Department of Regulatory Agencies

2009 Annual Report

Of The

Commission on Mandated Health Insurance Benefits

To The

Colorado General Assembly

December 1, 2009

Colorado Commission on Mandated Health Insurance Benefits

Annual Report to the General Assembly
December 1, 2009

Introduction

The Commission on Mandated Health Insurance Benefits was created through the enactment of Senate Bill 03-068, sponsored by Senator Hagedorn and Representative Brophy. The Commission is charged with reviewing existing and proposed health benefit mandates for their impact on individuals, employers and health insurers. The statutory authority for the Commission is found at Colo. Rev. Stat. §10-16-103.3.

In 2004, the Commission adopted the following mission statement, consistent with the enabling legislation, as a guide to its work:

> *To serve the people of Colorado and the State Legislature by providing objective information and recommendations on the impact and structure of current and proposed health insurance mandated benefits.*

Commission Membership

The Commission's membership is set by statute. Colo. Rev. Stat. §10-16-103.3(1)(a)(III) provides that the Governor appoint members representing the following groups:

- An employee of the Division of Insurance
- A representative of the health insurance industry
- A representative of a health maintenance organization
- Two health care providers
- Two citizen members – one with an interest in mandated health insurance benefits, and one representing a consumer health advocacy group
- Two members who are business owners with less than 50 employees, one from Denver and one from a rural area

Two legislators, one each from the House and Senate, and members of the Business Affairs and Labor Committees are appointed by the legislative leadership. Colo. Rev. Stat. § 10-16-103.3(1)(a)(I and II). All members of the Commission are appointed for five year terms. Colo. Rev. Stat. §10-16-103.3(1)(b).

As all of the terms of prior Commission members terminated on August 1, 2008, Governor Ritter appointed members to the Commission by Executive Orders A-031-09, A-043-09, and A-044-09 on February 3, 2009. The House and Senate legislative members were appointed by their respective leaders. A list of the current Commission membership is attached at Appendix A and is available on the Division of Insurance's website at http://www.dora.state.co.us/insurance/meet/MHBC/MHB.htm.

The Commission functioned without a chair for 2009 with Leo Tokar, as the former vice-chair and Deputy Insurance Commissioner for Consumer Affairs Peg Brown assuming the leadership responsibilities to organize and conduct the meetings. Colo. Rev. Stat. §10-16-103.3(1)(c).

Processes and Procedures

Pursuant to the provisions of Colo. Rev. Stat. §10-16-103.3(6) and Senate Joint Resolution 05-04, the legislative chairs of committees having jurisdiction over proposed legislation containing health insurance mandates are to request the Commission study and assess the social and financial impact of a proposed mandate and forward the Commission's findings to the committee prior to the initial hearing of the bill.

In 2009, two bills were referred to the Commission for consideration: SB09-159, Concerning the Mandatory Offer of Dependent Coverage to an Unmarried Child and SB09-244, Concerning Health Insurance Benefits for the Treatment of Autism Spectrum Disorders. The Commission met on SB09-159 on February 13, 2009 and issued its report on February 17, 2009. *See* Appendix B attached. The Commission met on SB09-244 on March 20, 2009 and issued its report on that bill on March 30, 2009. *See* Appendix C attached.

The Commission also met one other time during 2009 on March 6, 2009 to orient new Commission members to the responsibilities and operations of the Commission. Copies of the Minutes of the Commission's meetings are attached as Appendix D. The Commission also sent a letter to the legislative leadership concerning the Commission’s appointment and operations. A copy of this letter is attached as Appendix E. Copies of all Commission documents are available on the Division of Insurance website at: http://www.dora.state.co.us/insurance/meet/MHBC/MHB.htm.

Future

Pursuant to the continuation of the Commission enacted in 2005, the Commission will sunset on July 1, 2010 unless it is continued by the Colorado General Assembly. Commission members recognize that there is some controversy about whether the Commission should exist, how it is structured and operates, and whether it provides value to the General Assembly and the public. The Commission urges full and fair discussion of the issues involved and looks forward to their resolution.

Appendix A

Roster of Commission Members

Commission on Mandated Health Insurance Benefits

Membership Categories from CRS 10-16-103.3(1)(a)	
Member of Senate Business Affairs and Labor Committee	The Honorable Lois Tochtrop Colorado State Senate 200 East Colfax, Room 346 Denver, CO 80203
Member of House Business Affairs and Labor Committee	The Honorable Christine Scanlan Colorado House of Representative 200 East Colfax, Room 271 Denver, CO 80203
Employee of the Division of Insurance	Peg Brown Deputy Commissioner for Consumer Affairs 1560 Broadway, Suite 850 Denver, CO 80202 303-894-7501 Peg.Brown@Dora.state.co.us
Representative of the Health Insurance Industry	Molly McCoy Attorney Anthem Blue Cross and Blue Shield 700 Broadway Denver, CO 80273
Representative of a Health Maintenance Organization	Leo Tokar Vice President – Marketing, Sales and Business Development Kaiser Permanente 10350 E. Dakota Avenue Denver, CO 80247
Representative of Health Providers	Whitney Kennedy, M.D. Family Practice Physician 4104 Tejon Street Denver, CO 80211
Representative of Health Providers	Pam Nicholson Senior Vice President – Strategic Integration Centura Health 188 Inverness Drive W. Suite 500 Englewood, CO 80112

Private citizen with an interest in mandated health insurance benefits	Ranmali Bopitiya Caplan and Earnest LLC 1800 Broadway, Suite 200 Boulder, CO 80302-5289
Representative of a consumer health advocacy group	Wanda Cason 1812 CR 119 Hesperus, CO 81326
Business owner with less than 50 employees – Denver	
Business owner with less than 50 employees -- Rural	Leo Mailander Unique Realty and Subway Sandwiches 143 S. Campbell Avenue Holyoke, CO 80734

Appendix B

Report on SB09-159
Concerning the Mandatory Offer of Dependent Coverage to an Unmarried Child

Commission on Mandated Health Insurance Benefits

Review of

SB09-159 – Concerning the Mandatory Offer of Dependent Coverage to an Unmarried Child

February 13, 2009

Introduction

The Commission on Mandated Health Insurance Benefits exists to serve the people of Colorado and the Colorado General Assembly by providing objective information and recommendations on the impact and structure of current and proposed health insurance mandated benefits.

On February 13, 2009, the Commission met to review SB09-159 – Concerning the Mandatory Offer of Dependent Coverage to an Unmarried Child. The bill was referred to the Commission on February 4, 2009 by Senator Betty Boyd, Chair of the Senate Health and Human Services Committee.

Commission members Molly McCoy, Whitney Kennedy and Peg Brown were present at the meeting with Wanda Cason, Leo Mailander, and Leo Tokar participating by telephone conference call.

Senator Paula Sandoval attended the Commission meeting. Also in attendance at the meeting were: Clay Vigoda, lobbyist; Ben Price, Colorado Association of Health Plans, Denise DePercin, Colorado Consumer Health Initiative; and Jerry McElroy, Kaiser Permanente.

Senator Sandoval presented the bill to the Commission, providing the Commission with the assessment form as attached.

Background

Current Colorado Law

Current Colorado law requires individual and group (both small and large group) health benefit plans (other than individual health plans issued by nonprofit hospital, medical-surgical and health service corporations, and health maintenance organizations) that offer dependent coverage to offer to the parent, for an additional premium if applicable, by rider or supplemental policy provision, the same dependent coverage for an unmarried child who is under twenty-five years of age, who does not meet the definition of dependent as defined by C.R.S. §10-16-102(14)[1], if the child has the same legal residence as the parent or if the child is financially dependent on the parent. This provision of statute, C.R.S. 10-16-104.3, was enacted in 2005 as HB05-1101.

The Division of Insurance issued "Frequently Asked Questions" (FAQs) in 2005 as HB05-1101 was being implemented. A copy of these FAQs is attached. It should be noted that in the FAQs the Division of Insurance identified and answered several technical issues which were raised in the discussion on February 13, 2009 including: How financial dependency is determined, what plans are included in the mandatory offer, when must the offer be made, etc.? It is anticipated that these FAQs and the interpretations therein would be carried forward if the subject legislation would be enacted as currently structured.

SB09-159 Provisions

SB09-159 would increase the age for the mandatory offer of coverage under C.R.S. 10-16-104.3 from under age 25 to under age 30 and have such provision take effect on January 1, 2010.

New Federal Law – Michelle's Law

A new federal law was enacted October 9, 2008 which intersects with the current age 25 and proposed age 30 provisions. Public Law 110-381, known as Michelle's Law, requires that individual and group (both small and large) health plans which provide coverage to a dependent child enrolled in a postsecondary educational institution to continue medical coverage due to a medically necessary leave of absence for up to one year or upon such date as the coverage would otherwise terminate. A "medically necessary leave of absence" is defined by federal law as:

> . . . a leave of absence of such child from a postsecondary educational institution . . . or any other change in enrollment of such child at such institution, that
>
> (1) commences while such child is suffering from a serious illness or injury;
> (2) is medically necessary; and
> (3) causes such child to lose student status for purposes of coverage under the terms of the plan or coverage.

See 29 U.S.C. §1185c(a) of the Employee Retirement and Income Security Act (ERISA) and 42 U.S.C. §300gg-7(b)(2) of the Public Health Service Act (PHSA).

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[1] C.R.S. 10-16-102(14) defines "dependent" as "a spouse, an unmarried child under nineteen years of age, an unmarried child who is a full-time student under twenty four years of age and who is financially dependent upon the parent, and an unmarried child of any age who is medically certified as disabled and dependent upon the parent.

The requirements of Michelle's law are to be put in place by plans beginning October 9, 2009 and it is recommended that Colorado statute be amended to indicate that any dependent coverage tied to student status based on enrollment in a postsecondary educational institution may not be terminated for one year or upon the date such coverage would otherwise terminate if the child takes a medically necessary leave of absence. It is further recommended that the statutory change include a definition of "medically necessary leave of absence" consonant with the federal definition.

Social Impact

It is generally recognized that young adults between the ages of 19 and 29 inclusive represent one of the largest and most rapidly growing segments of the U.S. population lacking health coverage. According to the National Conference of State Legislatures, young adults account for over 13 million of the nearly 47 million Americans living without health coverage. They calculate that approximately 30% of the population between age 19 and 29 are uninsured. Among the reasons given for this are: "aging off" their parent's coverage at age 19 or when they graduate from college; employment in positions without health coverage; and/or serial employment in temporary, part-time, or seasonal work in which they do not qualify for an employer-provided health plan.

American society appears also to be changing in that an increasing proportion of young adults continue to live with their parents, and are delaying marriage and becoming parents until their late 20s or early 30s. Many of these young adults are in school part-time and working part-time, not eligible for health coverage at their work, and don't currently qualify for continued coverage under their parent's policies. Individual health coverage, which can be underwritten on health status, may be an option for this segment of the market, but the take-up of this type of coverage is limited. Individual health plans providing relatively lower cost coverage to healthy persons in this age segment are available, though may not be utilized as broadly as desired by public policy makers due to lack of education about and prioritization of health coverage in a young adult's management of their life. Young adults who believe they will never fall victim to adversity often fail to recognize, seek out and obtain insurance coverage against such eventualities.

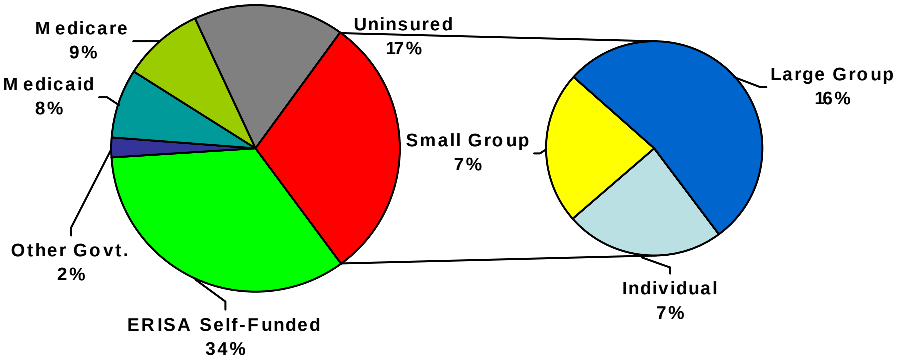
It should also be noted that young adults in this age group do not generally qualify for a governmental health care program (Medicare, Medicaid, etc.) without a disabling condition or a special status (pregnancy) which would qualify them for such program. Without health care coverage, a 2002 study found that over 40% of uninsured adults postponed seeking medical care, 28% said they needed but did not get medical care, and another study showed that uninsured adults were 30% more likely to forgo preventive care and did not have a medical checkup in the previous year.

While the age group of 19 to 29 is among the healthiest as a group, an unforeseen medical condition, accident, or emergency (particularly if life-threatening) to anyone uninsured may result in a life-long financial burden. Moreover, a key contributor to the rising cost of health care is the cost of caring for the uninsured according to the Colorado Blue Ribbon Commission for Health Care Reform Final Report.

Financial Impact

Senator Sandoval stated that her intent with this legislation is that the additional cost be borne entirely by the parents. She presented information from the Commonwealth Fund that expanding dependent coverage on family policies to age 23 would increase premium by 3 to 5 percent. Kaiser Permanente indicated that for those groups which took up the offer under HB05-1101 to age 25, the additional premium cost was 5% more. If the cost had been spread across all groups, the increase would have been 1%. Mr. McElroy noted problems which had been encountered in implementing the expansion to age 25 under HB05-1101 to include: Employers were not happy about having to modify their health coverage to offer to an employee's qualifying children up to age 25 and that employers found the addition hard to administer, including changing systems to determine who had dependents eligible for coverage and who had elected coverage. He further noted that in the large group market, state requirements provide incentive to employers to self-fund their health benefits and avoid all state requirements.

As demonstrated in the chart below, SB09-159 would only affect approximately 30 % of the Colorado marketplace under the jurisdiction of the Division of Insurance comprised of the 16% of the marketplace in commercial large group plans, 7% in Colorado small group plans, and 7% in individual coverage regulated by Colorado. SB09-159 would not reach the 34% of the Colorado marketplace covered by ERISA self-funded plans, or the 19% covered by government (federal and state) programs.



For individual and large group plans, the current structure of underwriting may permit incorporation of young adults under a family coverage in that the premiums are not constrained by statutory rating factors. In these market segments, a young adult could be covered by payment of determinable additional premium for a supplemental policy provision or rider as under current law. However, in the Colorado small group market, carriers are limited to certain demographic characteristics for determination of premium rates. If a carrier uses family size to calculate premium rates, it is required to use only the four categories listed below:

- One adult;
- One adult and any children;
- Two adults; and
- Two adults and any children.

See C.R.S. 10-16-102(10)(b)(III) and Colorado Insurance Regulation 4-6-7, Section 5(A)(3)(c). Thus, under this statutory structure, a carrier arguably could not increase the premium to provide coverage for a 25 to 29 year old in their parent's home with two younger siblings.

Two states have enacted general expansions of health coverage to age 30, New Jersey in 2005 and effective in 2006, and Florida effective October 1, 2008. The Florida statute "permits young adults who would otherwise qualify for coverage under a parent's employer's group health benefits plan to be covered as an 'over-age' dependent until age 30 if the eligibility standards are met." According to the sponsor of SB09-159, when the up-take of New Jersey's program was last measured, it provided coverage for an additional 10,000 out of a total regulated commercial market of 2.4 million.

The New Jersey requirement is different than that proposed in Colorado in that it is limited to employer group coverage. It may also be different in that it permits an "over-age" dependent to join their parent's coverage with evidence of "prior creditable coverage" or evidence of receipt of benefits, rather than just continue on the coverage after they would otherwise "age-off." SB09-159 does not address this circumstance. Under the Florida law, the young adult (not the parent) may be charged up to 102% of the "rate attributable to child dependents for the employer's group" or approximately 20 to 40% less than the single employee's rate.

Senator Sandoval reported that New Jersey has proactively sought to collect information about any negative impacts or unintended consequences of their law, but none have been reported. However, a Commission member noted that the Colorado proposal may provide some incentive for adverse selection by "unhealthy" young adults who would be subject to medical underwriting in Colorado's individual health coverage market. It should also be noted that Illinois has expanded coverage for dependents under their parent's policy for veterans until their 30th birthday. Both the Florida and Illinois laws are too new to assess whether there are problems or unintended consequences from them.

Medical Efficacy

It was noted earlier in this report that the uninsured postpone getting care and that approximately 30% of the uninsured forgo preventive care. While the 19 to 29 age group is relatively among the healthiest, they are not without preventive care needs. Of particular note are the newer vaccine available for human papilloma virus (HPV) which prevents some cervical cancers, and the increased incidence of diabetes and pre-diabetes in the population.

Balance

The proportion of the population which does not have adequate health coverage is a concern for policymakers and citizens. With a substantial proportion of this population being young and relatively healthy, and a changing societal structure of continued "dependency" on parents past the age historically recognized, SB09-159 is intended to build on the previous expansion of HB05-1101. In this, it could provide needed coverage to a substantial group of the uninsured.

However, such expansion is not without some cost, estimated to be about 1% across the board or 5% for those groups which would selectively choose the coverage. The true cost to carriers and families in the small group market is difficult to gauge because of the rate-setting requirements of state law. No information was provided on the cost in the individual or large group markets, except that individual coverage is available for relatively lower cost though it may not be available, except for higher cost through CoverColorado, for those with existing medical conditions. Some on the Commission would like to see expanded education efforts to encourage this population segment to seek and obtain health coverage and make it a higher priority in their management of their life.

If the intent of the legislation is to have the parents pay for the full cost of adding or continuing their young adult children on their policy, changes must be made in the small group statutes to permit this. However, such changes may not be without opposition as they will result in some administrative cost added onto employers and in a system with decreasing ability to absorb and reflect additional costs.

Recommendations

The Commission commends Senator Sandoval for trying to address the problem of the uninsured. If the intent is that the parent's pay the full marginal cost of coverage for adding a young adult child onto their coverage, changes must be made to the small group laws to accomplish this. Otherwise, the laws as they currently exist require that the additional cost is spread across all members of those groups who choose the coverage. Further, it may be worthwhile to investigate whether employers will be able to accommodate the administrative implementation of this legislation as currently written or whether individual coverage may be a more effective means to target this population.

The Division of Insurance would further respectfully request inclusion of provisions to make the changes to Colorado law to comply with the requirements of Michelle's Law.

Appendix C

Report on SB09-244
Concerning Health Insurance Benefits for the Treatment of Autism Spectrum Disorders

Commission on Mandated Health Insurance Benefits

Review of

SB09-244 – Concerning Health Insurance Benefits for the Treatment of Autism Spectrum Disorders

March 20, 2009

Introduction

The Commission on Mandated Health Insurance Benefits exists to serve the people of Colorado and the Colorado General Assembly by providing objective information and recommendations on the impact and structure of current and proposed health insurance mandated benefits.

On March 20, 2009, the Commission met to review SB09-244 – Concerning Health Insurance Benefits for the Treatment of Autism Spectrum Disorders. The bill was referred to the Commission on March 9, 2009 by Senator Betty Boyd, Chair of the Senate Health and Human Services Committee.

Commission members Whitney Kennedy, Leo Mailander and Peg Brown were present at the meeting with Wanda Cason, Molly McCoy, and Ranmali Bopitiya participating by telephone conference call. Senator Brandon Shaffer attended the Commission meeting. Also in attendance at the meeting were: Betty Lehman, Colorado Autism Commission; Denise DePercin, Colorado Consumer Health Initiative; Rosalie Byrd, Provider; Ben Price, Colorado Association of Health Plans; Susan Cox and Dr. Jandell Allen-Davis, Kaiser Permanente; Beth Dickhaus, Hall and Evans; Linda Daniel, Rocky Mountain Health Plans; Edie Sonn, Colorado Medical Society; and Ken Gordon.

Senator Shaffer presented the bill to the Commission. He requested that Betty Lehman review for the Commission the assessment form (Attachment A). In addition, Rosalie Byrd provided comments to the Commission based on her experience as a provider of services. Susan Cox and Dr. Jandell Allen-Davis presented testimony and information to the Commission in opposition to certain provisions within the legislation.

Medical Efficacy

Autism Spectral Disorders (ASD) are a group of biologically based neurodevelopmental disorders characterized by impairments in socialization, communication and behavior. The United States Center for Disease Control along with the American Academy of Pediatrics initiated the “Learn the signs- act early” campaign along with the ALARM initiative: A- Autism is prevalent; L-Listen to parents; A-Act early; R-Refer; M-Monitor. Prevalence of ASD is estimated to be 1 in 150 to 1 in 500 children. Early signs can be seen before 18 months in some cases.

The American Academy of Neurology recommends that children who fail developmental screening, especially in language and social areas undergo autism-specific screening that can be done at the primary care level. If autism-specific screening is positive then the child should be referred for specialty evaluation and intervention. Referral for intervention services should not be delayed pending specialty evaluation and confirmation of diagnosis. Once the diagnosis is made, patients and families will need ongoing support and medical management.

Although there is no “cure” for ASD and no consensus regarding the optimal intervention strategies, early diagnosis and treatment have the potential to affect outcomes particularly in management of behavior, functional skills and communication. Practical and ethical factors have made it challenging to evaluate intervention programs in randomized, controlled trials. This is particularly due to the fact that control groups are hard to define since it is considered unethical to provide a group with no treatment. Despite the lack of evidence from randomized, controlled trials, it is the general consensus of the professional community and therefore standard-of-care that children with ASD participate in therapeutic programs as early as possible.

Based on their review of the available evidence, the National Academy of Science Committee on Educational Interventions for Children with Autism and the New York Clinical Practice Guidelines recommend specialized, intensive early educational intervention for children with ASD.

The core features of successful autism educational programs include:

- A high staff-to-student ratio of 1:1 or 1:2
- Individualized programming for each child

- Teachers with special expertise in working with children with autism
- A minimum of 25 hours per week of services
- Ongoing program evaluation and adjustment
- A curriculum emphasizing attention, imitation, communication, play, and social interaction
- A highly supportive teaching environment
- Predictability and structure
- Functional analysis of behavior problems
- Transition planning
- Family involvement

Early identification facilitates earlier education planning, provisions for family support, management of family stress and delivery of appropriate medical care and treatment for associated conditions. Early identification is also critical for providing timely and accurate genetic counseling before the conception of a second child.

The child is not the only one who suffers medically without appropriate diagnosis and treatment coverage. In 2007 the Kennedy Krieger Institute launched the Interactive Autism Network, an autism registry. It found that 46% of mothers who had children with autism reported diagnoses of depression compared to the 20% of women in the population as a whole who report this diagnosis. With all of the family's focus and money being spent on the child with ASD, the health of others in the family are likely to decline secondary to stress, decreased focus on preventive services and lifestyle and lack of funds.

There certainly is a large medical component to ASD. Other diseases that consume similar resources are, for example, Down Syndrome and Alzheimer disease. These diseases currently have medical coverage for a large part of their treatment. As with many complex diseases, treatment regimens and standard of care will change over time. Defining the exact treatments that will be covered would be difficult to do at any one point in time, although generally it is agreed by Commission members that treatments should be based on objective medical evidence. The bill appears to give adequate flexibility in terms of broad categories of treatment, although the bill as presented does not limit required coverage to evidence-based treatments. Certainly defining the credentialing of the medical provider is very important. What ultimately will and will not be covered usually comes down to a complex interaction between carriers, physicians and the medical literature. There is concern that the bill as presented may establish exceptions to the current appeals processes (including independent external review) required by statute and regulation.

There doesn't appear to be any dispute that autism spectral disorders are medically, economically and socially devastating for the patient, family and society as a whole if not diagnosed and treated appropriately. Currently the average age of diagnosis of autism in Colorado is 5 years and 2 months. The US Centers for Disease Control and the American Academy of Pediatrics cannot hope to be successful with their early identification initiatives unless there is adequate access to affordable diagnosis and treatment. No physician likes to suspect or screen for a disease that doesn't have economically feasible treatments for their patients.

ASD is a difficult disorder to manage. Representatives from Kaiser noted that the treatments cross several areas of expertise including medical treatment and educational and social development. The question remains, who should bear the burden of the cost of treatment for this disease -- families, private medical insurance carrriers/insured, state government, the federal government, the educational system, charities, foundations supported by grants, or some combination thereof? It is very often the case that families have to have one parent stay out of work to care for a child with ASD. Many families end up filing for bankruptcy as a result. It seems that all of the above interested parties would benefit from early diagnosis and treatment of this disorder. Certainly returning a parent to the workforce and potentially raising a child who can contribute to society, rather than depend on society to meet his or her needs seems the most productive approach.[1]

Social Impact

The number of children diagnosed with autism has increased over the last several years apparently due in part to increased screening and identification of children at earlier ages. The Commission received copies of a number of studies and references to a number of medical journal articles and other literature regarding the impact of caring for individuals with a diagnosis of autism from the proponents of SB09-244.

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[1] The information for the medical portion of this report was obtained through testimony to the Commission on Mandated Health Insurance Benefits, articles and documentation presented to this commission and largely from the trusted physician resource *Up to Date* which is a company devoted to regular review and summarization of the most important and recent literature on medical topics.

Included was information from a University of North Carolina at Chapel Hill study based on 2002 data from the National Survey of American Families which determined that the financial impact on families is substantial. According to the study, 40 percent of the families with disabled children who earned between two to three times the federal poverty level (between $36,200 and $54,300 for a family of four, for example) experienced at least one food hardship, including worrying that food would run out or skipping meals because of a lack of money. Fifteen percent of families with incomes at three or more times the federal poverty level ($54,300 and up for a family of four) experienced housing instability, meaning they were unable to pay their rent or had to move in with others.

The proponents provided information from testimony presented at the Legislative hearing that indicated that many adults with autism are not self-sufficient and that children with autism are more likely to display severe destructive behavior, such as self-injury and aggression, which means they are more likely to be segregated from peers or even institutionalized.

According to the proponents, research shows that 20-25 hours per week of intensive behavior analytic treatment that begins when a child is first diagnosed and under the age of 3 can result in significant gains in communication, intelligence and social competence which can allow these children to enter the first grade with a normal study curriculum as well as possibly become self-sufficient when they become adults. However, parents are unable to provide the type or level of intensive treatment on their own and few are able to afford the costs of the treatment. Additionally, one parent will usually have to quit working in order to provide the 24 hour “line of sight” care required for many of the most severely affected children.

Opponents to SB09-244 expressed a concern that health carriers would bear the burden of becoming the “payor” of treatment services for individuals with autism, which many times includes treatment that is non-medical in nature. It should be noted that many in Colorado’s insurance industry advocate giving ASD full parity with other medical conditions, including coverage of ABA services with reasonable limitations and licensed providers, but do not support the creation of a new mandate that eliminates benefit limits, parity requirements, and licensing requirements. A concern was also expressed that there are a number of uninsured individuals and those covered by governmental programs such as Medicaid who would still not have coverage for the therapies involved in the treatment of autism proposed in SB09-244.

Financial Impact

The Commission received and reviewed a substantial quantity of information about the costs of a mandate for autism treatment services. As the methodology for calculation of the prevalence, costs and extent of treatment and services, and consequent premium costs for coverage varied between the various sources, the Commission is limited in being able to provide, with high confidence, an “apples to apples” comparison given the complexity of the statistical analysis and the time allotted.

Information provided the Commission by SB09-244’s proponents included “Actuarial Cost Estimates” prepared by Marc Lambright of Oliver Wyman for Georgia, Missouri, Nevada, and Virginia. Mr. Lambright has apparently developed an algorithm to provide an estimate of the increased service cost and premium cost for an autism mandate. According to the bill’s proponents, use of this algorithm for Colorado variously provides a premium rate impact of 0.54% PMPM (per member per month) or a $0.54 PMPM increase. To resolve the conflict between these statements, an actuary of the Division of Insurance reviewed the information provided (see Attachment B) and using the information provided calculated a 0.54% increase in total premium which can be restated as a $4.12 PMPM increase and annualized to a total $49.41 increase in premium.

Other information provided by the bill’s proponents provided the following estimates:

- Article in the Journal of Autism and Developmental Disorders, February 13, 2009 (online), in an article entitled “Brief Report: Quantifying the Impact of Autism Coverage on Private Insurance Premiums,” (Bouder, Spielman and Mandell):

> “Estimated increases in health care premiums ranged from 0.19% (assuming a treated prevalence of 2 per 1,000 children and annual expenditures of $10,000), to 2.31% (assuming a treated prevalence of 6.7 per 1,000 children and annual expenditures of $36,000 ;) . . .”
>
> “Our analysis suggests that, using current treated prevalence estimates and an annual expenditure for children with autism of $10,000, the average family would pay an additional $0.54 a month or $6.44 a year. If

> current treated prevalence were to double as a result of the new benefit and annual expenditures rose to $20,000, families' annual increased contribution would be $26.10. Even in the unlikely event that treated prevalence were to rise to the accepted community prevalence of 1 in 150 children, and per capita expenditures rose to $36,000 per year, the increase in the family contribution would reach $6.53 a month, or $78.31 a year."

- Paper on the "Social and Financial Impact of Senate Bill 12 (Kate's Law) in Fulfillment of the Requirements of K.S.A. 40-2248 & 40-3349" prepared by Michael L. Wasmer, DVM, Diplomate ACVIM (SAIM); Elizabeth Emken; and Judith Ursitti, CPA, on behalf of the Kansas Coalition for Autism Legislation estimated the increase in family premiums in Kansas depending on estimated treatment costs ranging from 0.17% (low), 0.44% (medium), to 1.86% (high).[2]

The Commission also reviewed the fiscal note prepared by Legislative Council staff on SB09-244 as introduced in which the Department of Health Care Policy and Financing actuary estimated the per member per month increase for the Children's Basic Health Plan to be $2.93 PMPM, or $35.16 per member annually, and adjusted for next fiscal year to $41.43 in additional annual cost.

The report prepared for the Pennsylvania Health Care Cost Containment Commission on the "Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150 [2008]," Abt Associates, Inc., June 18, 2008, was found to be instructive as to the issues and difficulties in analyzing legislative proposals for mandated health insurance benefits for services and treatment of autism spectrum disorders. However, even this report provided varying calculations of the cost and premium increase anticipated due to an autism mandate. The report found variously:

> "The preponderance of evidence submitted indicates that the premium cost impact of Pennsylvania's mandated ASD benefit will be in the range of one (1) to one and one-half (1 ½) percent. Based on the KFF reports on average family health insurance premiums of $1,008 per month, the range of premium

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[2] Using the Kaiser Family Foundation 2009 adjusted premium amount for Colorado and applying the Kansas calculations would result in annual premium increases from $22.67 (low), $58.66 (medium), and $248.00 (high).

> increase would be between $10.08 and $15.12 per month." Abt Associates, Inc. report at 43.
>
> "In summary, the evidence submitted to the Pennsylvania Health Care Cost Containment Commission is sufficient to evaluate the impact of the HB 1150 mandate. The analyses and research papers support a finding of marginal premium increase costs of approximately $1 PM/PM attributable to the ASD benefit. These cost increases are modest relative to: ongoing insurance cost increases; estimated cost offsets for families and the Commonwealth; and better results for children and youth with ASD." Abt Associates, Inc. report at 51.

The Colorado Association of Health Plans provided a report from Thomas E. Cummins, Consulting Actuary, about SB 1537 in Oklahoma. Mr. Cummins estimated premium increases of between 7.8% and 19.8% based on differences in average claims costs and loss ratios. However, a formal complaint has been lodged against Mr. Cummins with the Actuarial Board for Counseling and Discipline by the Oklahoma bill's proponents. It should be noted that the actuary who prepared the report has been providing actuarial studies to the Oklahoma legislature for more than 20 years and has been a practicing actuary for 35 years. Leadership in the Oklahoma state house continue to support the veracity of Mr. Cummin's report. The Association further provided a chart of cost estimates for other states which have pursued autism mandate legislation this year. This chart provides conclusory statements about the cost estimates attributable to the various states' legislation but did not provide background as to how the estimates were derived.

To try to organize the information provided by proponents and opponents, the Commission has prepared a chart incorporating submissions received as to the cost estimates based on legislation in various states. Commission staff attempted to utilize the various calculations to provide comparable dollar amounts as to cost estimates, though such undertaking is fraught with the danger of error or misunderstanding of how certain amounts were derived. Staff also conducted further research as to the status of the legislation in the various states. *See* Attachment C.

Balance

The individual, familial and social impacts of a childhood diagnosis of an autism spectrum disorder are well documented and recognized.

ASD has a current incidence of 1 in 150 children, and the incidence is thought to be increasing. There are current medical efforts underway to diagnose the family of conditions earlier, and there is some evidence that treatment effectiveness spans a spectrum of efficacy. The treatment is often quite intensive at 20 to 35 hours a week of one-on-one work with a therapist under the direction of a treating physician or clinical psychologist. The treatment involves some therapies in the traditional medical model, but the majority of treatment is provided by specialized therapists not licensed in Colorado as medical professionals (though certified through a private national certifying organization). This course of treatment can last variously for weeks, months or years and has high overall costs which, to this point, have had limited, if any, insurance reimbursement.

There are very limited governmental programs available in Colorado to provide the treatment and services for ASD. Requiring Colorado regulated health insurance plans to cover extensive ASD treatment and services will add costs into the system and necessitate increases in premiums across all Coloradans purchasing Colorado-regulated coverage. In the absence of similar treatments being provided by governmental programs and/or public agencies (e.g., public schools, Medicaid), and a disparity of coverage between Colorado regulated and non-regulated (ERISA self-funded) health plans, the possibility of adverse selection into the Colorado regulated plans with benefits for ASD treatment and services may be significant.

The fundamental policy question is what financing structure for providing the treatment would be most efficacious and equitable. Factors affecting the financing structure choice include: the increasing prevalence of the conditions, the high cost of providing treatment at the intensity sought to be effective, and the concomitant individual, family and societal impacts of failing to effectively treat as many individuals to reach their highest lifetime potential.

Attachment A

Commission on Mandated Health Insurance Benefits
Assessment Tool

INTRODUCTION
The Commission on Mandated Health Insurance Benefits exists to serve the people of Colorado and the State Legislature by providing objective information and recommendations on the impact and structure of current and proposed health insurance mandated benefits. In order to accomplish our mission, the Commission requests that all proposed mandates clearly define:

- the scope of services to be covered,
- the level of benefit intended, and
- the health insurance markets directly impacted (e.g., individual, group, etc.)

In providing answers to the following questions, the Commission requests that sources be cited, or actuarial analysis be presented, for the information provided. Information without a source cited or analysis submitted will be assumed to be opinion and anecdotal.

A. Social Impact

1. If coverage is not generally available, what is the extent to which the lack of coverage results in persons being unable to obtain necessary health care treatment due to cost, access to care, or other factors? Specify:
   a) Financial impact to an individual seeking the specified course of treatment;
      - Research shows that 20-25 hours per week of intensive behavior analytic treatment can increase functioning and even lead to 19% of individuals achieving optimal outcome (Diagnosis of Autism by history only). (Kleinman, Ventola, Pandey, Verbalis, Barton, Hodgson, Green, Dumont-Mathieu, Robins, and Fein. (2007) Diagnostic Stability in Very Young Children with Autism Spectrum Disorders. *Journal of Developmental Disorders.* 38. 606-615.)
      - Financial impact on families who can afford research supported number of hours (Cordelia Robinson, Ph.D., Director of JFK Partners, University of Colorado Health Sciences Center, personal communication):

Clinical level	Rate Per Hour	Number of Hours Per Month	Cost Per Month	Cost Per Year
Ph.D BCBA Supervision	$140	4 Hours	$560	$6,720
Master/BCaBA	$75	4 Hours	$300	$3,600

Supervision				
Bachelor Direct Service	$55	80-100 hours	$4,400-$5,500	$52,800-$66,000

- Total cost for families for early intensive behavior analytic treatment supervised at the appropriate level is between $65,400-$72,720 annually.

Families with disabled children are struggling to keep food on the table, a roof over their heads, and to pay for needed health and dental care. But according to a new study from the University of North Carolina at Chapel Hill, these challenges are now falling on middle-income households and not just on poor families as previous research has found.

These latest findings show that long-held federal standards for identifying the nation's poor are not capturing everyone in need and should be re-evaluated, especially for the financial effects on disabled children, said Susan L. Parish, Ph.D., the study's lead investigator and an assistant professor in the UNC School of Social Work.

"The bottom line is that U.S. families raising children with disabilities are reporting severe hardships at rates that are chilling, including families that are solidly middle-class," she said. "We were shocked to find such high rates of hardship among upper-income families."

The study, which is based on 2002 data from the National Survey of American Families, is being published in this month's journal Exceptional Children. The survey analyzed 28,141 households.

The UNC study found that overall, families across all income levels who are raising disabled children are significantly more challenged by food, housing and health issues compared to families without disabled children. Many also struggled to pay their phone bills.

Most surprising, Parish said, was data indicating that a significant percentage of those struggling are higher-income households. Yet based on federal poverty guidelines – which have remained unchanged since the 1960s and are used to determine eligibility for many income, food, health and disability-related programs – those same households would not be classified as "poor," she said. They also would not qualify for assistance, despite the higher costs of raising children with disabilities, Parish noted. In 2002, the federal poverty level for a family of four was $18,100.

According to the study, 40 percent of the surveyed families with disabled children who earned between two to three times the federal poverty level (between $36,200 and $54,300 for a family of four, for example) experienced at least one food hardship, including worrying that food would run out or skipping meals because of a lack of money. Fifteen percent of families with incomes at three or more times the federal poverty level ($54,300 and up for a family of four) experienced housing instability, meaning they were unable to pay their rent or had to move in with others.

b) Barriers to care, aside from financial hardship, that arise due to lack of coverage; and

- Limited number of Board Certified Behavior Analysts. Colorado has just over 40 certified individuals whereas states like Florida that does have mandated coverage, has over 1000 certified individuals. (Numbers retrieved from certificate database at www.bacb.com) This not only affects the availability of services, but the quality of services. If coverage is provided in Colorado it is likely that more Board Certified Behavior Analyst will decide to practice in the state. This will allow for more individuals to be served in a more effective manner.

c) Medical outcomes likely to result from a lack of treatment.

   - In April 2007, the Kennedy Krieger Institute launched the Interactive Autism Network (IAN), the nation's first autism registry. A year later, with 22,000 registrants, highlights of data collected so far reveal two trends. First, 46 percent of mothers of children with autism reported a diagnosis of depression, versus the general population where approximately 20 percent of women are faced with clinical depression in their lifetime. Secondly, most children with autism are on 5 or more different treatments at any given time, 67 percent of which are not covered by insurance. Parents report spending an average of $500 per month on treatments. Read more at http://www.kennedykrieger.org/kki_news.jsp?pid=6981.

2. The extent to which coverage for the proposed benefit mandate is already available through coverage provided by the following entities:
   a) Medicare;
   b) Medicaid;
      - CES (Children's Extensive Services) Medicaid Waiver: Personal Assistance; Home Modification; Home Modification; Specialized Medical Equipment and Supplies; Professional Services; and Community Connections. Funds are capped at 35,000 per year. However, not all children even receive the full 35,000. It is a needs based cap that is given to every child. There is a cap of 10,000 for intervention services. There is a 4-6 year waiting list for these services. A limited number of children are served on this waiver.
      - CWA (Children with Autism) Medicaid Waiver: Services from diagnosis until the age of 6 25,000 per year. There is a 2-4 year waiting list for these services. A limited number (75) of children are served per year. Services are not required to be behavior analytic in nature, just behavioral. This includes RDI which is has no empirical support to suggest that it is effective in treating the core deficits of Autism.
   c) FEHBP;
   d) Colorado State employee plan;
   e) Major insurance carriers (specify if offered market segments to which benefit is offered);
   f) Any government, community, or charitable programs.
      - Most community center boards have Family Support Services. This provides families with around $1,500 per quarter for intervention

services while they are on a waiting list for a waiver. There are more than 4,500 families on wait lists for Family Support.

75 kids with the diagnosis of Autism are served under the Children With Autism Medicaid Waiver and at this point in time, there are 179 kids enrolled in Children's Extensive Support (CES) Medicaid Waiver with a diagnosis of Autism. There aren't any other avenues for ABA in Medicaid so the number of kids potentially being provided ABA through Medicaid is 75, and if the families choose to spend CES funding (the average total benefit is approximately $12,000 annually) on ABA, then in a limited way the number could be 254. Both Waivers have wait lists in excess of 225 children each.

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Colorado currently has more than 12,400 people with developmental disabilities with IQ's below 70 who are not in services. More than 4,200 require 24/7 line of sight care and more than 60% of them are living with their parents over the age of 60. Colorado's budget is in crisis. It is unlikely that the State of Colorado will have further resources to fund treatment of autism.

Colorado is 49th in funding for education and 50th in funding for regular education. Public schools do not have the resources to fund treatment of autism beyond the responsibility of providing a free education. It is not an appropriate education for children with autism spectrum disorders.

3. What is the level of public demand from consumers and/or providers for the service or treatment? Is meeting this demand consistent with the role of health insurance and the prudent management of medical expenses for the greater good of the general populace?
    - There is a huge demand for services throughout Colorado. There are limited treatment providers (four that provide in home ABA services and three that provide center based ABA services) and limited sources for financial help (Four year waiver wait lists and $1,500 family support per quarter).

Testimony Regarding Colorado
Senate Bill 09-244

By Phillip S. Strain, Ph.D.

Thursday, March 19th, 2009

Good afternoon and thank you for allowing me to speak on behalf of children and families affected by autism. I am a professor of Educational Psychology and Psychiatry at the University of Colorado Denver and have conducted treatment research with children with Autism since 1974. Although I work at the University and serve as a science advisor to the National Institute on Mental Health, the National Institute on Child Health and Human Development, the National Academy of Sciences and the National Autism Center I am expressing my personal opinions today and not representing the University or any other agency of government.

We have seen in the last 9 months the consequences of being ignorant of and/or pretending that fiscal train wrecks are not headed our way. We have all become the victims of public policy and private behavior that focused on the present and turned a blind-eye toward collective and future consequences of inaction and action.

Regrettably, my message to you is that we have replicated the same mistakes regarding the treatment of individuals with Autism for far too long. The good news is that you have before you a bill that can mitigate that train wreck for all Coloradans and provide thousands of other affected families with treatments that are life changing. True legacy opportunities do not come along every day. This is one!

I'd like to remind you that Autism Spectrum Disorders are serious, lifelong conditions that impact multiple areas of development and have significant and lasting consequences for affected individuals and their families. One in 150 children is diagnosed with autism. In fact, autism is 10 times more common than juvenile diabetes, muscular dystrophy, childhood leukemia, and cystic fibrosis combined.

The potentially devastating effects of autism are evidenced by the fact that the vast majority of adults with autism do not become self-sufficient. Children with autism are much more likely to display severe destructive behavior, such as self-injury and aggression, and are more likely to be segregated from peers or even institutionalized. And the overwhelming effects of autism extend beyond the individual. The divorce rate for parents of children with autism is over 75% in some parts of the country, and siblings and parents of children with autism are more likely to experience stress-related, mental health problems. Families of children with autism lose between 30 and 80 thousand dollars each year in potential wages because of unmet treatment needs. Obviously, autism is a problem that requires our immediate and sustained attention if we are going to make an impact on these children and their families.

What is the Colorado Translation of the Numbers?

1. 32,000 citizens in Colorado with ASD (based upon Center of Disease Control's 1:150 reported rate and confirmed by UC Denver's surveillance data)

2. Lifetime cost of care for individuals with ASD range in the literature from 2.0 to 3.2 million.

3. Current Colorado commitment in dollars is:
    32,000 x 2.0 million = 6.4 billion
    (After adjustments for inflation and distribution in age of individuals with ASD, the net effect is zero).

4. Total amount in #3 above increases by <u>at least</u> 2 million <u>daily</u>.

5. This debt-producing experiment in not even slowing? medically necessary treatment needs.

Real Potential of Bill to Positively Impact Status Quo Numbers

1. Centerpiece of Bill is reimbursement for medically necessary treatment services based upon principles of Applied Behavior Analysis (ABA)

2. ABA has been shown to significantly impact all clinical features of ASD in over 700 studies.

3. This is why ABA has been recognized as the evidence-based treatment of choice by the National Research Council, the US Surgeon General, the National Institute of Mental Health and the Department of Defense.

4. In both controlled experimental studies (22 studies) and in a system-wide application (Province of Ontario, Canada) of ABA services, large percentages

of children have been shown to need either far fewer or no continuing services after treatment. Percentages range from 37% to 47%.

5. Based upon the data in #4 above, if we assume that only 25% of Colorado individuals with ASD show similar improvement, the fiscal savings to Colorado citizens is equal to about 2 billion dollars.

   (Assuming that 4,000 children under age 5 take advantage of benefits and 1,000 are "best outcome" patients)

6. If a more complete cost figure is used (3.2 million) then the savings are equal to 3.2 billion under the same 25% "best outcome" scenario.

4. In which states has a similar mandate been promulgated? What is the likelihood of achieving the objectives of meeting a consumer need as evidenced by the experience of other states?
   - Five other states have passed similar legislation, Louisiana, Texas, Florida, South Carolina, and Arizona.

5. What are possible alternatives to meeting the identified need?

B. Financial Impact

1. What is the health insurance premium impact on a pmpm basis anticipated over the next three years due to the proposed benefit mandate? Specify:
   - Kansas Senate Bill 12 suggested that in Kansas there would be between a 0.17% to 1.86% increase on health insurance premiums. Colorado increase is determined to be $.54 pmpm increase. In March, 2009 the Journal of Autism and Developmental Disabilities (JADD) published findings that actuarial reports from states more than a dozen states are revealing an impact on premium increases of less than 1%.

   a) Direct health care costs (cost per service), utilization assumptions, and administrative expenses;
   b) Indirect costs, such as inappropriate or excessive treatment;
   c) Savings directly related to the proposed mandate, such as improved health outcomes; and
   d) Indirect savings related to the proposed mandate, such as employee productivity.

For b and d – c addressed above and in 3 below:

Financial Issues Associated with Having a Child with Autism

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ORIGINAL PAPER

Introduction

Autism is a diagnosis no parent wants to hear. As any family that has a child with autism can attest, receiving that diagnosis begins a journey that places profound demands on family human and financial resources for the remaining lifetime of the child (Schall, 2000).

Autism is a biologically based developmental disorder that impairs an individual's ability to communicate, build relationships, and relate appropriately to the environment. Diagnosis is usually made in early childhood after a multi-disciplinary assessment of behavior, developmental level, and communication ability (Autism Society of America [ASA], 2004c).

Fifteen years ago, the incidence of autism was 1–2 per 10,000 in the United States. Now, the incidence rate is 2–6 per 1,000 or between 1/500 and 1/166; 50 families a day hear their child has autism (Betts, 2005; Centers for Disease Control, 2005).

Over the past decade, the U.S. population has grown about 13%; non-autism related disabilities have increased around 16%, while the recorded incidence of Autism Spectrum Disorders has risen 173% (Betts, 2005). Today, one in four Americans knows someone with autism; most frequently a family member (Autism Today, n.d.). A 10–17% annual growth rate for autism is projected (ASA, 2004c).

Reasons for the sudden and insistent surge in incidence of autism are hotly debated; no consensus regarding cause exists (Fombonne, 2003b). Evidence is mounting, however, that behavioral and other therapeutic intervention early in the life of a child with autism is critical for improving communication, forming relationships, decreasing maladaptive behavior and developing independence (Larsson, 2005). Efficacy of early intervention depends on several factors, not the least of which is the specific nature and severity of autism.

Intervention strategies are expensive. Many strategies require long hours of one-on-one interaction with a trained therapist or use of costly foods or drug supplements. Health insurance falls far short of covering these needs. As of March 2006 17 states have mandated that insurers provide some level of autism coverage. Despite these mandates, the majority of costs are not covered (Sheinin, 2006). Making matters worse, there is recent evidence that health shocks such as autism increase the risk of loss of health insurance over time (Tseng, 2005). Special education services do not fill the gap either. Although public school districts are legally obligated to provide a fair and appropriate education to children with autism, the educational programs that are provided are rarely sufficient to address the needs of school-aged children with autism and are not available to young adults with autism. Thus, despite high costs, most parents feel compelled to seek out and try early intervention strategies for the sake of their child’s future.

Costs associated with having a child with autism are not, however, limited to the cost of interventions. As is the case with many other forms of childhood disability, parents of a child with autism often face greater outlays of time and money than they would for a neurologically typical child. For example, specialized childcare is costly and often such care must be purchased for a longer period of time than a neurologically typical child would need. Additional cost is also associated with extracurricular activities for children with disabilities. One or both parents often must reduce work hours or step out of the labor market altogether (Gould, 2004). Though some assert that there may be financial benefits of having a child with disability such as saving the cost of forgone family vacations (Jarbrink, Fombonne, & Knapp, 2003), such savings are likely to be much smaller than the additional costs.

Although much research effort has been given to autism’s cause and treatment, aside from anecdotal accounts in the media or pilot studies with fewer than 25 participants (Jarbrink et al., 2003) remarkably little attention has focused on the financial issues faced by families that have a child with autism. To address this gap in the literature, quantitative and qualitative data from the Family Experiences with Autism Survey are used in this study to investigate factors associated with financial problems in families that have a child with autism.
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Background

Autism is a complex neurological disorder. To understand the reasons for and extent to which having a child with autism can affect family finances, it is helpful to review the characteristics of the disorder, the recorded rise in its incidence, the efficacy of different types of early intervention therapies and the financial burdens families that have a young child with autism shoulder despite federal law first enacted in 1975 that guarantees a fair and appropriate education for all children with a disability (Silverstein, 2005).

What is Autism?

Autism is a lifelong developmental disability resulting from abnormal brain function. The term autism comes from the Greek word autos meaning self. Leo Kanner (1943) used the term in 1943 to describe children who had profound impairment in communication and social skills, engaging in behavior that made them appear to withdraw into their own world.

Understanding of autism and related disorders has evolved over time. Autism is now recognized as a spectral disorder. The terms autism and autism spectral disorder (or ASD) are often used interchangeably to refer to three of five disorders that come under the broader category of Pervasive Developmental Disorders (PDD): Autistic Disorder, Asperger's syndrome, and Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS). The other two DDs, Rett's Disorder and Child Disintegrative Disorder, are less common and manifest substantially differently than autism. The Diagnostic & Statistical Manual of Mental Disorders (DSM-IV-TR) of the American Psychiatric Association (APA) specifies diagnostic criteria for these five disorders (ASA, 2004c).

All those on the autism spectrum will, to a greater or lesser degree, experience developmental disability that is significant enough to impair daily life and social relationships. Language and communication skills, ability to relate to their environment and others, and ability to use imagination or abstract thought will be delayed or absent. At the same time, no two people with an Autism Spectral Disorder will act alike or have the same skill set. At the low functioning end of the spectrum is classic autism or Kanner's autism. Persons at this end of the spectrum may have little to no speech, resist change in routine, engage in ritualistic behavior such as hand flapping, rocking or spinning. Some are mentally retarded as well. At the other end of the spectrum, individuals with High Functioning Autism meet the criteria for diagnosis of autism, but are less severly affected. Those with Asperger's Syndrome are usually of normal or above normal intelligence, have age appropriate speech development but are seriously impaired in ability to communicate (language pragmatics).

PDD-NOS characterizes a person who exhibits characteristics of autism or Asperger's Syndrome, but not of sufficient number or severity to be diagnosed in either category (Autism Victoria, 2005).

Why is Autism on the Rise?

While it is agreed that differences in the early development of the brain and central nervous system cause autism, reasons for this neurological difference are not so clear J Fam Econ Iss (2007) 28:247–264 249 and are hotly debated (University of Michigan Health Systems [UMHS], 2005).

Theories have ranged from mercury in vaccines; revisions in diagnostic criteria over time; improvement in trained observation by educators and health care professionals; increase in environmental pollution; mate selection; and the relationship between diagnosis and access to services (Fombonne, 2003a). Changes in data, measurement, and definitions over time call for exercise of caution when computing change rates in autism incidence (Fombonne, 2001). Most estimates of autism incidence reported today come from referral statistics gathered by the U.S.
Department of Education and other government agencies (ASA, 2004c). A 1995 National Institutes of Health research team meeting concluded that autism is most likely the result of a genetic susceptibility. Research continues to identify which genetic, immunological, infectious, or environmental agents might contribute to presence of an autism spectral disorder at birth or prompt its development early in life (UMHS, 2005).

Autism is found worldwide; its incidence and growth rate appears consistent around the globe. It is found among families of all racial and ethnic backgrounds, and levels of socioeconomic status. Boys are four times as likely as girls to have an Autism Spectral Disorder (ASA, 2004c).

Importance of Early Interventions
There is no single, universally accepted treatment for autism. No cure exists for this lifelong condition. Indeed, some higher functioning adults with autism protest the notion of cure on the grounds that society has a responsibility to accommodate neurodiversity. Given current social conditions, however, the large part of the burden of accommodation rests on the individual with autism and his/her family.
Consequently, most parents of a child with autism focus considerable resources on trying to maximize the potential their child has for integration into the dominant culture. Achieving integration almost always requires some kind of deliberate intervention, but no guidelines exist regarding which treatment option is best. The number of treatment options currently available can generate frustration and confusion as well as hope for families seeking help for a child with autism. Efficacy of some treatments is supported by scientific studies, while other treatments may be experimental and have only anecdotal evidence of any beneficial results (ASA, 2004c). A comprehensive comparison of the success of different interventions has yet to be completed
(Marcus, Rubin, & Rubin, 2000). Existence of a variety of therapies and interventions currently used by families that have a child with autism complicates estimating the costs associated with autism (Ja¨rbrink et al., 2003).

Research indicates that the earlier treatment begins the greater the chance for improvement if the intervention is comprehensive, intensive, individualized, extended over time and delivered directly to the child (Bryson, Rogers, & Fombonne, 2003; Guralnick, 1998). The first few years of a child’s life is the optimal time to begin treatment, while the child’s brain and social understanding is still developing.

Autism treatment has four broad categories. Behavioral interventions utilize discrete trial training where a child is asked to perform a specific action and responds. The therapist reacts with reward (usually praise) or correction. Backed by 250 J Fam Econ Iss

(2007) 28:247–264 research, Applied Behavioral Analysis (ABA) is the most widely recommended and utilized behavioral intervention. It is quite intense, requiring children to work one-on-one with a trained therapist for 30–40 h per week. It is expensive—up to $30,000 per year. It aims to correct maladaptive or injurious behavior and teach life skills. Detractors criticize its invasion of family life, intensity, and cost. They also see it as reshaping the child's original personality, a goal they do not like. Supporters point to measured improvement in behavior and learning.

ABA is not the only behavior-based intervention for autism currently available; another is Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), a structured teaching approach that strives to adapt environment to a child's functional level. This intervention, which was first developed by Eric Schopler during the 1970s, seeks to build on the existing strategies and interests of the individual with autism (ASA, 2004c). Unlike ABA therapy, TEACCH explicitly accepts a culture of autism that maintains ''people with autism are part of a distinctive group with common characteristics that are different, but not necessarily inferior, to the rest of us'' (Mesibov, 2005). More recently, a new intervention called Relationship Development Intervention (RDI) has been developed.

Speech and language therapy helps a child with autism master the expressive and pragmatic language necessary for successful social interaction. This therapy and behavioral intervention are the prevalent therapies for young children with autism. Both are most frequently accredited with beneficial results, although they do not help all children with autism. Other therapies are somewhat experimental and less likely deemed helpful to any significant or consistent degree. Speech and language therapy is the predominate therapy available in public school system at no additional cost. Unlike behavior-based interventions, speech and language techniques used with children with autism are not necessarily uniquely developed for individuals with autism.

Neurosensory therapies such as sensory integration, over-stimulation and patterning, music therapy and supervised horseback riding are designed to help the child with autism integrate sensory experience, brain function, and response; overcome aversion to certain stimuli; and expand ability to adapt to sensory aspects of their environment (e.g., stay calm during a fire drill).

Biochemical interventions include treatment of food allergies, medication, food and vitamin supplementation. These interventions often involve doctors rather than educators, especially for dispensing prescription medication to manage behavior. Some families find diet and drug therapy helps reduce undesirable behavior and increase attention span, sometimes quite dramatically. Others do not.

Typically, professionals working with a child with autism will tailor treatments for that child and include more than one approach as no one treatment addresses all needs. Family members often try a variety of treatments, eventually stopping those that seem to have little benefit and retaining those that seem to be effective. Options for treatment also depend on what is available in a given community and what a family can afford.

Why the Financial Aspects of Autism Matter

A free and appropriate education for every child with a disabilty is guaranteed under the federal Individuals with Disabilities Education Act (IDEA). But, appropriate does not mean ideal, nor is it necessarily what parents believe is best for their child J Fam Econ Iss (2007) 28:247–264 251 (ASA, 2004a).

Schools typically offer speech and language therapy, but districts simply cannot afford to pay the high cost of ABA therapy for each child with an autism diagnosis and, even if they could, they might not be able to hire the necessary personnel. Public schools are short more than 12,000 special education teachers, and the shortage is expected to rise as teachers retire or leave teaching (Tarkan, 2002).

Health insurance will sometimes cover the cost of medical tests used in the diagnostic process and the cost of prescription medication, but it will not pay for behavioral or other types of therapy for autism. The wait to participate in state or community funded therapy programs can be a year or more. As a result, parents desperate to find ways to help their child will pay thousands of dollars out-of-pocket or attempt to administer some therapies themselves.

Review of Literature

A literature review found only one study that dealt specifically with the financial impact of autism on the family. Ja¨rbrink et al. (2003) conducted a pilot study in the United Kingdom with 15 parents of a child with autism. Even with this small sample, they found the parents, on average, had weekly out-of-pocket costs equivalent to $120 that were directly related to the education and care of their child with autism, costs that would not have been borne with a neurologically typical child.

A literature exists on the broader question of the economic cost of caring for a child with special needs, however. Relevant work from that literature is reviewed here.

Substantial attention has been given to women as caregivers across the lifespan (Marks, 1996, 1998), predominately focusing on 50- to 64-year-old women caring for frail elderly family members (Marks, 1996). Analysis of the financial, employment, psychological, and social consequences of caregiving has centered on this relatively older group (Aneshensel, Perline, & Schuler, 1993; Seltzer & Li, 2000). Recently, attention has turned to midlife women in atypical caregiving roles (Kahana, Biegel, & Wykle, 1994), including care of severely disabled children.

Leiter, Krauss, Anderson, and Wells (2004) used a 1997 data collection to investigate caregiving time and employment choices of women with severely disabled children under age 18. Almost 20% of the sample of 1,954 provided more than 20 h a week of non-routine care for a disabled—child—equivalent to part-time employment. Half of employed mothers had reduced work hours and half of not employed mothers had quit work to better meet their child’s needs. Most reported cutting back time for other children and household tasks.

Using data from the second wave of the 1995 California AFDC (Aid to Families with Dependent Children) Household Survey, Meyers, Lukemeyer, and Smeeding (1998) investigated the prevalence of childhood disability and chronic illness among families receiving welfare in California. Over 10% of low-income welfare recipient families cared for a severely disabled child or children with special needs. Mothers providing care for those children were less likely to be employed than mothers who did not have a severely disabled child. Among the very low-income group, tradeoffs were made between expenditures for the special needs child and basic living expenses and between care of child and other demands. They concluded that although relationships among disability, poverty, and welfare are complex, it does 252 J Fam Econ Iss (2007) 28:247–264 appear that families caring for special needs children are at greater risk of experiencing poverty or material hardship. For these families, government programs such as Supplemental Security Income provide vital additional income support.

Childcare workers are not usually trained to meet the needs of special needs children, making it difficult for parents to find adequate care while they work. Fewell (1993) documented need for increase in such training and encouraged state agencies to utilize public funding to help parents afford daycare for special needs children so that they could be employed.

Using data from several states, Amo, Levine, and Memmott (1999) estimated that the national economic value of informal unpaid caregiving within families was almost $200 billion in 1997, a figure substantially higher than the $32 billion spent on formal home health care or the $83 billion spent on nursing home care in the same year. They concluded that more effective ways must be developed to support family caregivers. A similar study conducted by the National Alliance for Caregiving and AARP (American Association of Retired Persons) in 2004 estimated the value of unpaid caregiving activities to be even higher at $257 billion per year (Payndya,
2005).

In summary, literature focusing on the financial effects of care of special needs children indicates that caregiving time rivals part time employment and often precludes work outside the home. Time and money are often focused on the disabled child to the exclusion of the needs of other family members. Caregiving expenses are large. Federal programs help, but many families with special needs children still shoulder a large financial burden. Whether these same effects exist autism diagnosis and treatment can seriously outstrip family resources. For at least low-income families, lawmakers should consider creating incentives for health insurance companies to cover some of these expenses or increase public funding for some of these costs.

Insight into Reasons for Financial Problems

Reasons given for financial problems by survey respondents give rare and poignant insight into the choices made by families that have a child with autism. Qualitative research techniques (Strauss & Corbin, 1998) were used to classify respondent report into several broad themes. Discussion and comment on some additional common experiences of families follows listing of the themes. To give voice to the families, some representative direct quotes are given for each theme (themes are in bold type).
Parents were painfully caught by the sharp edges of their suddenly changed world:

Because of the constant battle with the special education director and the legal issues, I had to resign from my job...I LOST MY CAREER!!!! Now trying to live off of student loans and homeschooling so that we can survive and hope to get my son back on track with his education.

Robbed future to pay for today–planning horizon was dramatically shortened from long term future to day to day

Cashed out my 401k from my former employer.

Have sold all our stock.

Taken out an equity line of credit on our house to pay for therapies.

Used up all our equity in our home and ... most of our retirement funds saved since we were married [in] 1984.

Choosing our child's welfare over family needs, paying for special diet foods, instead of bills, putting off bills to pay for supplements, etc.

Decreased ability to provide in future—life ins., retirement, trust for two kids with disabilities ... stopped contributing to a college fund for our sons and an IRA for me.

Autism's demands outstripped resources

We are struggling to meet our bills...My husband and I often do not eat lunch or dinner because we have no money left to buy food for ourselves ...We are hard pressed to make a choice between heat for our family and food.

Husband has taken on a second job to help make ends meet. Still, we live from paycheck to paycheck.

I had to quit my full-time job at $40k/40 hrs wk—to take PT job at $10k/ 20 hrs a week. This cut the family income in half. Our student loan debt has not been paid on since his diagnosis—2 yrs ago. Our general cash flow has been reduced so much that is it is hard to pay bills on time every month. Our automobiles are getting old but we don't have good credit so could not buy a replacement at a decent % rate. We would love to refinance our home, but same story. My husband has a hard time getting 40 hrs. a week in at work due to issues with our son—resulting in reduced income again

Non-reimbursed therapies and equipment put strain on family budget. Other family members need counseling and medication to cope with the stress of living with autistic child. These costs further strain family budget.

> *Bankruptcy, once unthinkable, now seemed inevitable*
>
> *We have maxed out our credit card and if it gets any worse are going to have to place our son in fostercare to have all his needs met or file for bankruptcy.*
>
> *[We're facing] bankruptcy due to mounting medical bills not only involving our child but stress-induced illness and physical problems for parents*
>
> *Family has been forced into bankruptcy—filed 3 months ago. Once a $100,000/yr. family*
>
> *Since Jan '03 when diagnosis of Autism was first given our family debt has grown by $10,000. Bankruptcy is now a feasible option.*

Family experience chronicles a sudden detour off a known paved road to an uncharted, rocky terrain that is fraught with unseen hazards in a vehicle running out of fuel and no additional resources in sight! Deep frustration, fear, and desperation permeate family comments. Watching their actions, it seems these families shifted the value placed on the future (their future discount rate in economic terms), from saver to spender in response to autism's demands. It also could be argued, however, that these families are still future-oriented and still investing in the future but that future now takes the form of the life of their child with autism versus their 401k.

Across responses, it was clear that obtaining therapy for a child with autism took precedence over all other family needs—even own basic needs as so poignantly noted by the parents who gave up their own meals to provide necessary therapy for their child with autism.

> Specific causes given for financial difficulty varied. Some families cited their child's behavior. *One parent noted the expense of replacing ''2 broken windows, multiple VCR's, wall paper ... dresses, clothing, etc.'' that had been destroyed by their child with autism. Others cited therapy cost: ''ABA costs $33,000 per year!''*
> *One battled an insurance company to ''CONTINUE language therapy coverage.''*
> *Payment was refused for three months pending a final decision. Another remarked:*
> *''We have good medical insurance, but they do not cover all autism/Asperger's aspect of treatments.''*

Several families write of major lifestyle changes after pulling a child out of what was perceived to be at best ineffective and at worst hostile public education system.

Endless and bitter battles were enjoined with school districts to obtain the fair and equal education promised by federal law under IDEA. One family *''spent over $70,000 in due process costs and will probably spend over $100,000 in the next year with school* *appeals.''* The mother in another family *''has been unable to get a part-time job because she's had to home school [their son] due to inadequate public school options.''*

Perhaps the most distressing comment came from a family hit hard by an inadvertent misstep following what was to them new and complex rules: *''Kicked off SSI because I have an IRA (didn't know this was not permissible) and am now reimbursing the govt. nearly $10,000.''*

Situations such as this give rise to an impassioned plea to financial advisory professions to become more involved with education and outreach to families dealing with autism to forestall such unfortunate and costly misunderstanding of regulations, eligibility requirements, and financial opportunity and constraint under current tax law.

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experiences. Clinical Pediatrics, 33(5), 297–300.

2. Does the proposed mandate provide for a more or less expensive treatment alternative than is already commonly covered in the market today? Explain.

C. Medical Efficacy

1. How does the proposed benefit mandate meet generally accepted medical treatment standards?
   - While every child with autism presents with specific deficits they are given an individualized treatment plan. These treatment plans utilize the principals of Applied Behavior Analysis to increase deficit behaviors (Talking) and decrease excessive behaviors (Self Injury).
   - Applied Behavior Analysis is an empirically supported treatment for Autism Spectrum Disorders. Just like Chemotherapy is an empirically supported treatment for most cancers.
   - Certified behavior analyst, per their ethical code, must take data to determine efficacy of their treatments. (www.bacb.com)

2. What criteria exist to determine the appropriateness (medical necessity) of providing the proposed mandated benefit?

   - A 2009 Blue Cross/Blue Shield Special Report acknowledges that autism research involving no-treatment controls is unethical[1]. Technology Evaluation Center (2009). Special report: Early intensive behavioral intervention based on Applied Behavior Analysis among children with Autism Spectrum Disorders. BlueCross BlueShield Association, Assessment Program, Vol. 25, No. 9, pp. 1-62.

   - Without adequate treatment, individuals with Autism are likely to remain mentally retarded or profoundly socially impaired. Research from the University of Connecticut found as many as 20% of individuals who received effective treatment at an adequate dose lost the diagnosis of any Autistic Spectrum Disorder after just 2 years of treatment[2]. Sutera, S., Pandey, J. et al. (2007). Predictors of optimal outcome in toddlers diagnosed with autism spectrum disorders. Journal of Autism and Developmental Disorders, Vol 37(1), pp. 98-107.

Testimony Regarding Colorado
Senate Bill 09-244

By Tasha Aper, M.A.

Thursday, March 19th, 2009

Good afternoon. Thank you for the privilege to speak in support of this critical legislation. I have a Master's degree in Clinical Psychology and have had the pleasure of working as an autism treatment provider for the past 6 years; serving many children and families affected by autism in Colorado.

As you may have heard today, autism is generally a lifelong, neurodevelopmental disability causing impairments in communication and social interaction as well as repetitive behaviors or problematic restricted interests. Although not a core deficit, a side effect of untreated autism is frequently mental retardation and diminished IQ. With Early Applied Behavior Analysis (ABA) therapy, however, individuals with autism can make significant gains in communication and intelligence as well as social competence. Early meaning treatment begins at or before 3 years of age, and intensive meaning 25 or more hours per week of ABA therapy.

Individuals with an IQ below 80 are unlikely to participate in regular education classrooms. This means that, without Early ABA, many children with autism will always require extensive special education services and, subsequently, never live or work independently as adults. This has profound fiscal implications for the State of Colorado.

Approximately 20 years of research from varied and reputable academic institutions across the US demonstrate significant improvement in IQ as a result of Early ABA. Language, a core deficit in autism, correlates significantly with IQ. I am providing you with data highlighting several of these group studies that show an average gain of about 25 IQ points when children receive early, intensive ABA therapy.

I'd like to draw your attention to figure 1. This shows that individuals in the treatment groups achieved substantially higher IQ's than those who received less treatment or alternate treatment. Figure 2 shows that the outcome IQ's for individuals in the treatment groups were no longer in the mentally retarded range. Sadly, individuals who did not receive Early ABA typically remained mentally retarded.

Such gains in intellectual functioning are critical. They can mean the difference between an individual who will require extensive, state-funded services for the rest of their life and one who will flourish in a regular education classroom and lead an independent and productive life including meaningful employment.

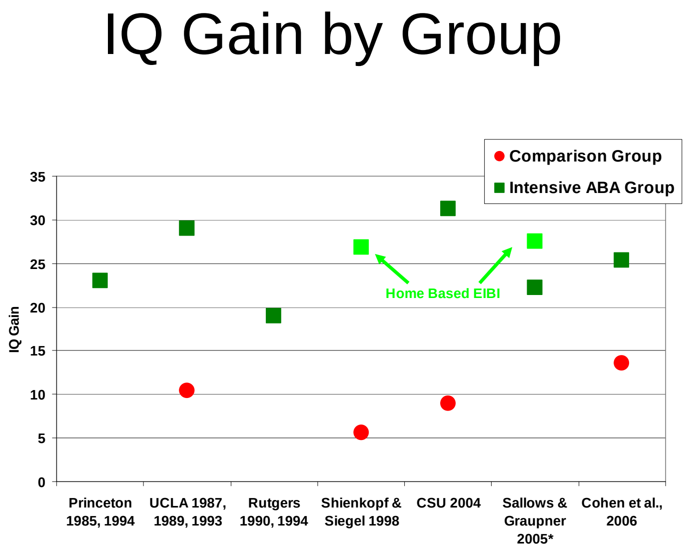

Fig. 1 Children who received Intensive ABA treatment achieved substantially higher IQ's than people who got less or no treatment

▪

3. What improved and lasting outcomes will result from providing the proposed mandate?

    - 19% of Children if given the right dose 20-25 hours per week of treatment that is behavior analytic in nature can have an optimal outcome (no need further services) Kleinman, Ventola, Pandey, Verbalis, Barton, Hodgson, Green, Dumont-Mathieu, Robins, and Fein. (2007) Diagnostic Stability in Very Young Children with Autism Spectrum Disorders. *Journal of Developmental Disorders.* 38. 606-615.)

.

- Reduced cost of healthcare in later life due to the ability to communicate, the reduction of self injurious, aggressive, and other dangerous behaviors.

4. What medical, behavioral, and lifestyle alternatives exist for treating the specified conditions?

D. Balance

1. To what extent does the need for coverage of the proposed mandate outweigh the costs of mandating the benefit?

- Research with children who have, or are at risk for, various disabilities has shown that effective early intervention can substantially reduce their need for specialized services later on. To be effective, however, Guralnick (1998) and Ramey and Ramey (1998) found that early intervention must be (1) comprehensive, (2) intensive, (3) extended over time, (4) individualized, and (5) delivered directly to children. Of course, such intervention is neither cheap nor easy, so it is important to determine how this kind of intervention is likely to pay off not only in benefits to particular children and families but also in financial savings.

- The Harvard School of Public Health (Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. Archives of Pediatric and Adolescent Medicine, Vol. 161, pp. 343-349) estimated families averaged $32k/year in 2007 on behavior therapy until their child was age 8. These are costs that the Harvard authors acknowledge may require legal proceedings to secure. This is not purported to be adequate therapy to treat Autism. Indeed, non-profit organizations here in Denver already charge as much as $65k/year for treatment of Autism.
- Since the average age of diagnosis for Autism in Colorado is 5 ½ years, coverage to age 6 would mean that most individuals would receive less than 6 months of treatment for a condition that is typically lifelong and costs twice as much as the typical American in direct medical costs (Alemayehu, B. & Warner, K. E. (2004). The lifetime distribution of health care costs. Health Services Research 39:3, pp. 627-642)

2. What is the potential number of persons that may no longer be able to afford coverage as a result of this mandate?

- Although it is estimated that providing coverage for treatment of Autism would increase insurance premiums by only 1%, (Bouder, J. N., Spielman, S. & Mandell, D. S. (2009). Brief report: Quantifying the impact of autism coverage on private insurance premiums. Journal of Autism and Developmental Disorders, Published online: February 13, 2009) inadequate treatment of Autism currently costs the state of Colorado billions of dollars. Since the societal costs of just one person with Autism are estimated to be $3.2MM (Ganz, 2007), covering adequate treatment costs could provide the state of Colorado over $555MM in otherwise lost income tax alone.

Attachment B

Per member Per Month Cost of Autism Insurance Treatment - SB09-244

weighted average for age category

Ages	Cost per SB09-244	Population	
birth - age 1	0	142,919	
Age 1 - age 10	75,000	701,744	
Age 11 - age 21	25,000	784,555	
Age 22 - 55	15,000	2,542,384	(disabled qualify for Medicare at age 55)
		4,171,602	
26459.9631		population average maximum benefit	

weighted cost including high functioning ASD. With high functioning =55% of total number and 33% total cost

High Functioning Proportion	0.55	
Low Functioning Proportion	0.45	
High Functioning Cost	8,820	
Low Functioning Cost	26,460	

weighted average max considering ability

.55(8820)+.45(26,459)	16,758	
total population 0-55	4,171,602	
total insurance= pop*23%	959,468	per Div of Insurance, 23% of group insureds in Colorado are in commercial plans
population using services 1/390	2460.175538	*
total cost	41,227,564	
Admin +15%	47,411,699	
total direct premiums collected	8,775,323,000	
%rate impact - per member, per month	0.540284373	

*Leslie et al 2007 1/520 used services
Liptak et al 2006 1/476 used services
Mandell et al 2008 1/500 used services
Pennsylvania DOI 2008 1/233 used services
Average = 1/390

Attachment C

2009 State Legislation Providing for Insurance Coverage of Autism Spectrum Disorder Treatment

State, Bill No., Status	Coverage	Effective Date	Types of Plans	Age Limit	Caps	Cost Estimate
Georgia HB426 SB 161 Status: converted into committee study of issue of autism insurance reform	Diagnosis and treatment of autism spectrum disorders Includes applied behavioral analysis	Uncertain	Individual Small Group (2-50) Large Group	None	Annual cap of $55,000 for applied behavioral analysis Inflation adjusted annually	Oliver Wyman – 0.63% or $21.20 annually CAHP – $7.31 PMPM (first year), $87.72 annually
Missouri SB167 HB 357 Status: Passed by committees, pending floor action in respective chambers	Diagnosis and treatment of autism spectrum disorders Includes applied behavioral analysis	August 28, 2009	Group, presumably including both small and large group	0-21	Annual caps of: $72,000 for ages 0-6 $36,000 for ages 6-14 $18,000 for ages 14-21 Inflation adjusted annually	Oliver Wyman – 0.76% or $27.10 annually CAHP -- $8.30 PMPM (first year), $99.60 annually
Nevada AB 162 Status: heard by Assembly	Diagnosis and treatment of autism spectrum disorders	October 1, 2009	Individual Small Group Large Group Government Agencies	None	No limits – parity	Oliver Wyman – 0.71% or $22.90 annually CAHP --

Commerce & Labor Committee – no vote taken	Includes applied behavior analysis					$9.81 PMPM, $117.72 annually
Virginia HB1588 Status: Dead	Diagnosis and treatment of autism spectrum disorder	n/a	Small group Large Group	Under age 21	$36,000	Oliver Wyman – 0.60% or $22.90 annually
Kentucky SB 74 HB 190	Diagnosis and treatment of autism spectrum disorder	30 days after enactment	Individual Small group Large Group	None	None	CAHP -- $9.57 PMPM, $114.84 annually
Wisconsin SB 3 (Amdt.) AB 15 SB 3 amended and sent to Senate Finance Committee	Diagnosis and treatment autism spectrum disorder	Uncertain	Individual Small Group Large Group Government agencies	None	$60,000 annually for 4 years for minimum of 30 to 35 hours a week of intensive services $30,000 annually for post-intensive period services Inflation adjusted	CAHP -- $8.00 PMPM, $96.00 annually

Appendix D

Minutes of the Commission on Mandated Health
Insurance Benefits Commission
February 13, March 6 and 20, 2009

Commission on Mandated Health Insurance Benefits

February 13, 2009

Meeting Minutes

Commission Members in Attendance

Leo Tokar, Vice Chair (via teleconference)
Peg Brown
Molly McCoy
Whitney Kennedy, M.D.
Wanda Cason (via teleconference)
Leo Mailander (via teleconference)

Division of Insurance Personnel

Dayle Axman, Supervisor, Life and Health Section, Consumer Affairs

Public Attendees

Senator Paula Sandoval
Clay Vigoda
Denise de Percin, Colorado Consumer Health Initiative
Jerry McElroy, Kaiser Permanente
Ben Price, Colorado Association of Health Plans

I. Call to Order and Introductions

Leo Tokar, Vice Chair, called the meeting to order and asked the Commission members to introduce themselves. As many of the members of the Commission are new this year, each member took a view minutes to explain their interest in serving on the Mandates' Commission.

II. Review of Commission Processes and Procedures

Peg Brown gave an overview of the materials provided to the Commission members prior to the meeting. She asked each member to review his/her contact information as well as providing a brief overview of the requirements contained in CRS 10-16-103.3. Ms. Brown also led a discussion of the challenges of the timing necessary to meet legislative deadlines. A typical bill requiring the Commission's review will be referred on a Wednesday afternoon with the Commission's report due Monday. This timetable has lead past Commission members to schedule meetings on Friday afternoons.

The Commission's "assessment tool" was briefly reviewed. Ms. Brown stated that some criticism of the tool has been received, primarily due to its length; however, the information it requests is similar to that required when bills are proposed and it provides valuable assistance to the Commission's review process. Due to the timing of the referred bills, Commission members do not typically have much time for independent research. The Commission discussed that the Commission's report should provide a balanced assessment of the bill versus expressing a "for/against" recommendation.

The other documents provided to the Commission members was related to Senate Bill 09-159 and a copy of a previous year's Commission report for similar legislation.

III. Referral of Senate Bill 09-159 and Commission Discussion

Senator Sandoval provided the Commission members with a copy of the "assessment tool" she had completed for SB09-159. The assessment tool is incorporated into these minutes and is attached. Senator Sandoval took several minutes to review the highpoints of each of the items listed in the assessment tool. Two states, New Jersey (2003) and Florida (2008), have passed legislation covering dependents to age 30. Senator Sandoval would like the coverage of dependents to age 30 to be "self-supporting" by the addition of a rider to the policy and requiring the parent to pay the additional cost. Current statutory language in CRS 10-16-104.3 does not require the parent to pay the additional cost. Senator Sandoval stated that she may revisit the statutory language in order to accomplish this. She also indicated that New Jersey's actuary provided the information contained in items 4 and 5 of the assessment tool.

A Commission member asked if the dependent would still be covered if he/she moved to another state. It was noted that as long as the dependency requirements of CRS 10-16-104.3 are met, the dependent could move to another state, as may be the case with college students. Another question posed by a Commission member: can a dependent go back on the parent's coverage if no longer financially independent? Senator Sandoval stated that both New Jersey and Florida do allow the dependents to "re-qualify", but Colorado law is silent so she may need to revisit Colorado's statutory language in order to allow dependents to re-qualify if they meet the qualifications at the time of application. Clay Vigoda assisted Senator Sandoval in presenting the bill to the Commission and in answering questions. He stated that although he is a lobbyist, he was representing any particular group.

It was stated that there is no large body of evidence, but New Jersey, which has had this law for three years, has been proactively collecting information and has found no reports of a negative impact or of unintended consequences. In Florida, this law is not only bringing on uninsurable individuals but is also encouraging parents to make sure that healthy children have coverage to protect against future problems. However, it is too soon for statistically valid data.

A Commission member asked if Senator Sandoval had contacted employers to discuss their ability to administer separate riders for some employees, but not others? No, she hasn't. It was noted that the State of Colorado, because it does not have the ability to administer separate riders, has incorporated the cost into the premium costs for all of its employees. Another Commission member pointed out that most self-funded employer health plans, since they aren't subject to Colorado insurance laws, would not provide this mandated coverage. It was also noted that small group employers, due to current small group rating laws, would be unable to apply a separate rate to an older dependent of the family so the costs would have to be spread over all employees of the group. The Commission members were advised that the small group rating case characteristics are defined in Colorado law.

Mr. Vigoda stated that this age group, on the whole, is healthy and should help the overall risk. Mr. Vigoda asked if adding healthy risks to a group always added to costs? A Commission member stated that the total dollars for overall addition to risk versus the specific costs to a group are not comparable and another Commission member noted that the small group rating laws do not allow for premiums associated with separate riders be charged on an employee-by-employee basis. The challenge to employers is how to administer separate premiums for these riders on an employee-by-employee basis. Why wouldn't these healthy individuals buy individual health plans and have their parents pay the premium?

Senator Sandoval noted that group coverage usually provides better coverage than individual coverage which is why these dependents would be better off covered under their parents' group plans than individual plans. Additionally, some of these individuals may not be able, due to another health condition, to purchase individual coverage. It was noted that individual health coverage underwriting guidelines vary from carrier to carrier. Senator Sandoval also noted that with some individual health plans, under-insurance is a concern. A Commission member stated that Anthem has a "Tonik" policy that is targeted to young adults and costs about $69 per month.

A Commission member asked if coverage available through CoverColorado was mentioned in the assessment tool? Senator Sandoval said that it was included in the "government sponsored" coverage information. It was also noted that CoverColorado coverage is typically much more expensive than regular group or individual health insurance coverage.

A Commission member noted that New Jersey requires that the dependent have had some type of creditable coverage in order to qualify for coverage versus just coming back on the parents' plan at anytime. Senator Sandoval stated that was true. In reference to item 3 of the assessment tool, a Commission member stated that it is not only hospitals that have to absorb the costs of the uninsured, but also small practitioners. Also, item 2, regarding Medicare coverage of these individuals, was clarified for a Commission member.

IV. Discussion and Public Comment on SB09-159

Denise de Percin stated that the Colorado Consumer Health Initiative supports this bill.

Jerry McElroy stated that Senator Sandoval, a small business owner, is well-respected and noted that when Kaiser implemented the requirements of House Bill 05-1101, it did cost 5% more and that employers were not happy about having to provide this additional coverage. Additionally, the employers stated it was hard to administer the additional cost and coverage—determining who has it, who doesn't. Large employers stated that it was more of an incentive to self-fund to avoid all insurance mandates. Kaiser would prefer having the requirement of having each parent pay for the rider deleted due to the problems with administering it. He also believes insurance is more expensive in New Jersey and Florida.

Ben Price stated that the plans that are members of the Colorado Association of Health Plans are concerned about the additional costs for policyholders.

Senator Sandoval stated that her business has small group coverage and that rates go up every year anyway. How does Mr. McElroy know what amount is specifically attributable to HB05-1101? She doesn't expect an answer at this specific time, but she would be interested in the information. A Commission member asked if there was a 5% increase "across the board"? Kaiser is able to isolate costs based on "age groupings". Senator Sandoval would be interested in knowing what percentage of people are taking advantage of the additional coverage in order to tie it to overall increasing costs. It was noted that many employers did not advise their employees of the ability to cover dependents to age 25. Senator Sandoval asked if many employers did not tell their employees about the coverage, why would there have been a 5% increase in costs? It was stated that the 5% costs were not "across the board"; only 5% for those that did take it, but a 1% increase when applied to all policyholders. There is no question that the additional coverage is helping, but it may also be hurting.

Additional discussion by Commission members:

Another clarification of Kaiser's 5% versus 1% costs was provided at the request of one of the Commission members. The 5% cost is for a small subgroup; had this cost been spread out among all policyholders, it would have been a 1% overall cost. It is unknown exactly how many small groups actually have dependents in this group. Another Commission member noted that more and more requests about dependent age 25 coverage are being received now versus when HB05-1101 was first passed. A Commission member asked how financial dependency is determined. Financial dependency is not specifically defined in Colorado law, but the IRS guidelines are used for some guidance. A concern was expressed that this coverage may provide a disincentive for these dependents to become financially independent, but Senator Sandoval does not believe this to be the case as most individuals in this age group want to be independent. Another comment was made that this might encourage some individuals to try to more working in more creative fields versus traditional types of employment that provide health insurance.

Senator Sandoval thanked the Commission for its time and interest.

Assessment Tool comments:

Item A.1.: "Other factors" include education of this age group in the marketplace regarding the availability of health insurance.

Item A.3.: Increased questions about the availability of this type of coverage provided earlier was anecdotal.

Item A.4.: It was noted that the New Jersey and Florida laws are not identical to this law.

Item B.1.: It is the sponsor's intent to have parents pick up the cost, but small group rating does not allow for this and the individual health market does have some reasonably priced products. There could be come potential for adverse selection for "richer benefit" parent plans.

Additionally, the Commission members are unsure that this age group is "uninsurable", but it may be more of a lack of knowledge and interest in the individual health insurance market. It was noted that the actual reasons for more uninsured members in this age group are unknown. A concern was expressed that increasing the overall rates could result in some individuals moving into the "uninsured" market. Also, a continuing concern was expressed over the administrative costs incurred by employers. It was also noted that the individuals in this age group may have more access to care, including preventive care when they have this coverage versus the lack of care when these individuals don't have any coverage or only have catastrophic coverage.

It was recommended that the report include the number of Coloradoans that would not be impacted by this bill.

V. Direction on Preparation of Commission's Report

Ms. Brown, for the benefit of the new Commission members and Senator Sandoval, advised that a draft report will be provided to the Commission members for review by Monday, February 16, 2009. Commission member comments will be incorporated and the final report will be provided to the Legislature by close of business, Tuesday, February 17, 2009.

VI. Scheduling of Future Meetings and Administrative Matters

Since there are a number of new Commission members, it was decided that it would be helpful to have an administrative meeting prior to the referral of another bill. This would include an overview of the legislative process, review of the assessment tool, the election of a new chairperson, and a determination of whether to change any of the processes and procedures used by past Commissions. Ms. Brown will poll the members about the best time to schedule this meeting. The Division of Insurance website (www.dora.state.co.us/insurance) has links to the previous years' reports and minutes.

## VII.	Adjournment

Commission on Mandated Health Insurance Benefits
March 6, 2009
Minutes

Commission Members in Attendance

Leo Tokar
Peg Brown
Wanda Cason
Pam Nicholson
Whitney Kennedy
Molly McCoy
Sen. Lois Tochtrop
Leo Mailander
Ranmali Bopitya

Public Attendees

Steve Bieringer, American Diabetes Association
DeDe DePercin, Colorado Consumer Health Initiative

Division of Insurance Personnel

Cameron Lewis, Director of Consumer Education

I. Call to Order and Introductions

Deputy Commissioner Brown noted the presence of a quorum of the Commission at 3:02 p.m.

Acting chairman Leo Tokar welcomed Commission members and described the purpose of the meeting as an administrative meeting to familiarize Commission members with the Commission's responsibilities and operations.

II. Approval of Minutes of February 13, 2009 Meeting

Ms. McCoy moved for, and Dr. Kennedy seconded, approval of the Commission Minutes of February 13, 2009. The motion was adopted unanimously.

III. Open Discussion of the Role and Value of the Commission

Ms. Brown discussed briefly the information sent to Commission members and passed out at the Commission meeting. This information included:

- A copy of CRS 10-15-103.3, the authorizing statute for the Commission
- A summary of the statutory provisions concerning the Commission entitled "Fast Facts"
- The Assessment Tool used by the past Commission and requested of a mandate's proponents
- A list compiled by the Division of Insurance of Colorado's Mandated Health Insurance Provisions
- A document entitled "The Legislative Process"

The Commission discussed its statutory responsibilities and the process used previously to fulfill its duties. Ms. Brown briefly reviewed how some other states' commissions operate. She also referenced the Annual Reports of the Commission in previous years as a reference discussing the challenges that the Commission has faced. The Annual Report is due to the General Assembly in

December of every year. A draft is prepared by Division of Insurance staff and circulated to Commission members for comment and approval. It follows generally the same process as reports on legislation referred to the Commission and the Commission's report on such bills.

Acting Chair Tokar asked Senator Tochtrop for her comments on the Commission. Sen. Tochtrop said bills can be referred in many ways to the Commission for review. An example is Rep. Sandoval's bill on raising the age of dependent children who can be covered

Ms. Brown said the general procedure is that if a bill includes mandated benefit, the chairmen of the committee with jurisdiction are supposed to send bill to the Commission. However, some committee chairs do not refer bills to the Commission.

Sen. Tochtrop agreed that not all bills come to the Commission for review. A bill for preventive services, including colorectal screening, did not come to the Commission last year. She reported that a Senate member requested that bill go to the Commission, but it was too late in the legislative session and the Commission was unable to get a quorum.

The Commission discussed what value, apparent and actual, the Commission could bring to the process of determining whether a proposed mandate is good public policy. Ms. Brown reported that in her experience, given the "short track" timeframes, the Commission's reports were not fully utilized by the Legislature. She also noted that there were some assertions that referral of bills to the Commission might violate the separation of powers doctrine. Ms. Nicholson said that from her experience the Commission tries to evaluate all sides of the issue, but all sides have wanted the Commission to take a position when prior Commissions chose not to and focused their reports as an educational tool on the issues presented.

Dr. Kennedy queried whether the composition of the Commission was designed to ensure a breadth of experience from different perspectives in analyzing a proposal. The Commission generally discussed how to determine if a proposed bill was "the right thing to do?" and how to get an objective view. Ms. Ranmali said she will contact a variety of people to get information to understand a proposed bill.

Sen. Tochtrop stated the intent of the legislation creating the Commission was good – but the biggest constraint is the time frame. Ms. Brown agreed the time frame and structure of the Commission was challenging. She reported that as staff to the Commission it is possible to get a call on a Wednesday requesting the Commission to meet and report on a bill before a legislative committee hears the bill the following Monday. She said it has been difficult in the past to get a quorum present on short notice.

Other Commission members noted that that some bill sponsors or proponents do not have adequate time to use the assessment tool. Some criticism has been lodged that referring proposed legislation to the Commission has been used as a tactic designed to delay or kill a bill. There was discussion about the difficulty for members trying to review complicated legislation in short timeframes.

Ms. Nicolson commented that a different political party is in power, now, than when the Commission was created and wondered if that would create a difference in the way the Commission is perceived and used. Mr. Tokar said that in the past, some people felt the Commission was the 4th branch of government, and circumvented due process because of the majority of our members were appointed by the Governor.

Ms. Brown briefly discussed other states and how their versions of the Commission are set up, utilized, funded, and the timeframes they operate under.   She also noted that the 2007 annual report included discussion indicating that the Commission was perceived as unfriendly, biased, with possible violations of administrative procedures and the open meetings act. Ms. McCoy and Ms. Nicolson said they wanted to get some feedback from the Legislature. If the Commission isn't seen as valuable, and the General Assembly isn't going to refer bills to us – they would request notification so we don’t have to meet.   The membership agreed by consensus to draft a letter to be sent to Legislative leadership and/or committee chairs of specific committees to introduce the reconstituted Commission. MS. Brown said she would take the Commission’s comments and prepare a draft letter for approval by the Commission.

V. Upcoming Meeting

The Commission decided to set a tentative meeting for two weeks out, March 20, 2009, from 2 to 4:00 p.m. at the Division of Insurance conference room. This meeting may continue the discussion of the role and purpose of the Commission, but it is also possible that the Legislature will refer any of several proposed bills to the Commission for review, so it was thought prudent to set a meeting date in advance. No bills have been referred at this point, but the group was aware of several bills that could be sent to the Commission for comment.

VI. Summary of Actions to be Taken

- Ms. Brown to draft a letter from the Commission to Legislative leadership for review

VII. Adjournment

The Commission adjourned the meeting at 4:35 p.m.

Commission on Mandated Health Insurance Benefits

March 20, 2009

Meeting Minutes
(unapproved)

Commission Members in Attendance

Whitney Kennedy, M.D.
Peg Brown
Leo Mailander
Wanda Cason (via teleconference)
Ranmali Bopitiya (via teleconference)
Molly McCoy (via teleconference)

Division of Insurance Personnel

Commissioner Marcy Morrison
Jo Donlin
Dayle Axman, Supervisor, Life and Health Section, Consumer Affairs

Department of Regulatory Agencies Personnel

Chris Lines

Public Attendees

Senator Brandon Shaffer
Betty Lehman, Colorado Autism Commission
Denise de Percin, Colorado Consumer Health Initiative
Susan Cox, Kaiser Permanente
Dr. Jandell Allen-Davis, Kaiser Permanente
Ben Price, Colorado Association of Health Plans
Rosalie Byrd, Provider
Beth Dickhaus, Hall and Evans
Edie Sonn, Colorado Medical Society(CMS)

II. Call to Order and Introductions

Peg Brown called the meeting to order and asked the Commission members to introduce themselves.

II. Approval of the Minutes of March 6, 2009

Dr. Whitney Kennedy made a motion to approve the March 6, 2009 minutes. Leo Mailander seconded the motion. Peg Brown asked for an approval of the minutes; all members were in favor and the minutes were approved.

III. Presentation and Discussion of Senate Bill 09-244 Concerning Health Insurance Benefits for the Treatment of Autism Spectrum Disorders

Senator Shaffer provided a brief summary of SB09-244, which is to proscribe the required coverage for people diagnosed with autism spectrum disorder. He directed the Commission members to page

6, lines 20-27 and page 7, lines 1-4 of Amendment SB 244_L.005, which describes the mandated benefit coverages which he believes is the focus of the Mandates Commission's review.

He referenced the Commission's Assessment Tool which was completed by Betty Lehman and Rosalie Byrd and stated that he understand that a report will be prepared based its review.

Betty Lehman reviewed the Assessment Tool, beginning with a correction to the date listed in the document's header. She stated that she would not read the document but that she would summarize and review the most relevant information. She noted that all of the financial data presented on page one is current and that it is Colorado-specific. She pointed out that a new study from the University of North Carolina at Chapel Hill resulted in the following comment by Susan L. Parish, Ph.D., the study's lead investigator and an assistant professor in the UNC School of Social Work:

"The bottom line is that U.S. families raising children with disabilities are reporting severe hardships at rates that are chilling, including families that are solidly middle-class," she said. "We were shocked to find such high rates of hardship among upper-income families."

Regarding the barriers to care, Ms. Lehman mentioned Colorado's lack of board certified behavior analysts. There are currently only 40 certified individuals in Colorado whereas other states with mandated coverage have many more of these providers. She noted that Florida has over 1,000 certified individuals. She believes that more certified providers will move to Colorado once this coverage is mandated. She also noted that the Kennedy Krieger Institute launched an autism registry in April 2007 and found, a year later, that 46% of mothers of children with autism included in the 22,000 registrants report a diagnosis of depression.

Ms. Lehman reviewed the other sources of coverage that currently exist for the proposed mandated benefits (page 3). She stated that no data was included for the FEHBP item since she was not sure what that was. A Commission member advised that the acronym refers to the federal employee health benefit plans. She stated that TRICARE does provide coverage and Ms. Byrd mentioned that TRICARE does cover certified providers.

Ms. Lehman mentioned the information provided by Michelle Cason Roger, Program Administrator for Medicaid's HCBS Children with Autism Waiver, which indicates that 75 children with a diagnosis of autism are currently being served under the Waiver and 179 children are enrolled in Children's Extensive Support (CES) Medicaid Waiver. There is limited coverage for Applied Behavioral Analysis (ABA) and both Waivers have wait lists in excess of 225 children each. She pointed out the statistics provided related to more than 12,400 people in Colorado with developmental disabilities with IQ's below 70 who are not receiving services and more than 60% of them are living with parents who are over the age of 60. She also stated that Colorado is 49th in funding for education and 50th in funding for regular education. Due to Colorado's current budget crisis, she does not believe that the State of Colorado will have further resources to fund the treatment of autism.

Ms. Lehman noted the inclusion of the testimony provided by Phillip S. Strain, Ph.D., on March 19, 2009 in the Assessment Tool. Dr. Strain provided the Colorado numbers listed on page 5 of the document. She noted that the Center for Disease Control's new numbers are expected to be worse based on information she gathered at a recent autism conference she attended in Utah. She directed the Commission members to review the 2009 State Initiatives document prepared by Autism Speaks and stated that New Mexico recently passed autism insurance reform legislation. She also stated that President Obama believes autism to be a serious national health matter.

Ms. Lehman review the "Financial Impact" section of the Assessment Tool (page 7), noting the number of Coloradoans this mandated coverage would impact based on the number of people covered by group health plans subject to Colorado's insurance mandates. She pointed to the information included in the Assessment Tool from the "Financial Issues Associated with Having a Child with Autism" (pages 7-18) as well as the separate document provided entitled "Brief Report:

Quantifying the Impact of Autism Coverage on Private Insurance Premiums". She stated that the authors have offered to provide Colorado with a free analysis. This paper discusses intervention strategies as well as providing a background on autism and why autism diagnoses are on the rise. She pointed out the information provided about the importance of early interventions (page 10), noting that "sustained engagement" of 20-25 hours per week for children with autism is not something that parents are able to do on their own. Ms. Lehman read aloud several of the quotes provided by parents of children with autism (pages 13-15). She noted that these are "gut-wrenching" stories from parents who are currently responsible for paying most, if not all, of the associated expenses of this medical condition. Ms. Lehman believes that private insurers should be a participating payor of the expenses associated with this medical condition. She also noted the three pages of reference material provided by the authors of this paper.

Regarding the "Medical Efficacy" section, Ms. Lehman referred Commission members to the "Autism Speaks" website, which she said documents the medical efficacy of autism treatment. She also pointed out the information included in Assessment Tool regarding a 2009 Blue Cross/Blue Shield Report (page 19) and noted that research from the University of Connecticut found that "as many as 20% of individuals who received effective treatment at an adequate dose lost the diagnosis of any Autistic Spectrum Disorder after just 2 years of treatment".

Ms. Lehman directed the Commission members to the inclusion of the testimony of Tasha Aper, M.A., which was made March 19, 2009, and noted that when ABA is provided at or before 3 years of age, these children can make significant gains in communication, intelligence and social competence which can allow them to enter the first grade with a normal curriculum.

In Colorado, the average age of diagnosis is 5 years, 2 months, compared to the national average of 5 years, 4 months. Ms. Lehman stated that this is due in part to children who are "high-functioning" at a level where the diagnosis is missed by the physicians. Only about a quarter of the children who are diagnosed have a severe impairment. Physicians are being encouraged to identify children with autism at an earlier age so that interventions can begin. The physicians are now finding that when they do so, there are no services or service providers to help these children. Ms. Byrd mentioned that there is a six month waiting list for autism evaluation at Children's Hospital. Ms. Lehman stated that many parents contact her organization looking for help in paying the cost of this evaluation. Ms. Byrd pointed to the information provided by Ms. Aper regarding the gains made in IQ.

In discussing the "Balance" section, Ms. Lehman stated that currently, only 5% of autistic adults are self-supporting. However, when treatment has been provided, 20% don't need government support and 45% only need minimal governmental support. As an example, Ms. Lehman talked about her son who has a job and will be a future taxpayer even though he as an IQ of 43. She also pointed out the societal costs provided by the publications listed on page 22 of the Assessment Tool.

Ms. Lehman stated that she was grateful for the opportunity to provide detailed information for the Commission members consideration and mentioned this Assessment Tool only provides a condensed version of some of the information available in over 1,000 pages of reference material. She referred to other documents that she has provided, specifically the Kansas version of an "assessment tool" which is similar to Colorado's.

IV. Discussion and Public Comment on SB09-244

A Commission member asked Ms. Lehman about the services available from Developmental Pathways. Ms. Lehman explained that Developmental Pathways is one of 20 community-centered boards responsible for providing support and services, primarily from birth to age 3, and that she is unsure of its waiting lists. She noted that if Amendment 51 from the 2008 Colorado ballot had passed, it would have provided additional funds in providing assistance to already identified disabled individuals, but would not have provided assistance for individuals with Asperger's Disorder or for high-functioning individuals. She stated that there is a two-year waiting list for emergency services and stated that her organization receives a number of calls from 90-year old parents still caring for their 70-year old autistic children who are worried about what will happen when they die. These kinds of situations can’t be solved with state resources and that it should be considered a terrible crisis.

Another Commission member asked what the average age of onset is. Ms. Lehman stated that it varies and the American Academy of Pediatrics has issued mandatory screening guidelines for 18 and 24 month old children, but there are waiting lists for evaluations. The rate of diagnosis was 1 in 10,000 when her son was diagnosed. When a child is diagnosed, the physician tells the parent: the bad news is that their child has autism; the good news is that it is treatable; but, the bad news is the parent will probably not be able to afford the treatment costs. One of the problems is that an autistic child will usually require “24 hour line of sight” care. This usually means that one parent has to quit their job in order to take care of the child.

A Commission member asked if Medicaid has a waiting list, because isn’t Medicaid obligated to provide these services? Ms. Lehman responded that no state’s Medicaid program provides coverage for autism but Colorado does have 75 children on the Waiver and 225 children on a waiting list for the Waiver. A follow-up question was asked about the number of autistic children who have private insurance. Ms. Lehman stated that the data is not available. Additionally, many children have multiple disability diagnoses and schools don’t typically list the autism diagnosis. Eight years ago, the CDC established six Centers of Excellence Surveillance Projects. When providing statistics, they counted 8-year olds with autism because it was believed that most children would have been diagnosed by that age. The CO Department of Education originally refused accessed to school records, but later allow researchers to review the student records looking for autism behavior patterns.

Ms. Byrd stated that 20% of the children who receive 20-25 hours per week of ABA therapy will “lose” their autism diagnosis, which is a great success rate.

A Commission member asked how early does the treatment start and how long does it last? Ms. Byrd stated as early as when it’s diagnosed and the length of time the therapy is required depends on where the child is in the autism spectrum.

Ms. Lehman stated that the brain is most “plastic” before the age of three so it is best to start the therapy before the age of three. She stated that ABA can also be used with adults as a means to assist the autistic individual in communicating with the world. She again used her son as an example: he is multiple-disabled and he would self-injure as a means of communicating as well as a means of attention. At age 15, he began taking medication that eased his suffering but he was still self-injuring. Within six months of starting ABA therapy, he went from 8-10 hours a day of self-injury to one hour per week. Now, at age 20, he is very successful in school and he works even though he is still medically fragile. Babies and toddlers can develop compensating skills that will allow them to lead normal lives.

A Commission member asked if this was the reason for the age-tiered benefits. Ms. Byrd noted that less intensive services are typically required as children get older and start school. Ms. Lehman stated that ABA therapy is a very difficult therapy and there is little danger of over-utilization as parents are looking to decrease the frequency of the therapy as soon as they can. Each child has an individualized treatment plan and out of the 1 in 169 children diagnosed with autism in Colorado, about a quarter are “high functioning” and a quarter are severely affected.

Senator Shaffer stated that the age-tiered approach was his idea in order to provide the best care options. The benefit levels are still being discussed with health plans, some of which have requested a $32,000 cap. There has been a lot of information provided as well as informative information about the implication of this mandate on insurance premiums. He noted that there is a lot of empathy and sympathy related to this bill, but it will come down to a “dollars and cents” issue. A parent provided a chart listing the increase in the rates each year since 1998 and the mandates passed in each year. Senator Shaffer reviewed this information in detail. He understands that this is raw data, but it does provide some information about how little correlation there is in the increase in rates due to the passage of the mandates. (A Commission member noted that the information listed for 2003 was incorrectly stated: the law to remove certain mandates from small group was only for an offer of a single plan design without the specified mandates.) Senator Shaffer stated that he is willing to work on the rate increase concerns and that it is important to weigh the real-life benefits and real-life costs savings that would be achieved with this type of mandated coverage and that he is convinced that it is the best public policy. Ms. Lehman stated that the rate increases listed on the document add up to 83.8%.

A Commission member asked if the waiting lists will still be a problem if this bill passes. Ms. Lehman and Ms. Byrd believe that the coverage will attract providers to Colorado and that it will keep parents from leaving Colorado.

When asked when the report is needed, Senator Shaffer stated that the bill should go to Appropriations on Friday, March 27. He is working on making necessary changes to the bill in order to reduce the fiscal note. He thanked the Commission members for their time and attention.

Public Comment

Susan Cox and Dr. Jandell Allen-Davis (Kaiser Permanente)

Susan Cox stated that Kaiser doesn’t disagree that providing medical coverage for autism should be covered and it has been working for several months on coordinated care issues and it is involved in 15 studies. However, ABA therapy is a shift from medical care to IQ improvement and social development. Kaiser is concerned with moving educational expenses into the health insurance arena and they are concerned that any increase in premiums will result in more individuals without any health insurance coverage. Is it the role of health insurance to provide coverage for educational therapies? There are a number of “blended” medical and education therapies and it is difficult to separate the costs. Additionally, a search of “Ask.com” provides a list of a number of other therapies so Kaiser is unsure that ABA therapy is the only way to go. Also, in relation to Ms. Lehman’s earlier comment: health insurance would become “the payor” instead of “a payor”.

A $50,000 benefit cap is 15% of Kaiser’s mental health budget and a $75,000 cap is 20% of its mental health budget. Kaiser discussed SB 937 (Senator Clinton) and the identification of evidenced-based therapies and the awarding of grants to assist with the funding of coverage and indicated that the Baucus “White Paper” makes no mention of autism. Kaiser also noted the layering effect of all mandates, particularly with the costs of new technology and increasing medical costs.

Dr. Allen-Davis stated it was difficult for her to testify against this bill, but one of the drivers of increasing health costs is the provision of care without good outcomes. She does not believe that evidenced-based studies support the use of ABA therapy. The March 2009 Journal of Pediatrics reviewed the last 25 years of literature and it didn’t demonstrate better outcomes for ABA over regular therapies such as speech, physical and occupational therapies. Kaiser is continually reviewing all types of therapies and new technologies and does add coverage when supported by outcomes. In 2008, there was no support for wide-spread use of ABA therapy and she is concerned with the wide-spread adoption of this therapy technique. Will it be used responsibly? Once it’s a covered benefit, she doesn’t believe there will be good utilization control. When or if controlled studies provide the medical efficacy of ABA therapy, Kaiser will cover it. Also, this mandate only applies to the insured population: what about the uninsured and those individuals covered by Medicaid?

A Commission member stated that if Colorado could do something to keep from losing the productivity of one of the parents, there may be less need for Medicaid coverage. Another Commission member heard a mixed message in the Kaiser testimony: if it turned out that ABA therapy was medically effective, would Kaiser pay for it even though it was a blended medical-educational therapy?

Dr. Allen-Davis responded that behavioral therapy is covered now even when part of a blended therapy, but not covered in an unlimited manner. She's more concerned with evidenced-based results of this therapy.

A Commission member asked Dr. Allen-Davis to address the certification of therapists. She stated that she believes the bill's language related to who's able to provide the ABA therapy should be strengthened and that there should be a clear line in demonstrating how the therapists are credentialed and regulated. She is concerned about the vulnerability of this population and the possibility of unscrupulous providers.

A Commission member commented that evidence-based results is important but, due to the current crisis in the care needed and impact to the economy, can we wait until the data is developed?

Susan Cox stated that Kaiser would like to work at finding a balance, but this is difficult when Kaiser is working on a number of initiatives due to the difficulty in providing the staff members with the necessary expertise to participate in all of these discussions. Dr. Allen-Davis added that there has not been much lead time to review and develop this mandate due to when this bill was introduced. Also, at the beginning of the discussions, there was a hope expressed for collaboration between advocates and the health plans, but she is not sure that it has been realized. Kaiser is looking for time to work on the best outcome for this coverage mandate. It was noted that the cost, per member per month, ranges from $7.00 to $13.00 in the other states with mandated coverage and she referenced the "2009 State Autism Mandate Bills Cost Estimates" that was provided by the Colorado Association of Health Plans.

Additional Discussion by Commission Members

A Commission member asked for clarification: is only ABA therapy covered by this mandate? Another Commission member answered that other therapies are also covered. There was also confusion expressed regarding the utilization review process specified in the bill. In one section, it specifies that the physician determines medical necessity, but later provides the carrier with the ability to review the treatment plan and for the application of the appeals process provided by CRS 10-16-113 and CRS 10-16-113.5. It appears that the carrier cannot review the treatment plan more often that every six months and that it may not be able to do the first review until after the first six months of therapy has occurred. It was expressed that this may be a technical language conflict in the bill.

A Commission member stated that it would be helpful for the Colorado Medical Society to provide some guidance. Ms. Sonn stated:

1. She agrees that this is a big problem.
2. Regarding the question of who should pay for the services: Education, the State, or insurance? If insurance pays for the services, what happens to the services needed by those who are uninsured?
3. There is the potential for fraud. There should be appropriate evaluation and feedback and evidence-based data related to what is economically and therapeutically beneficial.
4. Credentialing should be more clearly defined.
5. Continued therapy should be potentially held to improvement standards if it is not providing improvement.

A Commission member asked if the mandate only impacts fully-insured Coloradoans, is it the Commission's role to determine the impact to the insured population only? Another Commission member expressed an opinion that the impact to all Coloradoans should be considered. There was more discussion related to the utilization review aspect of the mandate with one Commission member stating that having the treating physician determining medical necessity would create a "super mandate" with no real limit. There is not a mandate in any other state that compares to the proposed Colorado mandate in the benefit amount as well as covering treatment by non-licensed providers. There was also some discussion about which physician would be determining the medically-necessary treatment: the pediatrician who diagnoses the condition or the physician overseeing the therapists? A concern was expressed that a physician running a clinic could certify medical necessity and also be receiving a financial benefit from the services being provided at the clinic. A Commission member recommended that the credentialing and utilization review requirements be “tightened”. A Commission member stated that California has high school students “approved” to provide autism treatment services. It was also noted by another Commission member that the bill requires that the therapy continue to be covered while the carrier is reviewing the treatment plan.

It was also recommended by a Commission member that the conflict of the apparent inability of the carrier to review medical necessity during the first six months of treatment versus the usual utilization review and appeals process also included in the bill be mentioned in the Commission’s report. It is up to the Commission to provide a balanced report and all of the information that has been provided to the Commission will be posted on the Commission’s website. Other concerns noted by Commission members: the bill presented today is not the final version and it is difficult to take an emotional issue and balance it with other concerns. It was noted that it is not the job of the Commission to make a specific “recommendation”, but concerns should be noted in the report. It was recommended by a Commission member that different Commission members draft the three sections related to “Social Impact”, “Financial Impact” and “Medical Efficacy” and then put them together in the draft report and then write the “Balance” section of the report. The draft report will be circulated for comments by noon on Wednesday, March 25. The final draft will be sent out for review by close of business on Wednesday.

V. <u>Adjournment</u>

Appendix E

Commission on
Mandated Health Insurance Benefits
Letter to Legislative Leadership

Mandated Health Insurance Benefits Commission

March 13, 2009

The Honorable Peter Groff
President
Colorado State Senate
200 East Colfax, Room 346
Denver, Colorado 80203

The Honorable Terrence Carroll
Speaker of the House
Colorado House of Representatives
200 East Colfax, Room 271
Denver, Colorado 80203

The Honorable Betty Boyd
President Pro-Tem and Chair
Committee on Health and
Human Services
200 East Colfax, Room 346
Denver, Colorado 80203

The Honorable Jim Riesberg
Chair
Committee on Health and Human
Services
200 East Colfax, Room 271
Denver, Colorado 80203

The Honorable Jennifer Veiga
Chair
Committee on Business, Labor
And Technology
200 East Colfax, Room 346
Denver, Colorado 80203

The Honorable Joe Rice
Chair
Committee on Business Affairs and
Labor
200 East Colfax, Room 271
Denver, Colorado 80203

Dear Senators and Representatives:

As the newly appointed members of the reconstituted Mandated Health Insurance Benefits Commission, we are writing to request your assistance in fulfilling the responsibilities of the Commission to provide analysis to the General Assembly and the Division of Insurance assessing the impact of mandated health insurance benefits and proposals to establish such benefits.

The Mandated Health Insurance Benefits Commission was created by statute at C.R.S. 10-16-103.3 in 2002. The initial appointments to the Commission expired in August 2008. Over the past few weeks, Governor Ritter and the legislative leadership made new appointments to the Commission. A copy of the Commission's current roster is attached.

We believe the Commission can add value to legislative deliberations on proposed health insurance mandates by providing analysis of the balance of social and financial impacts of existing and proposed mandated benefits. The Commission does not want to hinder the legislative process, but rather to help inform that process by receiving and analyzing information from a variety of sources and presenting its analysis to the General Assembly.

The Commission has organized and is available to fulfill its responsibilities, but needs your assistance in doing so. The Commission is primarily made of citizens who as volunteers need advance notice and flexibility to attend Commission meetings and participate in developing Commission analyses. To this end, the Commission would like to work with the legislative leadership on timely referral of proposals for the Commission to analyze and report back.

The Commission has identified the following legislation as containing proposed health insurance mandated benefits which, pursuant to CRS 10-16-103.3, we would ask be considered for referral:

HB09-1059 – Health Coverage During Clinical Trials – Pending Second Reading in Senate as of March 12

HB09-1204 – Priority Preventive Health Services – Scheduled for House Business Affairs Committee hearing on March 25

Other bills which might be considered to include a health insurance mandate include:

SB09-88 – State Group Benefits for Domestic Partners –Referred by the House State, Veterans, and Military Affairs Committee to the House Committee on Appropriations

SB09-103 – Unfair Practice for Incentives to Deny Claims – Scheduled for Senate Appropriations Committee on March 13

The Commission has already reported on SB09-159 increasing the dependent health care coverage age and our report transmitted to the Senate Health and Human Services Committee. The Commission was asked to meet and report on SB09-244 on coverage for autism before March 19th, but we were unable to ensure a quorum would be present and will be meeting on the bill on March 20th.

Please understand that the Commission wants to provide a useful service to the General Assembly and Division of Insurance but cannot do so without being granted the consideration of time to fully study, consider the issues, hear from all interested parties, and prepare its analysis. We would also appreciate your guidance as to what information from the Commission would be of assistance to you in your deliberations on these proposals.

In the past, the practice has been to refer bills to the Commission with a short deadline for Commission to report back. This has frustrated all parties: Legislators object to being forced into a separate executive process before their bills can be heard in committee; proponents of proposals found the

Commission’s assessment tool and process intimidating; opponents of proposals were disappointed the Commission did not take positions in favor of or opposed to legislation; and, the Commission members found the time constraints for them to meet and report unreasonable and sometimes unachievable.

To overcome these difficulties, the Commission respectfully requests that early consideration be given as to whether a legislative proposal will be referred to the Commission. If proposals are to be analyzed by the Commission, the Commission needs time to schedule meetings with sufficient advance notice that interested parties may participate, Commission staff may conduct research on the issues, and the Commission may discuss and prepare its analyses.

Separately, if a proposal will not be sent to the Commission, it would be most efficient for the Commission to know this beforehand. As you know, Commission members are not compensated for their service. We are physicians, consumer advocates, industry employees, small business owners from as far away as Durango, and state legislators. To convene regularly only to try and predict the Legislature’s intent with regard to whether we can expect a particular mandate to be referred is unproductive and likely not what was intended when the Commission was established.

Please advise us of how you would like us to proceed. We look forward to working with you and appreciate the opportunity to serve our State and its citizens.

Sincerely,

The Members of the Colorado Mandated Health Insurance Benefits Commission

Senator Lois Tochtrop
Molly McCoy
Whitney Kennedy, M.D.
Ranmali Bopitiya
Leo Mailander
Rep. Christine Scanlan
Leo Tokar
Pam Nicholson
Wanda Cason
Peg Brown

Consumer protection is our mission

Consumer Protection