HEALTH SERVICES

Have	Need
------	------

- |   |   |
|---|---|
| <ul style="list-style-type: none"><li>• No Crisis Intervention</li><li>• CES Waiver-long wait list</li><li>• Children's Habilitative Residential Program<ul style="list-style-type: none"><li>– No fault dependency and neglect</li><li>– Innovations for Children-Child Placement Agency</li></ul></li></ul> | <ul style="list-style-type: none"><li>• Autism Center to plan and implement system for in home/ out of home crisis intervention and prevention.</li><li>• <b>FUNDING and INFRASTRUCTURE!</b></li><li>• End Wait Lists</li></ul> |
|---|---|

## 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-occurring 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.	<p>Access to sedation and coordination of procedures for children with ASD.</p> <p>Adequate reimbursement for time to examine children.</p> <p>Funding for space that is sensitive to the needs of children with ASD.</p>
<p>University based training programs in Internal Medicine and Family Practice. (No ASD specific training for adults)</p> <p>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 <a href="http://www.cms.hhs.gov/center/fqhc.asp">www.cms.hhs.gov/center/fqhc.asp</a></p> <p>Physician trained in both internal medicine and pediatrics at Kaiser sees individuals with disabilities.</p> <p>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</p>	<p>Transition Services and PCP's for adults with ASD.</p> <p>Incorporate training in management of individuals with ASD into training programs for Internal Medicine and Family Practice.</p> <p>Support for clinics for adults with ASD. Need coordinators and social workers.</p> <p>Need for access to specialists.</p> <p>Need for access to patient oriented hospital services such as radiology and phlebotomy. This is a huge issue for adults.</p> <p>Coordination of care under anesthesia.</p> <p>Dental Care for adults with ASD. There are fewer providers for adults than for children.</p>	<p>Funding for transition services.</p> <p>Funding for training programs to address medical needs of adults with ASD.</p> <p>Funding for clinics for adults with ASD. Most have Medicaid, at least as backup, but some may be underinsured.</p> <p>Address need for specialists who take Medicaid.</p> <p>Training in patient centered/family centered care and funding for coordination of care.</p> <p>Funding for space and time to work with individuals with ASD.</p>

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

		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.
<p>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.</p> <p>Adams County has an in home crisis intervention program.</p> <p>DDRC has a behavior/ pharmacology team that is funded by Mill Levy money in Jefferson County.</p>	<p>Crisis Intervention: Hospital Based and Pre-Hospital/In Home</p> <p>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</p>	<p>An Autism Center to plan and implement a system for in home/and out of home crisis intervention and ongoing management and prevention.</p> <p><b>FUNDING and INFRASTRUCTURE!</b></p> <p>Awareness, training, funding for evaluation of possible medical/dental issues impacting behavior.</p>
<p><b>Inpatient Beds for Psychiatric Hospitalization in Colorado for Children with ASD</b></p> <p><b>ASD with Cognitive Disability – 3 overnight beds and 8 day treatment beds – all are at TCH</b></p> <p><b>High functioning ASD– 2 beds, 1 bed each at any given time at</b></p>	<p>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.</p>	<p>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</p>



Cedar Springs and Denver Health		inappropriate for a child with ASD. <b>This requires funding and training.</b>
<b>Inpatient Beds for Psychiatric Hospitalization in Colorado for Adults with ASD</b>  <b>None specifically for ASD.</b>		<b>Inpatient Psychiatric Beds for Adults with ASD</b>
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 –

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

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 fa-

cilitate 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 facili-

tated 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.

- **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

Joan B. Beasley is founder and former Director of the Sovner Center, Danvers, Massachusetts. She may be reached at 617/469-7391 or [jbbbeasley@rcn.com](mailto:jbbbeasley@rcn.com).

## 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 through 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 of **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...](#)

### Program Staff & Contacts

For more information about the **START** model, consultation, and training, contact:

Joan B. Beasley, PhD  
 Director, Center for **START** Services  
[joan.beasley@unh.edu](mailto:joan.beasley@unh.edu)  
 Institute on Disability / UCED  
 56 Old Suncook Road, Suite 2  
 Concord, NH 03301  
 Phone: 617.469.7391  
 Fax: 603.228.3270

Linda Bimbo, MS  
 Deputy Director, Institute on Disability  
[linda.bimbo@unh.edu](mailto:linda.bimbo@unh.edu)  
 Institute on Disability / UCED  
 56 Old Suncook Road, Suite 2  
 Concord, NH 03301  
 Phone: 603.228.2084  
 Fax: 603.228.3270

## **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 cited 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.