

*Information Summary and Recommendations*

# Treatment of Autism Spectrum Disorders Mandated Benefit Sunrise Review

January 2009





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## **THE SUNRISE REVIEW PROCESS**

In 1997 the Washington State Legislature passed House Bill 1191. This bill amended the statute on mandated health insurance benefits. The statute now requires proponents of such mandates to provide specific information to the legislature. If the legislature requests a review, and funds are available, the Department of Health makes recommendations on the proposal using statutory criteria. This review is done only at the request of the chairs of legislative committees, usually the House Health Care and Wellness Committee or Senate Health and Long-Term Care Committee.

The criteria for these “sunrise reviews” are contained in RCW 48.47.03. The legislature's intent is that all mandated benefits show a favorable cost-benefit ratio and do not unreasonably affect the cost and availability of health insurance. RCW 48.47.005 states, “...the cost ramifications of expanding health coverage is of continuing concern and that the merits of a particular mandated benefit must be balanced against a variety of consequences which may go far beyond the immediate impact upon the cost of insurance coverage.”



## **EXECUTIVE SUMMARY**

### **Proposal**

In August 2008 the Legislature directed the Department of Health to review a draft bill for a new mandated insurance benefit. Arzu Forough of Washington Autism Advocacy submitted a proposal to assess the bill based on the statutory criteria. The proposal would require plans to include coverage for the diagnosis and treatment of autism spectrum disorders (ASD). It would cover people less than 21 years of age. The benefit would have a \$50,000 per year maximum. It would apply to all state-purchased health plans, private health insurance plans, health maintenance organizations, and group disability plans.

Covered treatment would include:

- Habilitative or rehabilitative care, including applied behavior analysis;
- Pharmacy care;
- Psychiatric care;
- Psychological care;
- Therapeutic care;
- Any care determined medically necessary by a licensed physician or licensed psychologist.

Under the proposal, Department of Health would establish the standards used by health plans to credential autism service providers. The agency could require that a health plan grant credentials to an autism service provider if it determines meets or exceeds the standards.

### **Recommendation**

The legislature should not enact the bill in its current form. Children with autism spectrum disorder clearly need increased access and funding for treatment. However, the language of this bill is too vague to allow the department to determine whether the benefits outweigh the costs. In addition, it would not likely offer meaningful guidance to insurers, providers, or the department. The detailed recommendations on page 16 list concerns with the bill as drafted, as well as suggestions for addressing those concerns.



## SUMMARY OF INFORMATION

### Overview of Proceedings

Department of Health informed interested parties of the mandated benefit review. Interested parties included parents of children with autism spectrum disorders, insurance carriers, and health care providers. The proponent, Arzu Forough, submitted a proposal to assess the bill based on the statutory criteria (See Appendix A). The department shared the proposal with interested parties and invited them to comment. Agency staff did research when needed and reviewed all information submitted.

We conducted a public hearing on Sept. 5, 2008. Interested parties, including parents of children with autism spectrum disorders, health care providers, a representative from the insurance industry, and a representative from the state Health Care Authority (HCA), presented testimony. A review panel assisted with the hearing by asking clarifying questions of the hearing participants. We sought further comments from interested parties after the hearing.

We sent a draft report to participants and interested parties for review. There was a 10-day rebuttal period to comment on the draft report. Once the final comment period ended, staff finalized the recommendations. The final draft was reviewed and approved by the Assistant Secretary for Health Systems Quality Assurance and the Secretary of the Department of Health. The final report was sent to the legislature via the Office of Financial Management.

### Background

In 2007 the Caring for Washington Individuals with Autism Task Force issued a report on autism spectrum disorders. Their report listed an insurance mandate for evidence-based autism spectrum disorders services as its highest and most urgent priority. The proposal under review was not submitted by the task force. However, the task force's 2007 report included a recommendation for an analysis to assess the sunrise criteria.

Autism spectrum disorders (ASD) are pervasive developmental disorders characterized by impairments or delays in social interaction, communication and language, as well as by repetitive routines and behaviors. They are called spectrum disorders because of the wide range and severity of symptoms. Children diagnosed with ASD suffer from problems with sensory integration, speech, and basic functions like toilet training, getting dressed, eating meals, brushing teeth, or sitting still during classes. Many medical conditions can accompany autism spectrum disorders. These include digestive problems, severe allergies, inability to detoxify, very high rate of infection, and vision problems. Some children with ASD display violent or self-harmful behaviors. IQs in children with this disorder range from superior to severely mentally retarded.<sup>1,2</sup>

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<sup>1</sup> "Caring for Washington Individuals with Autism Task Force: Report to the Governor and Legislature," Caring for Washington Individuals with Autism Task Force, 2006, Executive Summary.

<sup>2</sup> *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> ed., American Psychiatric Association, Washington DC, 1994, pp. 65-66.

Autism spectrum disorders affect as many as one in 150 children nationally. It affects three to four times more boys than girls<sup>3</sup> and is as common as juvenile diabetes, and more common than childhood cancer, Down syndrome, deafness, or cystic fibrosis.<sup>4</sup> However, treatment for ASD is not covered under most insurance plans.

The proponent, parents, and medical professionals testified that autism spectrum disorders are a biological medical condition, not mental illness. However, there is some debate about this issue. The proposal defines ASD as “any of the pervasive developmental disorders as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM).” A report by the Surgeon General describes autism as, “a severe, chronic developmental disorder, which results in significant lifelong disability.” The Surgeon General report further states that autism “has roots in both structural brain abnormalities and genetic predispositions”.<sup>5</sup> Treatment for autism spectrum disorders can include psychiatric care, neurodevelopmental therapies, and treatment for co-occurring medical conditions. ASD is diagnosed by medical doctors and mental health providers.

### **Need for treatment**

“Autism spectrum disorders are considered habilitative, life-long conditions that are evident before the age of three years and persist throughout the life span. Habilitative means individuals may improve with ongoing appropriate treatment and intervention. Without ongoing treatment and intervention, individuals will regress. There is no cure for autism spectrum disorders; however, research shows that children with ASD and related disorders are greatly helped if they receive proper early intervention. Youth and adults with ASD and related disorders benefit greatly from ongoing appropriately designed environments, supports, and techniques that allow them to continue learning and to find meaningful work in the community.”<sup>6</sup>

The American Academy of Pediatrics (AAP) reports that early intervention is crucial for effective treatment of autism spectrum disorders. The AAP clinical report, “Management of Children with Autism Spectrum Disorders” strongly advises intervention as soon as an ASD diagnosis is seriously considered, rather than deferring until a definitive diagnosis is made. The report further states that the child should be actively engaged in intensive intervention at least 25 hours per week, 12 months per year.<sup>7</sup>

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<sup>3</sup>“Surveillance Summaries. Prevalence of Autism Spectrum Disorders--Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002,” *MMWR Morbidity Mortality Weekly Report*, Centers for Disease Control and Prevention, February 9, 2007, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm>, accessed on October 1, 2008, cited by proponent’s proposal, Appendix A.

<sup>4</sup>“Caring for Washington Individuals with Autism Task Force: Report to the Governor and Legislature”, 2006, Caring for Washington Individuals with Autism Task Force, 2006, pp. 4-5.

<sup>5</sup> “Mental Health: A Report of the Surgeon General”, The Surgeon General of the Public Health Service, 1999, pp. 6-7.

<sup>6</sup> “Caring for Washington Individuals with Autism Task Force: Report to Governor and Legislature: Priority Recommendations and Implementation Plans,” Caring for Washington Individuals with Autism Task Force, 2007, p. 3.

<sup>7</sup> Scott M. Meyers, Chris Plauche Johnson, MEd Council on Children with Disabilities, *Pediatrics*, Vol. 120, No. 5, November 2007, “Management of Children with Autism Spectrum Disorders,” pp. 1162-1182.

Intensive early intervention often leads to children with autism spectrum disorder being able to enter mainstream classes in school. It can lead to independence as an adult, ability to enter the workforce, and ability to achieve a higher quality of life than those who do not receive early treatment.

Lack of early intervention often leads to a greater need for services within the educational system, higher health care costs, and in severe cases, institutionalization. Testimony was provided at the hearing that over half of the children institutionalized in Washington state have autism.<sup>8</sup>

### **Treatment options**

The Surgeon General states, “Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child’s social and language development and minimize behaviors that interfere with the child’s functioning and learning. Intensive, sustained special education programs and behavior therapy early in life can increase the ability of the child with autism to acquire language and ability to learn.”<sup>9</sup>

There have been many studies that show the efficacy of applied behavioral methods for reducing inappropriate behavior and increasing communication, learning, and appropriate social behavior. The proponent provided a number of studies showing the efficacy of applied behavior analysis (ABA). ABA is described as a treatment concerned with the application of behavioral science in real-world settings such as clinics or schools with the aim of addressing socially important issues such as behavior problems and learning.

There are currently no licensing or regulatory standards relating specifically to the practice of ABA in Washington state. National certification is available through the Behavior Analyst Certification Board. Requirements for national certification include a master’s degree from an accredited institution, minimum training and fieldwork experience, an examination and continuing education.

Parents who testified at the hearing provided several consistent messages regarding ABA: 1) It is effective in addressing their children’s needs; 2) It is time intensive — as many as 35 hours or more per week; 3) Certified ABA providers are difficult to access; 4) Many parents are forced to employ providers with little or no formal training.

Although it was not discussed at length in the proposal, parents also testified regarding the efficacy of neurodevelopmental therapies (physical therapy, occupational therapy, and speech-language therapy). These are all licensed and regulated health care professions in the state of Washington. However, the parents also described the difficulties in accessing applied behavior analysis providers as frequently as is necessary for maximum results.

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<sup>8</sup> See testimony of Diana Stadden, Hearing Summary.

<sup>9</sup> “Mental Health: A Report of the Surgeon General”, The Surgeon General of the Public Health Service, 1999, pp. 6-7.

There are a number of other available treatments for autism spectrum disorder (ASD) that the proposal did not address. Public testimony suggested the following additional treatments are effective for treating some children with ASD. Please note that evidence of efficacy, and in some cases safety, was not provided for this review:

- Relationship Development Intervention (RDI): A parent-based clinical treatment program in which parents are given tools to effectively teach motivation and relationship intelligence to their child.
- Water Therapy or Aquatic Therapy: Water activities provide sensory input to children with significant sensory difficulties and who over or under-react to stimuli.
- Floortime or Developmental Individual Difference Relationship Model (DIR Model): Involves meeting a child at his or her current developmental level, and building upon a particular set of strengths. By entering into a child's world, support can be given to climb the 'developmental ladder' despite having ASD.
- Hippotherapy: Using horses as a means of treatment. The movement from the horse elicits an adaptive response from the child.
- The Handle Method: Embraces aspects of many other disciplines and therapies and provides an integrated structure for guiding and enhancing neurodevelopmental substrata which support social and academic learning. It also incorporates aspects of personal motivation and aspirations, and of empowering individuals and families to heal themselves.
- Chelation therapy: Removes heavy metals from the body.

### **Financial burden**

The proponent wrote about the financial burden, "In the absence of coverage, out-of-pocket expenses for services can cost upwards of \$50,000 per year. In the process of trying to attain medical treatments and therapies, many risk their homes and the educations of their unaffected children—essentially mortgaging their entire futures."

Many parents spoke at the public hearing and wrote letters describing the extraordinary financial burden of autism. They discussed treatments costing up to \$40,000 to \$100,000 per year for families with children most severely impacted by autism spectrum disorder (ASD). Many families told about being forced into bankruptcy or home foreclosure to pay for treatment. Others spoke of cashing in retirement and college funds, borrowing from extended family, and charging up the maximum on multiple credit cards.

### **Current coverage**

Some of the confusion over coverage for ASD arises from the fact that it is unclear whether treatments should be covered under mental health, physical health, or neurodevelopmental therapies.

#### *Neurodevelopmental therapy mandate:*

An insurance mandate already exists in Washington that covers occupational therapy, physical therapy, and speech-language therapy. However, there are limitations to this mandate:

- The mandate ends at age seven, even though the need often continues long after;

- Some insurance carriers only cover a small portion of the therapies necessary to treat ASD. They often limit treatment to \$1,000 to \$2,000 per year and/or limit the number of visits. Effective treatment for children with autism spectrum disorder can far surpass these limits.
- Low income children in Washington eligible for Medicaid have no age limits or therapy limits for neurodevelopmental therapy services.

### *Mental health parity*

There is also a mental health parity mandate. It is unclear at this time how much (if any) ASD treatment should be covered under this mandate. The statute defines mental health services as, “medically necessary outpatient and inpatient services provided to treat mental disorders covered by the diagnostic categories listed in the most current version of the Diagnostic and Statistical Manual of Mental Disorders (DSM)...” Autism spectrum disorder is a disorder included in the DSM.

### *State and federal programs*

There are some programs that provide limited treatment for autism spectrum disorder. These include the Infant and Toddler Early Intervention Program’s (ITEIP) Birth to Three Program, some programs through the Department of Social and Health Services, Department of Health’s Children with Special Health Care Needs Program, neurodevelopmental therapy services under Medicaid, and some other ASD coverage under Medicaid.

A number of states have insurance mandates for autism. The Council for Affordable Health Insurance reports 11 states as having mandates. However, the proponent counts eight states as having autism parity mandates. The proponent reports as many as 21 states that have either introduced legislation or are working on legislation for autism parity mandates.

### *Private insurance*

Many parents described the Premera Blue Cross Health Insurance plan offered by Microsoft as being a model for other plans to follow. This plan covers applied behavior analysis (ABA) therapy for children with ASD. Providers must meet strict qualifications including a master’s or doctoral degree in education, psychology, speech/language pathology, behavior analysis or occupational therapy (or have national ABA certification), and 1,500 supervised hours working with children with autism spectrum disorder.

### **Education or health care?**

Anecdotal evidence given during the review indicates that autism spectrum disorder (ASD) treatment is sometimes considered the responsibility of schools. Representatives from the insurance industry and the Health Care Authority questioned whether this is an educational issue, rather than a health care issue.

Limited treatment may be available in schools. However, it is designed, as required by law, to be educationally-relevant. It is designed to allow the child to participate in the educational program. The therapy does not include skills the child may need in other environments such as home, work place, and the community.

## ASSESSMENT OF THE SUNRISE CRITERIA

### Social impact

#### **To what extent is the benefit generally utilized by a significant portion of the population?**

It is estimated that one in 150 children has autism spectrum disorder. All of these children have need of some level of autism treatment.<sup>10,11</sup>

#### **To what extent is the benefit already generally available?**

Intensive early intervention for autism, such as applied behavior analysis (ABA), is not generally available, nor is it covered through most health insurance plans.

There are a few programs that provide limited treatment to a small number of children with autism. These programs include:

- Infant and Toddler Early Intervention Program's (ITEIP) Birth to Three Program
- Programs through the Department of Social and Health Services
- Department of Health's Children with Special Health Care Needs Program
- Microsoft's private health plan
- Neurodevelopmental therapy services under Medicaid
- Other coverage under Medicaid

These programs are not generally available to a large portion of the population of children with ASD.

According to the 2007 "Washington State Autism Task Force Report", medically necessary treatment for people with autism spectrum disorder (ASD) is not widely available. It is routinely denied by insurance plans based on certain misconceptions. These include:

- ASD is widely seen as a mental illness, leading to referrals to ineffective treatments such as counseling or psychotherapy
- Treatment is considered habilitative, rather than rehabilitative
- Treatments are incorrectly thought of as being available in schools

#### **If the benefit is not generally available, to what extent has its unavailability resulted in persons not receiving needed services?**

Many children with ASD go without necessary treatments and services because the costs are so high and insurance coverage is not generally available. Many families simply cannot afford to pay for the necessary early, intensive treatments.

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<sup>10</sup> "Surveillance Summaries. Prevalence of Autism Spectrum Disorders--Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002," *MMWR Morbidity Mortality Weekly Report*, Centers for Disease Control and Prevention, February 9, 2007, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm>, accessed on October 1, 2008, cited by proponent's proposal, Appendix A.

<sup>11</sup> Eric Fombonne, "Epidemiology of Autistic Disorder and Other Pervasive Developmental Disorders," *Journal of Clinical Psychiatry*, 66 (suppl 10), 2005, pp. 3-8, cited by proponent's proposal, Appendix A.

Several parents stated that they chose less expensive, less effective therapies or unqualified providers because that is all they could afford. Many families said they were forced to end effective treatments because they could no longer afford to pay for them.

**If the benefit is not generally available, to what extent has its unavailability resulted in unreasonable financial hardship?**

“In the absence of coverage, out-of-pocket expenses for services can cost upwards of \$50,000 per year. In the process of trying to attain medical treatments and therapies, many risk their homes and the educations of their unaffected children — essentially mortgaging their entire futures.”<sup>12</sup>

Many families wrote letters and testified at the hearing about the severe financial hardships caused by the high cost of treatment for autism spectrum disorder. The costs of treatments for children more severely impacted ranged from \$40,000 to \$100,000 per year. However, the proponent also notes that the cost for older children and those less severely impacted are often much lower, with average costs of \$9,000 to \$15,000 per year. Without adequate insurance coverage, parents were forced to cash in retirement accounts and college funds, charge up the maximum on multiple credit cards, borrow from extended families, take out second mortgages or sell their homes, or hold fundraisers in their communities.

We received testimony about families being in dire financial positions in order to pay for necessary treatments for their children with ASD. Many were forced to file bankruptcy or lost their homes to foreclosure. Many have spent their life savings on treatments. Some have been forced to quit their jobs because their children with ASD need full-time care. Parents also shared stories about siblings of children with this disorder being forced to sacrifice dental or vision care, sports, and other opportunities so their family could pay for treatment.

In addition, parents of children with autism spectrum disorder reported a higher than average divorce rate, which often results in increased financial hardship for the family. They believe effective ASD treatment provides a benefit to the entire family, not just the child.

**What is the level of public demand for the benefit?**

The demand for autism treatments is high. During the review, over 80 families stated there is a great need for an autism benefits mandate. No member of the public testified that ASD treatment is unnecessary. However, several parties commented that singling out ASD for a mandate unfairly excludes children with other developmental disabilities, such as Down syndrome.

**What is the level of interest of collective bargaining agents in negotiating privately for inclusion of this benefit in group contracts?**

The proponent did not have sufficient information to address this question.

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<sup>12</sup> See proponent’s response included in proposal.

## **Financial impact**

### **To what extent will the benefit increase or decrease the cost of treatment or service?**

Some testimony speculated that if ASD benefits were mandated, more health care professionals would elect to provide these services. Based on theories of supply and demand, an increased number of providers might possibly reduce the costs.

### **To what extent will the coverage increase the appropriate use of the benefit?**

Financial limitations are a major barrier to obtaining treatment for ASD. Anecdotal evidence shows that many families are forced to choose treatments based on financial restraints, rather than on what is in the best interest of their children. It is likely that removing or reducing the financial barriers will increase the appropriate use of autism benefits.

### **To what extent will the benefit be a substitute for a more expensive benefit?**

Lack of early intensive intervention can often lead to children with autism being placed in foster care, residential homes, and institutions. Lack of a current benefit is likely to increase the number of individuals who are dependent upon others (including state sponsored programs) for housing, supervision, and vocational support as adults.

According to the proposal, the cost estimate to tax payers for children who become wards of the state is \$4.3 million to \$7.2 million over the course of their lifetime. Costs for institutionalization ranged from \$76,000 per year to over \$192,000 per year.

### **To what extent will the benefit increase or decrease the administrative expenses of health carriers and the premium and administrative expenses of policyholders?**

- The proponent states the proposal as written will increase costs from 0.0023% to less than one percent.
- The Health Care Authority's (HCA) analysis of impact on the Public Employee Benefit Board (PEBB) programs estimates the annual cost increase to PEBB would be one percent or slightly greater.
- The Association of Washington Health Care Plans (AWHP) estimates the cost increase would be two percent. This estimate is higher than HCA's estimate because: (1) the PEBB already provides more benefits than most employer sponsored plans, and (2) AWHP used the rate of one in 150 children affected by autism spectrum disorders in their estimate, rather than the lower rate of one in 231 that was figured by HCA.

The proponent and many interested parties disagree with the HCA's estimate. They have stated they feel the assumption every child will generate \$50,000 in new claims is wrong. According to the proponent, the parents who testified to the highest costs were those with the most severely affected children. Since ASD is a spectrum disorder, those at the mild-to-moderate end will likely use a smaller percentage of the allowable amount, and for a shorter time period. The proponent showed an average cost per child of \$9,000 to \$15,000 per year for children less severely affected.

**What will be the impact of this benefit on the total cost of health care services and on premiums for health coverage?**

- The proponent estimates the proposal will raise premiums by about \$0.65 per member per month, with an impact on the monthly employer funding rate of \$1.25 per employee increase for fiscal year 2011.
- The Health Care Authority (HCA) estimates the proposal will raise premiums by over \$5.00 per member per month, with an impact on the monthly employer funding rate of \$9.80 per employee increase for fiscal year 2011.

**What will be the impact of this benefit on costs for state-purchased health care?**

The proponent stated the impact should be negligible. However, HCA estimates the costs of this mandate as drafted would be \$26,654,439 for the 09-11 biennium.<sup>13</sup>

**What will be the impact of this benefit on affordability and access to coverage?**

According to the proponent, this benefit would make treatments attainable and affordable to families who currently do not have access to them. This would, in turn, support and increase provider capacity, which would lead to much improved access to treatment. In the states where autism parity has been in existence, there has only been significant improvement in terms of affordability and access to coverage.

Mel Sorenson, who represents the insurance industry, stated that as the costs go up with mandating services, many small employers are forced to drop coverage they can no longer afford.

**Efficacy**

**If a mandatory benefit of a specific service is sought, to what extent has there been conducted professionally accepted controlled trials demonstrating the health consequences of that service compared to no service or an alternative service?**

Although the proposed bill would cover a large range of services, including “any care” determined medically necessary by a licensed physician or psychologist, the only specific service addressed is applied behavior analysis (ABA). The proponent submitted studies that support the efficacy of ABA compared to no treatment or alternative treatments. In these studies, the groups receiving ABA scored consistently higher in IQ, language and communication, and behavior at the end of each study.<sup>14</sup>

In addition, the Surgeon General states that 30 years of research has demonstrated the efficacy of applied behavioral methods.<sup>15</sup>

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<sup>13</sup>See Health Care Authority submission, Appendix D.

<sup>14</sup>Multiple sources used. See proponent’s response, Appendix A.

<sup>15</sup>“Mental Health: A Report of the Surgeon General, The Surgeon General of the Public Health Service, 1999, pp. 6-7.

Other treatments discussed during public testimony included Relationship Development Intervention, Developmental Individual Difference Relationship Model (DIR Models) such as Floortime, chelation therapy, hippotherapy, and the Handle Method. The proposal did not address these other treatments and in researching further, there may not be adequate clinical studies to prove their efficacy or in some cases, their safety.<sup>16</sup>

**If a mandated benefit of a category of health care provider is sought, to what extent has there been conducted professionally accepted controlled trials demonstrating the health consequences achieved by the mandated benefit of this category of health care provider?**

Applied Behavior Analyst would be a new category of health care credential in Washington. There is a national association called the Behavior Analyst Certification Board, which credentials BCBA's using the strict qualification standards discussed above.

The proponent did not provide information on professionally accepted controlled trials for this provider category. In addition, a sunrise review for this profession has not been requested and the sunrise criteria for a new health profession have not been addressed in this review.

**To what extent will the mandated benefit enhance the general health status of Washington residents?**

Enhancements cited by the proponent:

- Improved independent functioning and quality of life for those children and youth with autism spectrum disorder (ASD) who will have access to medically necessary treatments not currently attainable for them.
- Potentially lower rates of inpatient psychiatric hospital use (for children who receive early diagnosis and intensive early intervention).
- Substantial improvements in functioning in children with ASD (one study suggests 47 percent of the children in behavior treatment achieve normal intellectual and educational functioning as compared to two percent of those who received standard medical and educational benefits only).<sup>17</sup>
- Improved engagement, socialization, and communication, as well as reduced maladaptive behaviors in children with ASD.
- Easing of emotional and health strains on families and caregivers of individuals with autism.

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<sup>16</sup> "Report of the MADSEC Autism Task Force," Maine Administrators of Services for Children with Disabilities (MADSEC), February 2000, pp. 53-53.

<sup>17</sup> D. Mandell et al., "Medicaid expenditures for children with autistic spectrum disorders: 1994-1999," *Journal of Autism and Developmental Disorders*, 2006; 36(4), cited by proponent's proposal, appendix A.

## **FINDINGS**

- Autism Spectrum Disorder (ASD) affects as many as one in 150 children. It's as common as juvenile diabetes, and more common than childhood cancer, Down syndrome, deafness, or cystic fibrosis.
- In many cases, intensive early intervention enables children with ASD to enter mainstream classes in school and to grow into contributing members of society. Without treatment, both families and the state are often required to provide extensive support services for the rest of the child's life.
- Over half of the children institutionalized in Washington have ASD.
- Intensive remediation for autism is not covered by most health insurance plans.
- Many children in Washington with ASD go without treatment and services because the costs are so high and insurance coverage is not generally available.
- The high costs of treatments for ASD cause severe financial hardships for families.
- There have been studies proving efficacy of applied behavior analysis.
- Neurodevelopmental therapies are effective in treating ASD.
- We did not receive information on the efficacy of other treatments for ASD.
- Current coverage included in plans under the neurodevelopmental and mental health parity mandates are often insufficient for treatment of ASD.
- A number of states have enacted insurance mandates for autism spectrum disorders. Some specifically require coverage of applied behavior analysis.
- The limited treatment available in schools is designed, by law to be educationally relevant and allow the child to participate in the educational program. The therapy does not include skills the child may need in other environments such as the home, work place, and community.

## **DETAILED RECOMMENDATIONS TO THE LEGISLATURE**

The legislature should not enact the proposed bill in its current form. Children with autism spectrum disorder (ASD) clearly need increased access and funding for treatment. However, the language of this bill is too vague to allow the department to determine whether the benefits outweigh the costs. In addition, in its current form, the bill would likely fail to offer meaningful guidance to insurers, providers or Department of Health.

The proposed bill poses the following concerns:

1. The bill does not specify what treatments will be covered. The vague and over-broad language in section (3)(m) of the proposed bill does not provide sufficient guidance for insurers, providers, or consumers. The blurred lines between the medical, behavioral, and mental health aspects of ASD would likely cause extensive disputes regarding applicability and appropriate coverage. In addition there are numerous treatment modalities referenced for which there is no proof of efficacy.
2. The bill does not specify what providers could be compensated. Section (3)(o) requires the department to “establish standards to be utilized by health plans for the credentialing of autism service providers.” However, it does not require the department to have licensing or regulatory authority over those providers. Once again, the lack of clarity would likely result in extensive disputes regarding what providers and which services were covered by the mandate.
3. There are existing mandates that should be reviewed that may provide the coverage these families are seeking. These are the neurodevelopmental therapy mandate and the mental health parity mandate.
4. The costs to implement this mandate as proposed are difficult, if not impossible, to determine as is demonstrated by the three vastly different cost estimates.

The concerns listed above could be addressed in the following ways:

1. Expand the neurodevelopmental therapy mandate to:
  - a. Require increased coverage amounts. Currently many health plans limit the dollar amount and/or the number of visits available for these therapies. The limits do not meet the needs of children with ASD.
  - b. Require coverage for applied behavior analysis (ABA) when performed by (or under the supervision of) nationally certified providers. ABA is an effective treatment for ASD when provided by appropriately-educated and experienced professionals. Current standards for national certification ensure adequate training.
  - c. Raise or eliminate the age limit for benefits. Currently, benefits under this mandate end at age seven. Children with ASD often need therapy far past that age in order to become self-sufficient members of society. Treatment should be allowed for a significantly longer period.<sup>18</sup>
  - d. Match services currently available to low income children on Medicaid in Washington state.

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<sup>18</sup> In 2001, the department conducted a sunrise review that recommended in favor of removing the age limit of six and under for the neurodevelopmental therapy mandate.

2. Expand and/or clarify the mental health parity mandate to include treatment for ASD. ASD is defined as a developmental disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM). Psychiatric and psychological care is plainly envisioned by the proposed bill. Other therapies, such as ABA, appear to have significant mental health components. Treatment related to mental health care or provided by mental health providers should be covered by this mandate.



## APPENDIX A

### Proposal submitted to Department of Health

#### **Autism Insurance Parity Proposal prepared by Arzu Forough, Washington Autism Advocacy**

Autism and autism spectrum disorder (ASD) are complex biomedical brain disorders.<sup>19</sup> The severity of these disorders varies along a continuum, with some individuals having more profound problems in one key diagnostic area than others, and is associated with the full range of cognitive abilities. As is true of many other biomedical disorders, there is currently no cure for autism. Rather, autism care is focused on controlling or diminishing symptoms and associated impairments. In this way it does not differ from numerous other chronic medical disorders whose treatment is covered routinely by health insurance, including hypertension, diabetes, renal failure, and asthma.

Additionally, there is evidence that a number of diverse treatments can lead to improved functioning in autism, some to remarkable degrees. Like many other medical conditions these treatments include non-pharmacologic approaches. For instance, exercise, general diet, and avoidance of environmental factors such as salt and concentrated sugars are considered to be key elements of the management of hypertension and diabetes. Very often these treatments lead to markedly improved function.

#### **(a) Social impact:**

Multiple strands of the submitted evidence to the “The Caring for Washington Individuals with Autism Task Force” support the fact that ASD related services are needed by significant numbers of Washington children. In their executive report to the governor at the end of 2007, the task force named health insurance coverage of autism related treatments for individuals as the number one priority for the state of Washington. This was after two years of carefully studying available resources and the needs of the state. For a complete review of the report, please go to the following link (see pg. 17 of 139):

[http://www.doh.wa.gov/cfh/mch/Autism/documents/2007\\_Report/ATFRptFinal1207.pdf](http://www.doh.wa.gov/cfh/mch/Autism/documents/2007_Report/ATFRptFinal1207.pdf)

#### **(i) To what extent is the benefit generally utilized by a significant portion of the population?**

Because ASDs are chronic, often disabling disorders, by definition *all* children who meet the diagnostic criteria for ASDs have important health and related needs. Recent evidence from multiple epidemiologic studies, including two of those submitted<sup>20,21</sup> points to a population prevalence of ASDs of about 1 per

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<sup>19</sup> This is a clearly established fact that is also stated in several of the pieces of evidence such as the autism fact sheet from the National Institute for Child Health and Human Development which states “Autism is a complex neurobiological disorder”.

<sup>20</sup> Frombonne E, 2005. Epidemiology of autistic disorder and other pervasive developmental disorders. *Journal of Clinical Psychiatry* 66(suppl 10):3-8.

150 children. There is no reason to believe that the true prevalence of autism spectrum disorder among children in Washington is lower from that estimated in the recent studies. It is clear that a substantial number of Washington children have ASD according to Office of Superintendent of Public Instruction (OSPI) 6,025 children with ASD were served in Washington schools in 2007, a 15 percent increase from 2006. This does not include children who are pre-school age or younger, home schooled, or in private schools.

**(ii) To what extent is the benefit already generally available?**

Although the submitted evidence in the Caring for Washingtonians with Autism Task Force documents that many comprehensive services for children with ASD exist in Washington (such as comprehensive developmental assessment, combination of behavioral, physical, occupational, and speech therapies, and in some cases, medications, and other related medically necessary treatments), it also identifies important barriers that reduce access to those services.

Personal experiences described by parents and other family members, as well as the independent status report by the Washington State Autism Task Force in 2007 clearly show that medically necessary treatments for individuals with autism are not widely available through any state agencies and are routinely denied by insurance based on several misconceptions:

- Autism is widely regarded erroneously as a mental illness, which often leads to referrals to inappropriate and ineffective treatments such as counseling or psychotherapy instead of neurodevelopmental, cognitive behavioral or social communication therapies.
- The caps imposed on treatment under the neurodevelopmental therapies mandate make effective duration of treatment unattainable by most Washingtonians with autism. Children exceed their yearly benefit routinely and they are, in effect, uninsured for the rest of the year. In many cases, employer packages offer no neurodevelopmental therapies at all.
- Treatment is considered habilitative vs. rehabilitative and therefore is denied.
- Well-researched and well-established effective treatments for core symptoms of autism are only covered by two major employers, Microsoft (through Premera) and military (through Tricare), these treatments are also not available through any other state agency (DSHS, Mental Health agency).
- Medical treatment for autism is erroneously thought of as being available in schools and therefore not the responsibility of insurers.

Additionally substantial evidence in the scientific and medical literature that was included in the submissions documents demonstrate that early detection and intervention are critical to the ultimate functioning level of people with ASD, underscoring the importance of the benefit's focus on providing care for children under age 21.<sup>22</sup>

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<sup>21</sup> CDC Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network Surveillance, 14 sites, United States, 2002. Morbidity and Mortality Weekly Report 56/SS-1:12-28.

<sup>22</sup> There are too many pieces of submitted evidence attesting to this to list all of them, but examples include Bryson SE, Rogers SJ, Frombonne E, 2003. Autism spectrum disorders: early detection, intervention, education, and psychopharmacological intervention. Canadian Journal of Psychiatry, 48: 506-516; Rogers, SJ, 1998. Empirically supported comprehensive treatments for young children with autism. Journal of Clinical Child Psychology 27:168-179; New York State Department of Health, Clinical

There is broad consensus across medical and other fields that treat children with ASD (e.g., pediatrics, psychiatry, neurology and the allied fields of psychology, speech therapy, occupational therapy, and physical therapy) that the best and most efficacious treatment of autism requires early recognition and diagnosis, as well as early intensive treatment while the brain has the maximum potential to recover and/or compensate for the underlying pathophysiologic processes.

Intensive remediation through repeated appropriate behaviors in affected brain processes (communication, social responsiveness, sensory processing), which is analogous to physical therapy for victims of stroke or nerve damage, is very widely accepted as a critical element in the treatment of autism. The submitted evidence supporting this point is too numerous to list in their entirety but include the National Institute of Child Health and Human Development Autism Overview:

“Research shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms. . . . Because a young child’s brain is still forming, early intervention gives children the best start possible and best chance of developing their full potential. Even so . . . it’s never too late to benefit from treatment. **People of all ages with ASDs at all levels of ability generally respond positively to well designed interventions.**”<sup>5</sup>

However in Washington, intensive remediation for autism is not available to the general public. Aside from two employers, Microsoft and the military, intensive remediation for autism is **not** available through employer health benefits, state health agencies, DSHS, DDD, or mental health agencies.

**(iii) If the benefit is not generally available, to what extent has its unavailability resulted in persons not receiving needed services?**

Peele et al<sup>23</sup> analyzed data from 128 behavioral health plans that were in effect in 1996 and 1998 to determine the exclusions and limitation in coverage. They found that a significant proportion of plans had benefit exclusions and limitations for ASD. Thee authors concluded that affordability of treatment (health plan coverage increases affordability for families) is an important determinant of access. Exclusions and high co-payments were also important determinants of access. Because of benefit limitations, the authors report that parity legislation did not often meet the health care requirements of children with behavioral health needs. Furthermore if children exceeded their yearly benefit they would be, in effect, uninsured for the rest of the year.

Similar to the above study, the high cost of treatment has forced Washingtonians with autism to go without prescribed medically necessary treatments and needed services. This is widely reported by families from all across Washington State and documented by the Caring for Washingtonians Autism

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Practice Guideline, Report of the Recommendations Autism/Pervasive Developmental Disorders 1999; publication no 4215 and Clinical Practice Guideline: The Guideline Technical Report,1999.

<sup>23</sup> Peele PB, Lave JR, Kelleher KJ. Exclusions and limitations in children’s behavioral health care coverage. *Psychiatric Services*. 2002; 53:591-594.

Task Force final report to the Governor and Legislature.<sup>24</sup>

**(iv) If the benefit is not generally available, to what extent has its unavailability resulted in unreasonable financial hardship?**

In the absence of coverage, out-of-pocket expenses for services can cost upwards of \$50,000 per year. In the process of trying to attain medical treatments and therapies, many risk their homes and the educations of their unaffected children – essentially mortgaging their entire futures.

The Caring for Washingtonians with Autism Task Force Final Report to the Governor and Legislature Priority Recommendations and Implementation Plans<sup>6</sup> issued by the Department of Health in December 2007 contains extensive commentary on the inadequacies in the diagnosis, treatment, and support services for children in Washington with autism spectrum disorder and the impact of these inadequacies on families. The task force was comprised of family members of people living with autism, service providers, educators, administrators, and researchers. It was charged with developing a plan for a new system of organization, coordination, and delivery of services to people with autism in Washington. Among the inadequacies identified were limitations in the state agencies for identifying and treating autism and the shortage of qualified providers to diagnose and treat ASD due in part to the lack of insurance coverage for necessary services.

Sharpe & Baker (2007) have reported in the Journal of Family and Economic Issues on a study of financial issues associated with having a child with autism.<sup>25</sup> Between July 2003 and May 2004, the authors surveyed a convenience sample of 333 parents and primary caregivers living in the Midwest who had a child with autism under 19.

They asked questions about autism-related expenses, receipt of publicly funded services, financial problems, and employment difficulties. They analyzed responses to the following (yes/no) question: “During the past twelve months, has your family had financial problems because of your child’s autism or related conditions?”

Two main characteristics distinguished the families who reported experiencing financial problems:

(1) they utilized medical interventions and had un-reimbursed out-of-pocket expenditures for medical doctor or therapy or services (by 121%, 264%, and 289%, respectively) and

(2) those with incomes under \$40,000 were more likely to have financial problems than those with higher incomes. The authors also noted “*Many survey respondents forfeited financial security and even experienced bankruptcy to provide needed therapy for a child with autism*” (Sharpe & Baker, 2004, p. 247, 259).

**(v) What is the level of public demand for the benefit?**

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<sup>24</sup> The Caring for Washingtonians with Autism Task Force Final Report to the Governor and Legislature Priority Recommendations and Implementation Plans December 2007 [http://www.doh.wa.gov/cfh/mch/Autism/documents/2007\\_Report/ATFRptFinal1207.pdf](http://www.doh.wa.gov/cfh/mch/Autism/documents/2007_Report/ATFRptFinal1207.pdf)

<sup>25</sup> Sharpe DL & Baker DL (2007). Financial issues associated with having a child with autism. Journal of Family and Economic Issues 28:247-264.

To gauge the demand for the proposed benefit from the public, one would need to assess the amount of unmet need and the amount of family out-of-pocket costs that would be covered by the benefit. Washingtonians with autism and their families, treating physicians, therapy providers, medical centers, hospitals, and clinics are all affected adversely by the lack of benefit.

The evidence submitted on lack of health care coverage, health care costs and expenditures, health services use, and the burden of autism (financial and humanistic), have led all the above parties to demand for this benefit.

The submitted evidence, reviewed in detail below, does present evidence that caring for children and young adults who have autism spectrum disorder are expensive, and that the increased costs of care, relative to children and young adults without ASD, are driven by direct medical costs (physician visits, therapies, non-pharmacologic treatments, psychotropic medications, psychiatric hospitalizations), and indirect costs (lost productivity/income of parents and caregivers).

### *Burden of autism*

A number of articles are submitted as evidence about the burden of autism. Järbrink, and Knapp (2001)<sup>26</sup> and Ganz (2007)<sup>27</sup> present data on the financial burdens of autism and Sánchez-Valle et al (2008)<sup>28</sup> provide evidence about the humanistic burden of autism. Järbrink and Knapp present an often-cited cost of illness (COI) model from the

UK perspective that is similar in methodological approach to the one published by Ganz (2007).<sup>9</sup> Costs for hospital services, other health and social services, living support, voluntary support, special education, medications, sheltered work (supported employment), day activities, lost productivity, family members' time costs, and family expenses were enumerated, costed, and combined to estimate the cost of autism.

Informal care costs were excluded due to uncertainty and lack of information and direct costs did not include costs associated with investigational or experimental treatments or criminal justice. Although, in general, the cost model itself has face validity and is widely cited.

More recently Ganz<sup>9</sup> estimated the lifetime costs of autism from a societal perspective for the United States. Using age- and sex-specific data on direct medical, direct non-medical, and indirect costs, Ganz estimated an average per capita discounted lifetime

Cost of \$3.2 million per person.<sup>8</sup> This model is similar in construction to the model presented by Järbrink and Knapp. Ganz, however, provides the costs of each component of care in five-year age categories which allows the reader to understand which costs are more relevant at different ages. The relative importance of different costs at different ages provides information on the source of payments.

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<sup>26</sup> Järbrink K, Knapp M. The economic impact of autism in Britain. *Autism*. 2001;5:7-22.

<sup>27</sup> Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*. 2007;161:343-349.

<sup>28</sup> Sánchez-Valle E, Posada M, Villaverde-Hueso A, et al. Estimating the burden of disease for autism spectrum disorders in Spain in 2003. *Journal of Autism and Developmental Disorders*. 2008;38:288-296.

According to Ganz, the total discounted lifetime costs of behavioral therapies (ending at age 21) are \$206,333, which is the largest component of direct medical costs. These behavioral therapies were estimated to cost more than the total lifetime costs of special education per child (\$150,483).

This article has been cited numerous times by a number of state governments to support extended services and mandated health insurance expansions for children and adults with autism (Missouri Department of Mental Health, the Alaska Governor's Council on Disabilities and Special Education, Caring for Washington Individuals with Autism Task Force, Arizona Autism Insurance Council, and the Nevada Department of Health and Human Services Autism Summit report).

In addition to economic burden of autism, there is a considerable humanistic burden of autism. Sánchez-Valle, et al<sup>10</sup> present an estimate of the disability adjusted life years (DALY), which is a population-level measure of the burden of illness.

**(vi) What is the level of interest of collective bargaining agents in negotiating privately for inclusion of this benefit in group contracts?**

All who are affected adversely by lack of coverage of Autism related medical care and therapies are highly motivated to have this benefit included in group contracts. We do not have sufficient information at this time regarding interest in collective bargaining agents.

**(b) The financial impact:**

**(i) To what extent will the benefit increase or decrease the cost of treatment or service?**

There have been parity benefits for autism across the nation which have provided data on claims impact. According to "Health Watch, For Professional Recognition of the Health Actuary", Issue 54, January 2007, page 21, Table 1: Marginal costs of mandated benefits for Autism were 0.0023 percent increase in total cost.

According to Council for Affordable Health Insurance (CAHI) Health Insurance Mandates in the States 2008 report, a state-by-state breakdown of health insurance mandates and their costs, lists estimated cost of autism at an unspecified percentage of <1 percent.

**(ii) To what extent will the coverage increase the appropriate use of the benefit?**

Individuals with autism all throughout Washington state will have access to medically necessary treatments prescribed by their treating physicians.

Three different research groups found that autism specific services are used by about 1/500 children (range 1/476 to 1/521).<sup>29</sup> Johnson and Hastings<sup>30</sup> found that financial limitations are a significant barrier to obtaining early intensive intervention. Some of these barriers (e.g., limited resources to cover

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<sup>29</sup> Leslie DL, Martin A, (2007). Health care expenditures associated with autism spectrum disorders. Archives of Pediatrics and Adolescent Medicine 161:350-355.; Litak GS, Sutart T, Auinger P, (2006). Health care utilization and expenditures for children with autism: data from U.S. national samples. Journal of Autism and Developmental Disorders. 36:971-879; Mandell DS, Cao J, Ittenbach R, Pinto-Martin J (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. Journal of Autism and Developmental Disorders 36: 475-485.

<sup>30</sup> Johnson E, Hastings RP, 2002. Facilitating factors and barriers to the implementation of intensive homebased behavioral intervention for young children with autism. Child Care and Health Development. 28:123-129.

transportation to appointments) might still be in effect even if the insurance parity were in place. However, it is seems likely that with one barrier (cost of service which is probably the most expensive) eliminated, use would increase.

**(iii) To what extent will the benefit be a substitute for a more expensive benefit?**

In the absent of benefits and resources for effective treatment, Washington children with autism are placed in foster care, which is seldom available given their extensive health care needs, residential homes, and institutions. Fircrest, a Washington residential institution has had children referred as young as six years old. Here in Washington, the cost to taxpayers when a person becomes a ward of the state is \$4.3 million - \$7.2 million over the course of their lifetime.

In Washington treatment resources for school aged children with autism are only available in crisis situations in form out of home residential placement and institutional care.

Community ICF-MR's are private facilities in the community (only five or six in the state) SOLA's are state operated living arrangements (state employees working at state run residential homes) RHC- residential habilitation Center--"institution", we have five, Fircrest is one of them.

On average, what is the cost of a staffed residential placement for a child?

*Answer: \$298.15 = \$108,824.75 per yr*

What are the costs of the small community ICF/MRs?

*Answer: \$210 per day. FY08 to date. = \$76,650 per yr*

What are the Cost of SOLAs?

*Answer: \$348 per day. FY08 to date + estimate for non-ADSA costs (depreciation and indirect costs) = 127,020 per yr*

What is the current average annual cost of a person in RHCs?

*Answer: \$527 per day. FY08 to date + estimate for non-ADSA costs (depreciation and indirect costs)= \$192,355 per yr (this is an average of all the institutions, Fircrest being the most expensive- cost for children has been higher, see below.)*

Annual Claim Rates for Nursing Facilities and ICF-MRs	Nursing Facilities	ICF-MRs	Combined	
Fircrest				
Fircrest -MR		\$232,300		
Fircrest combined			\$215,900	

Frances Haddon Morgan ICF-MR		\$195,600		
Statewide				
Statewide ICF-MR				
Statewide combined		\$194,000	\$191,200	

Data: DDD3-26-2008; Chart: Margaret-Lee Thompson, King Co. Parent Coalition for D.D. 5-13-08

In a 2006 article, David Mandell cites 10 years of research articles that suggest substantial improvements in functioning among children with autism spectrum disorder after behavioral rather than pharmacologic interventions.<sup>31</sup> In one cited study, 47 percent of the children in the behavioral treatment conditions achieved “normal intellectual and educational functioning” as compared to two percent of those who received standard medical and educational benefits only.

Higher levels of functioning are associated with lower health care costs. Children with autism who are lower functioning are more likely to use higher amounts of health care services for outpatient visits, medication, and inpatient stays.

In another 2006 article, Liptak et al. report on data from three (3) national health surveys conducted in 1999 and 2000 that reveal health care utilization and expenditures for children with autism.

Findings from this study indicate that children with autism, who most often lack coverage for effective behavioral therapies, use substantially more outpatient visits and use physician time longer during each visit than.<sup>32</sup>

Lack of the benefit clearly leads to delays in diagnosis and in implementing recommended treatments. Such delays are likely to directly impact families and educators of affected children. In addition they are likely to indirectly effect public schools and the Washington Medicaid system, as they are required to provide specialized education and more intense psychiatric treatment to children who have more severe autism-related impairments because they failed to receive early intervention.

The resources expended by these public agencies to meet the needs of children with autism who do not receive the benefit will either be taken from other programs in the agencies that serve other Washingtonians or will need additional tax support. Lack of the benefit also results in un-reimbursed medical expenses for many families who feel compelled to provide whatever treatment they can and but are not accessing those services through Medicaid. Several citizens and one survey reported that it is frequent for one parent to withdraw from the work force in order to provide such services directly or advocate for them.

<sup>31</sup> Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).

<sup>32</sup> Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders*. 2006; 36:871-879.

Loss of these parents from the work force reduces the tax base and may increase the likelihood of family bankruptcy. In the case of single parent families, the requirement for intense parent involvement to the exclusion of paid work, may lead to need for welfare assistance. Utilizing all one's savings, retirement, and college funds also increases the likelihood of financial catastrophe and dependence on welfare agencies for both the parents and for the affected child with autism once s/he becomes an adult.

Finally lack of the benefit and failure to provide sufficiently intense treatment (applied behavior analysis) through Medicaid appears to reduce the number of individuals with autism who are able to achieve higher levels of functioning. Put another way, lack of the benefit and associated failure to provide sufficiently intense treatment is likely to increase the number of individuals who are dependent upon others for housing, supervision, and vocational support as adults. Such services must be provided by the state, which will require funds be taken from other programs or increased taxes. It also seems likely that the healthcare needs of more severely ill youth and adults with autism will be greater than the healthcare needs of youth and adults with milder symptoms.

Detailed discussion of each of these social impacts follows. Diagnostic and treatment delays as well as inadequate treatment resulting in more severe illness clearly increase stress on parents. One study found that the mean depression score among parents of children with autism was twice that found in community surveys and that 45 percent of the sample (68 parents) met the cut off for a major depression.<sup>33</sup> Parental depression is well established to adversely affect the mental health and development of typically developing children who may be siblings of the autistic child.

Further more severe autistic symptomatology is linked to higher levels of depression and stress, which – in contrast to moderate or mild symptomatology – was not sensitive to support provided by others in the community. Several studies (initial reports not provided) have noted that autism seems to affect the family (parents and siblings) to a greater extent than other developmental disorders.<sup>34</sup>

Autism Society of America as well as the National Autism Association have cited a divorce rate of 80-85 percent among parents of children with autism. With such a rate in divorce, there is social impact on higher costs of monitoring child support payments and greater likelihood that children will live in poverty if living in single parent families. Further, the rate of psychiatric hospitalization for children with autism in single parent families was greatly increased (odds ratio 2.54).<sup>35</sup>

In 2004 Mandell reported a study of publicly and privately insured Pennsylvania children with autism spectrum disorder, examining their rates of inpatient psychiatric hospital use. The chief finding of the study is that there was significant separation in rates of hospitalization between children who had earlier diagnosis and received Early Intervention and those who did not; the late diagnosed group who did not receive early behavioral interventions had significantly higher rates of self-injury and aggression.<sup>36</sup>

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<sup>33</sup> Benson, PR (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: the mediating role of stress proliferation. *Journal of Autism and Developmental Disabilities*. 36:685-695.

<sup>34</sup> Bouma; R & Schweitzer, R.; 1990. the impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*46:722-730.; Moes, D.; 1995. Parent education and parent stress. In RL Koegel & LK Koegel (Eds.) *Teaching children with autism* (pp. 79-94) Baltimore: PH Brooks Publishing.; Rodrigue, JR; Morgan, SB; Geffken.; 1990. Families of autistic children: psychosocial functioning of mothers. *Journal of Clinical Child Psychology* 19:371-379.

<sup>35</sup> Mandell,DS (2007). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, Nov 2007, epub ahead of print.

<sup>36</sup> Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).

In this Pennsylvania study, Mandell found significant variation in results across the counties, which he interpreted to reveal variation in health system factors that drove the differences, rather than differences inherent to the population of the Commonwealth's children with ASD. Mandell separately studied use of psychotropic medications nationally among children with ASD and found that as many as 56 percent are prescribed one or more psychotropic drugs and as many as 20 percent of these children are prescribed three or more drugs concurrently.<sup>37</sup>

**(iv) To what extent will the benefit increase or decrease the administrative expenses of health carriers and the premium and administrative expenses of policyholders?**

Analyses based on claims databases have been published by Health Watch "For Professional Recognition of the Health Actuary", Issue 54, January 2007, page 21, Table 1, Marginal Costs of Mandated Benefits report 0.0023 percent increase in total expenses.

Council for Affordable Health Insurance (CAHI) Health Insurance Mandates in the States 2008, a state-by-state breakdown of health insurance mandates and their costs, reports estimated cost of 11 states with mandates autism benefits to be <1 percent.

**(v) What will be the impact of this benefit on the total cost of health care services and on premiums for health coverage?**

Coverage has been in effect in 23 other states and the claims expenses have been documented both in Health Watch and CAHI. These marginal expenses are reported to be 0.0023 percent to an unspecified number of <1 percent. There are also 8 states that have passed Autism Insurance Parity in 2007-2008 legislative sessions. Cost analysis reports from Pennsylvania and Arizona has been submitted.

**(vi) What will be the impact of this benefit on costs for state-purchased health care?**

The impact should be negligible, comparable to the claims data that have been documented above. Microsoft Corporation is a Washington state company. They have had autism parity in place voluntarily for several years. Their claims impact on administrative costs can provide Washington state insight on whether there is any different than those published by insurance industry sources sited above.

**(vii) What will be the impact of this benefit on affordability and access to coverage?**

This benefit would make treatments attainable and affordable to families who currently have no access to medically necessary treatments, due to the prohibitive costs. This would in turn support and increase provider capacity leading to much improved access to treatment. In the states where autism parity has been in existence, there has only been significant improvement in terms of affordability and access to coverage. An overview of states with existing autism insurance parity laws have been submitted.

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<sup>37</sup> Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE. Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. *Pediatrics*. 2008; 121:e441-e448.

### **(c) Evidence of health care service efficacy**

There are over 700 published studies that document effectiveness of intensive behavioral therapies (Applied Behavior Analysis) for developing many important skills in people with autism spectrum disorder of all ages (e.g., Matson et al., 1996; New York State Department of Health, 1999; *Journal of Applied Behavior Analysis*):

- Learning to learn: looking, listening, imitating, following instructions, discriminating and matching stimuli, etc.  
Communication: verbal and nonverbal; comprehension and production; from simple vocalizations to complex conversations
- Social: simple reciprocal exchanges, playing with peers, sharing, expressing emotions, empathizing, dramatic play, etc.
- Self-care: hygiene, personal safety, community living, etc.
- Motor and leisure

And much more, for an array of these published studies, please refer to the documents submitted in support of the efficacy of treatments for autism.

Numerous published reports have been submitted as proof of efficacy of treatments for autism. There are simply too many to list individually. These empirically validated, peer reviewed published reports are from national sources as well as Washington state sources. Please refer to submitted peer reviewed empirically validated articles on efficacy of treatment in individuals with autism of all ages. A few notable studies have been mentioned and interspersed below. These studies have compared efficacy of early intensive behavioral interventions (EIBI) versus intensive traditional eclectic models (speech therapy, occupational therapy, TEACCH), as well as versus current models available through Washington state lead agencies.

### **(i) If a mandatory benefit of a specific service is sought, to what extent has there been conducted professionally accepted controlled trials demonstrating the health consequences of that service compared to no service or an alternative service?**

The proposed benefit mandates that “treatment for autism spectrum disorders” shall include the following care prescribed, provided or ordered for an individual diagnosed with an autism spectrum disorder by a [licensed professional] if the care is determined to be medically necessary” (i.e., as defined by the bill: any care, treatment, intervention, service or item which is prescribed, provided or ordered by a licensed physician, licensed psychologist or certified registered nurse practitioner in accordance with accepted standards of practice and which will, or is reasonably expected to, do any of the following:

- i) prevent onset of . . . disability;
- ii) reduce or ameliorate the physical, mental or developmental effects of an illness or disability;
- iii) assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account . . . those functional capacities that are appropriate of recipients of the same age,

Including:

- i) psychiatric care ii) psychological care iii) habilitative and rehabilitative care [which is defined to include applied behavioral analysis (ABA)]; iv) therapeutic care [defined to mean services provided by licensed or certified speech therapists, occupational therapists or physical therapists];
- v) pharmacy care [defined to mean medications prescribed by a licensed physician or certified registered nurse practitioner and any health related services deemed medically necessary to determine the need or effectiveness of the medications]
- vi) any care, treatment, intervention, service or item for individuals with an autism spectrum disorder developed by a licensed physician or licensed psychologist pursuant to a comprehensive evaluation or reevaluation performed in a manner consistent with most recent clinical report or recommendations of the American Academy of Pediatrics which is based upon review of best practices of evidence-based research, to be medically necessary and which is published in the Revised Code of Washington (RCW).

Thus the only “specific service” specifically mentioned by the Autism Insurance Parity is applied behavioral analysis (ABA).

There is extensive professionally accepted evidence supporting the efficacy of ABA compared to no or minimal therapies and to alternative therapies. The strongest evidence is provided by Eikeseth, Smith, Jahr, and Eldevik (2002<sup>38</sup>, 2007<sup>39</sup>). The Eikeseth et al., 2007 paper and Eikeseth et al., 2002 article, report on different phases of outcome in the same study.

In this study, 25 children with autism between the ages of four and seven were assigned to receive a minimum of 20 hours/week of either ABA treatment or eclectic treatment by an independent state-funded autism specialist. Treatment assignment was based upon availability of qualified supervisors with no regard to child characteristics or parent preference. Treatment assignments were made over a three-year period so cohort effects are likely to be minimal. Each child was integrated into a different school with their own individual therapists, so there were not treatment center effects.

The applied behavioral analysis (ABA) therapy used the manual and videotapes developed by Lovaas but did not include any aversive contingencies. The treatment focused on very simple tasks such as responding to an adult and gradually progressed to more complex tasks such as conversing and making friends. Initially all treatment was individual, discrete trial format but later focused on generalization to the classroom setting. The therapists did not have prior training but received 10 hours of supervision weekly from supervisors who had a minimum of 1,500 hours of experience implementing ABA treatment and met recommended ABA qualification criteria<sup>40</sup> and one to two hours weekly with the team directors, who were psychologists, each of whom had 10 years experience or more implementing the UCLA treatment. In addition weekly two-hour meetings were held with child, primary caretaker, therapists, supervisors, and director. Parental participation was also central with parents working along side therapists four hours per week during the first three months and then continuing the intervention in the

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<sup>38</sup> Eikeseth S, Smith T, Jahr E, Eldevik S, (2002). Intensive behavioral treatment at school for 4- to 7-year old children with autism. A 1-year comparison controlled study. *Behavior Modification* 26:49-68.

<sup>39</sup> Eikeseth S, Smith T, Jahr E, Eldevik S, (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7. A comparison controlled study. *Behavior Modification* 31:264-278.

<sup>40</sup> Smith T, Donahoe PA, Davis BJ, (2000). The UCLA treatment model. In S.L. Harris and J.S. Handelman (Eds.), *Preschool education programs for children with autism* (2nd edition, pp29-48). Austin, TX: Pro-Ed.

home setting.

The comparison eclectic treatment was designed to meet best practices as outlined by Dawson & Oesterling.<sup>41</sup> This treatment incorporated elements from Project TEACCH, sensory motor therapies, and ABA. The specific interventions were individually selected for the child based on recommendations from a multidisciplinary team. The interventions were implemented on a 1 to 1 basis with the same therapist serving as an aid during classroom activities. The therapists received weekly, 2-hour consultations from the supervisors and same directors as provided leadership for the ABA intervention group.

Outcome assessments were performed by a blinded psychologist or psychological examiner with a master's degree in special education, both of whom had extensive experience with children with autism. The outcomes included standardized tests of general cognitive functioning (IQ), visual-spatial skills, language and adaptive behaviors.

Treatment hours were 28 in the ABA group and 29 in the eclectic comparison group. Therapist education was similar for both groups. Mean intake IQ was 61.92 in the ABA group and 65.00 in the eclectic comparison group. On measures of language and adaptive behavior a similar pattern was observed with the ABA group showing numerically lower baseline values (including IQ 3.3 points lower, total language 8.2 points lower and adaptive behavior 4.2 points lower) for 10 of the 11 measures of interest.

After one year of treatment, the ABA group improved mean IQ by 17 points (SD = 11), total language by 27 points (SD = 20), and adaptive behavior by 11 points (SD = 15). In contrast, the eclectic comparison group improved IQ by only four points (SD = 8) points, total language by one point (SD = 17), and adaptive behavior by < 1 (8) point. All of these between group differences in change from baseline scores were statistically significant at the (one-sided)  $p < 0.01$  to 0.05 level.

At end of the follow-up period the ABA group's scores were consistently higher than the eclectic group.

The two treatments were then continued for nearly two more years. Three years after entering the study, the children were reassessed by blinded evaluators. The ABA group improved IQ from baseline by a total of 25 points, Vineland daily living skills by nine points and Vineland communication by 20 points. The eclectic comparison group improved IQ by a total of seven points, but showed decreases of six to 12 points on the Vineland subscales. In addition the ABA group showed fewer social problems, less aggression and fewer Vineland maladaptive behaviors than the eclectic group. Fifty-four percent (54 percent) of the ABA group and only 17 percent of the eclectic group scored within the normal range of IQ. Interestingly, IQ changed most dramatically early in ABA treatment and daily living skills and adaptive and social behaviors as reflected by Vineland scores changed most later in ABA treatment. A similar pattern was not observed in the eclectic comparison group.

In addition to this well-controlled study, there are a number of other studies comparing ABA to other treatments in a less rigorous way and in different treatment settings that also show fairly consistent evidence of benefit of ABA on cognitive functioning and ability to function in much more age-appropriate fashion. Three of these studies are discussed here.

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<sup>41</sup> Dawson G, Osterling J, (1997). Early intervention in autism. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 307-326). Baltimore: Paul H. Brookes.

A study by Howard et al. (2005)<sup>42</sup> compared 29 preschool children receiving ABA (25-40 hours/week), 16 children receiving 30 hours/week of 1:1 or 1:2 eclectic intervention (combination of TEACCH, sensory integration and some ABA) and 16 children in a non-intensive 15 hour/week 1:6 group intervention (13 of whom also received speech therapy). The treatment each child received was determined by regional early intervention center but heavily considered parental preference.

Treatment in the applied behavioral analysis (ABA) group was provided by college students under direct supervision of a master's level clinician with extensive ABA experience under the guidance of a Board Certified Behavior Analyst (PhD in psychology or speech therapist). Children were assessed after seven to 14 months of treatment by an independent contractor. Intervention groups differed significantly at baseline with respect to age of diagnosis, age at onset of treatment, age at follow-up testing, and parents' education.

Children in the ABA group showed a 11pt (SD 15) gain on a composite cognitive scale and a 21 (11) month gain in communication skills, compared to a one point (SD 12) decrease in the cognitive measure and a 8 (10) month gain in communication in the intensive eclectic program and a three point (14) decrease in the cognitive measure and 10 (nine) month gain in communication in the low intensity program. The differences with respect to each of these follow-up measures between the ABA group and the two comparison groups combined are statistically significant at the  $p < 0.05$  level. In addition, more than half of the children in the ABA group showed learning rates above normal after the intervention whereas very few in the other two groups did.

A randomized controlled trial conducted by Smith, Groen and Wynn<sup>43</sup> that provides nearly as strong evidence as the Eikeseth et al. study. In the Smith, Groen and Wynn study, 28 children with ASDs, mean age three years, were randomly assigned to receive intensive ABA which included a parent component for five hours/week for the first three months or parent training in ABA methods for five hours/week for three to nine months. In both condition's Lovaas's 1981 manual was utilized but did not include the use of negative consequences (aversives) except for a very brief period in the initiation of the study. The mean therapy received by the ABA group was 24.5 hours/week during the first year, with gradually reducing hours in the second and third years. ABA treatment was administered by college students who were supervised by the authors who had a combined total of 10 years experience under Lovaas's supervision. Further these student therapists were required to pass written tests on the treatment methodology and a standard behavioral test of them administering the intervention. Only therapists with a minimum of 1,500 hours of experience were allowed to become supervisors. The control group did not receive further intervention from the study once parent training was completed.

Participants were assessed at baseline and when they were seven to eight years old (two to three years following completion of the intervention). Assessments were done by a clinician who was blinded to the treatment each participant had received. At baseline, 82 percent of the children were nonverbal and none achieved a basal score on the Stanford-Binet IQ test; mean baseline IQ in both groups was 51. At follow-up, children in the ABA group had a mean IQ of 66 (increase of 16 points) while those in the parent-training group had a mean IQ of 50 (1 point decline).

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<sup>42</sup> Howard JS, Sparkman CR, Cohen HG, Green G, Stanislaw H, (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26:359-383.

<sup>43</sup> Smith T, Groen AD, Wynn JW, (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation* 105:269-285.

Total language scores increased by 58 points in the ABA group (29 to 87) and by 31 points in the parent group (30 to 61). Several children in the ABA group showed ceiling effects that may have reduced the apparent differences between the two groups. Six of the 15 children in the ABA group (40 percent) were in regular education (four without an aid) whereas only one of the 13 in the parent group (8 percent) was in regular education and had an aid. All of these changes were statistically significant. The authors speculate that the lower intensity of this program may account for the less dramatic response observed compared to Lovaas's initial study.

A similar study was conducted by Cohen and colleagues.<sup>44</sup> They studied 21 children younger than three years of age who received 35-40 hours/week of ABA therapy for three years and 21 age and IQ matched children in a variety of community early intervention services with fewer than nine hours/week ABA. Treatment assignment was not randomized but rather based on parent preference. Outcome assessments were conducted by independent examiners who appear blinded to the treatment each child received. At baseline, the ABA group had numerically higher IQ (61.6 vs. 59.4), nearly identical language skills and Vineland adaptive behavior scores. The mean IQ increased by 25 points in the ABA group and 14 points in the control group, language composite increased by 20 points in the ABA group and nine points in the comparison group, and Vineland adaptive behavior composite increased by nine points in the ABA group but declined by four points in the comparison group. Both of these comparisons were statistically significant.

Findings from these studies consistently show that focused ABA programs can provide outcome advantages over equally intense eclectic programs even when those programs incorporate ABA techniques.

**(ii) If a mandated benefit of a category of health care provider is sought, to what extent has there been conducted professionally accepted controlled trials demonstrating the health consequences achieved by the mandated benefit of this category of health care provider?**

At the clinical decision-making level, Autism Insurance Parity does not extend coverage to “an additional class of practitioners” who are not already planning and overseeing the implementation of treatment or other services to children with ASD. Specifically, Autism Insurance Parity amends Washington’s Insurance Laws to indicate that with respect to autism spectrum disorder:

(F) 9. “Medically necessary” means any care, treatment, intervention, service, or item that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist that will, or is reasonably expected to, do any of the following:

- a. Prevent the onset of an illness, condition, injury, or disability;
- b. Reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability; or
- c. Assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacities that are appropriate for individuals of the same age.

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<sup>44</sup> Cohen H, Amerine-Dickens M, Smith T, (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27:S145-S155.

The licensed and/or certified professionals who are empowered by Autism Insurance Parity to plan and oversee ASD treatment are the traditional groups who authorize and provide such treatment, and as such do not constitute an “additional class.”

One potential issue with respect to “new” practitioners, however, may be with Board Certified Behavior Analysts, Board Certified Associate Behavior Analysts and Therapy assistant non-clinical personnel who directly design, train, oversee, implement and provide applied behavioral analysis (ABA) treatment.

Currently BCBA’s, BCABA’s and therapy assistants are covered by Microsoft (Premera) and military (TriCare Echo) insurance.

Several peer-reviewed, controlled studies documenting the efficacy of ABA were included among the submitted evidence. The three studies described in detail in section (c) (i), all provide detailed descriptions of the content and procedures of ABA treatment and the training required for the therapists working most directly with the children.<sup>45</sup> Additionally, parental participation was a critical element of the treatment, and parents were also trained by therapists in implementing the one-to-one elements of the treatment.

### **(iii) To what extent will the mandated benefit enhance the general health status of the state residents?**

Autism Insurance Parity will lead to improved access to evidence based behavioral therapies, including Applied Behavioral Analysis. This will improve independent functioning and quality of life for those children and youth with ASD who will have access to medically necessary treatments not currently attainable for them.

In 2004 Mandell reported a study of publicly and privately insured Pennsylvania children with autism spectrum disorder (ASD), examining their rates of inpatient psychiatric hospital use. The chief finding of the study is that there was significant separation in rates of hospitalization between children who had earlier diagnosis and received Early Intervention and those who did not; the late diagnosed group who did not receive early behavioral interventions had significantly higher rates of self-injury and aggression.

In a 2006 article, David Mandell cites 10 years of research articles that suggest substantial improvements in functioning among children with ASD after behavioral rather than pharmacological and psychological interventions. In one cited study, 47 percent of the children in the behavioral treatment conditions achieved “normal intellectual and educational functioning” as compared to two percent of those who received standard medical and educational benefits only.<sup>46</sup>

In autism, enhanced health and diminished effects of the disorder is improved functioning, improved

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<sup>45</sup> Eikeseth S, Smith T, Jahr E, Eldevik S, (2002). Intensive behavioral treatment at school for 4- to 7-year old children with autism. A 1-year comparison controlled study. *Behavior Modification* 26:49-68. ; Eikeseth S, Smith T, Jahr E, Eldevik S, (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7. A comparison controlled study. *Behavior Modification* 31:264-278.; Smith T, Groen AD, Wynn JW, (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation* 105:269-285.; Cohen H, Amerine-Dickens M, Smith T, (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27:S145-S155.

<sup>46</sup> Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4)

engagement, socialization and communication, and reduced maladaptive behaviors. Autism Insurance Parity will enhance the general health status of the Washingtonians with autism significantly; furthermore it will alleviate much of the deterioration of health and emotional strain on families and caregivers of individuals with autism.



## APPENDIX B

### Follow Up Questions for Proponent

#### Questions

1. Can you provide additional clarification on what applied behavioral analysis (ABA) is? Can you give some real life examples of what would be included in an ABA treatment plan?
2. Do you feel ABA is mental health treatment?
3. Your proposal does not state that ABA is the only therapy that should be covered, however you focus on it heavily in your proposal and it is the only one you for which you provide evidence of efficacy. Do you have information on other types of treatments that are efficacious?
4. We are trying to determine what falls under mental health and neurodevelopmental therapies. Can the treatments be categorized in this way?

#### Proponent's responses

As I mentioned to the deputy insurance commissioner as well as Randy Revelle from the Hospital association that was the lead advocate behind Washington mental health parity, mental health parity does not cover autism, as autism is not a mental illness, rather a neurological medical condition.

There are certainly individuals with autism that may/will need psychiatric/psychological care, but autism is a medical diagnosis and therefore the treatments are medical and not under the mental health umbrella.

The neurodevelopmental therapies are mandated in Washington state for all neurodevelopmental disorders up to age six, however the caps were set in 1989 and even then they were set rather low for individuals with autism, so even with the expansion proposals for Washington state, the caps that are set for NDT's in Washington are grossly underserving individuals with autism. The caps range anywhere from no coverage or \$1000 per lifetime to 12-50 visits per year up to age six.

So individuals with autism are either uninsured or underinsured for neurodevelopmental therapies in Washington as well.

On your question about a real life example of an ABA treatment plan I have a powerpoint that outlines what an intensive ABA program is comprised of, however the intensity of the treatment significantly decreases with time, as the learners develop independent learning abilities and are able to learn from their natural environments without intensive intervention.

As an example, with our oldest son who was diagnosed with the severity range of less than one percent of the population (most severity) his ABA program looked like what I'm attaching from three to five years old, he is now 12 and his ABA program is at about 20 percent intensity of what is described. I'm also attaching an overview by an internationally known behavior analyst, Dr. Gina Green.



## APPENDIX C

### Request for Sunrise Review and Draft Bill



#### Washington State Senate

Olympia Office:  
PO Box 40433  
Olympia, WA 98504-0433

**Senator Karen Keiser**  
33rd Legislative District

(360) 786-7664  
TTY: 1-800-635-9993  
Toll-Free Hotline: 1-800-562-6000  
E-mail: keiser\_ka@leg.wa.gov

July 30, 2008

Mary Selecky, Secretary  
Washington State Department of Health  
PO Box 47890  
Olympia, WA 98504

Dear Secretary Selecky-

I write today to ask the Department of Health to conduct a Sunrise Review under RCW 48.47 in regard to a mandated health benefit covering autism and its treatment. Attached you will find a copy of a legislative proposal concerning this issue.

While we have made advances in detection and treatment options for autism, those procedures are not uniformly available to all families. Variance in diagnoses and inconsistent coverage of available treatments can often leave families paying for all costs of pocket, creating greater emotional hardship and adding financial burdens. Differences in insurance can create vastly different outcomes when consistency is what is needed.

As you know, the Legislature created a task force in 2005 to address issues in autism and supplemented that in 2007. It is with that commitment in mind that I request this review. I am available to assist in whatever way you may need.

Sincerely,

A handwritten signature in black ink that reads "Karen Keiser".

Senator Karen Keiser  
33<sup>rd</sup> Legislative District

cc: Senator Marilyn Rasmussen  
Representative Brendan Williams  
Kristi Weeks, Dept. of Health

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**Committees:** Health & Long-Term Care, Chair • Labor, Commerce, Research & Development • Ways & Means • Rules



David Knutson 360.786.7146  
Health Care and Wellness  
July 7, 2008 (9:07 AM)

AN ACT Relating to ---; and adding a new section to chapter ....  
RCW.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

NEW SECTION. **Sec. 1)** A new section is added to chapter 41.05 RCW  
to read as follows:

(1) Each health plan offered to public employees and their covered dependents under this chapter which is not subject to the provisions of Title 48 RCW shall include coverage for the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders in individuals less than twenty-one years of age. To the extent that the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders are not already covered by a health insurance policy, coverage under this section will be included in health insurance policies that are delivered, executed, issued, amended, adjusted, or renewed on or after 90 days from the effective date of this section. No insurer can terminate coverage, or refuse to deliver, execute, issue, amend, adjust, or renew coverage to an individual solely because the individual is diagnosed

Draft

p. 1

with one of the autism spectrum disorders or has received treatment for autism spectrum disorders.

(2) Coverage under this section will not be subject to any limits on the number of visits an individual may make to an autism services provider.

C. Coverage under this section may be subject to co-payment, deductible, and coinsurance provisions of a health insurance policy to the extent that other medical services covered by the health plan are subject to these provisions.

This section will not be construed as limiting benefits that are otherwise available to an individual under a health plan.

Coverage under this section will be subject to a maximum benefit of \$50,000 per year. After July 31, 2009, the insurance commissioner will, on an annual basis, adjust the maximum benefit for inflation by using the Medical Care Component of the United States Department of Labor Consumer Price Index for all urban consumers (CPI-U). The commissioner will submit the adjusted maximum benefit for publication annually no later than October of each calendar year, and the published adjusted maximum benefit will be applicable in the following calendar year to health insurance policies subject to this act. Payments made by an health plan on behalf of a covered individual for any care, treatment, intervention, service, or item unrelated to autism spectrum disorders will not be applied towards any maximum benefit established under this section.

(3) As used in this section:

a. "Applied behavior analysis" means the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relations between environment and behavior.

b. "Autism services provider" means any person, entity, or group that provides treatment of autism spectrum disorders.

c. "Autism spectrum disorders" means any of the pervasive developmental disorders as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), including

Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified.

d. "Diagnosis of autism spectrum disorders" means medically necessary assessment, evaluations, or tests to diagnose whether an individual has one of the autism spectrum disorders.

e. "Evidence-based research" means research that applies rigorous, systematic, and objective procedures to obtain valid knowledge relevant to autism spectrum disorders.

f. "Habilitative or rehabilitative care" means professional, counseling, and guidance services and treatment programs, including applied behavior analysis, that are necessary to develop, maintain, and restore, to the maximum extent practicable, the functioning of an individual.

g. "Health insurance policy" means any group health policy or contract issued by a health plan under chapter 48.21 RCW, chapter 48.44 RCW, or chapter 48.46 RCW.

h. "Medically necessary" means any care, treatment, intervention, service, or item that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist that will, or is reasonably expected to, do any of the following:

1. prevent the onset of an illness, condition, injury, or disability;

2. reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability; or

3. assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacities that are appropriate for individuals of the same age.

i. "Pharmacy care" means medications prescribed by a licensed physician and any health-related services deemed medically necessary to determine the need or effectiveness of the medications.

j. "Psychiatric care" means direct or consultative services provided by a psychiatrist licensed under Title 18 RCW.

k. "Psychological care" means direct or consultative services provided by a psychologist licensed under Title 18 RCW.

1. "Therapeutic care" means services provided by licensed or certified speech therapists, occupational therapists, or physical therapists.

m. "Treatment of autism spectrum disorders" will include the following care prescribed, provided, or ordered for an individual diagnosed with one of the autism spectrum disorders by a licensed physician or a licensed psychologist who determines the care to be medically necessary:

1. habilitative or rehabilitative care;
2. pharmacy care;
3. psychiatric care;
4. psychological care; and
5. therapeutic care.

6. Any care for individuals with autism spectrum disorders determined medically necessary by a licensed physician or licensed psychologist, based upon their review of evidence-based research, and that care is defined by the department of health by rule. Any such care, treatment, intervention, service, or item that was not previously covered will be included in any health insurance policy delivered, executed, issued, amended, adjusted, or renewed on or after 90 days following the adoption of a rule by the department of health specifying the care, treatment, intervention, service, or item.

n. Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer will have the right to request a review of that treatment not more than once every 6 months unless the insurer and the individual's licensed physician or licensed psychologist agrees that a more frequent review is necessary. The cost of obtaining any review will be borne by the insurer.

o. The state health department will establish standards to be utilized by health plans for the credentialing of autism service providers. The department may require that a health plan grant credentials to any autism services provider whom the department determines meets or exceeds the department's credentialing standards.

NEW SECTION. **Sec. 2)** A new section is added to chapter 48.43 RCW to read as follows:

(1) Each health plan offered to public under chapter 48.21 RCW, chapter 48.44 RCW and 48.46 RCW shall include coverage for the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders in individuals less than twenty-one years of age. To the extent that the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders are not already covered by a health insurance policy, coverage under this section will be included in health insurance policies that are delivered, executed, issued, amended, adjusted, or renewed on or after 90 days from the effective date of this section. No health plan can terminate coverage, or refuse to deliver, execute, issue, amend, adjust, or renew coverage to an individual solely because the individual is diagnosed with one of the autism spectrum disorders or has received treatment for autism spectrum disorders.

(2) Coverage under this section will not be subject to any limits on the number of visits an individual may make to an autism services provider.

C. Coverage under this section may be subject to co-payment, deductible, and coinsurance provisions of a health insurance policy to the extent that other medical services covered by the health plan are subject to these provisions.

This section will not be construed as limiting benefits that are otherwise available to an individual under a health plan.

Coverage under this section will be subject to a maximum benefit of \$50,000 per year. After July 31, 2010, the insurance commissioner will, on an annual basis, adjust the maximum benefit for inflation by using the Medical Care Component of the United States Department of Labor Consumer Price Index for all urban consumers (CPI-U). The commissioner will submit the adjusted maximum benefit for publication annually no later than October of each calendar year, and the published adjusted maximum benefit will be applicable in the following calendar year to health insurance policies subject to this act. Payments made by an health plan on behalf of a covered individual for any care, treatment, intervention, service, or item unrelated to autism spectrum disorders

will not be applied towards any maximum benefit established under this section.

(3) As used in this section:

a. "Applied behavior analysis" means the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relations between environment and behavior.

b. "Autism services provider" means any person, entity, or group that provides treatment of autism spectrum disorders.

c. "Autism spectrum disorders" means any of the pervasive developmental disorders as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), including Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified.

d. "Diagnosis of autism spectrum disorders" means medically necessary assessment, evaluations, or tests to diagnose whether an individual has one of the autism spectrum disorders.

e. "Evidence-based research" means research that applies rigorous, systematic, and objective procedures to obtain valid knowledge relevant to autism spectrum disorders.

f. "Habilitative or rehabilitative care" means professional, counseling, and guidance services and treatment programs, including applied behavior analysis, that are necessary to develop, maintain, and restore, to the maximum extent practicable, the functioning of an individual.

g. "Health insurance policy" means any group health policy or contract issued by a health plan under chapter 48.21 RCW, chapter 48.44 RCW, or chapter 48.46 RCW.

h. "Medically necessary" means any care, treatment, intervention, service, or item that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist that will, or is reasonably expected to, do any of the following:

1. prevent the onset of an illness, condition, injury, or disability;

2. reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability; or

3. assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacities that are appropriate for individuals of the same age.

i. "Pharmacy care" means medications prescribed by a licensed physician and any health-related services deemed medically necessary to determine the need or effectiveness of the medications.

j. "Psychiatric care" means direct or consultative services provided by a psychiatrist licensed under Title 18 RCW.

k. "Psychological care" means direct or consultative services provided by a psychologist licensed under Title 18 RCW.

l. "Therapeutic care" means services provided by licensed or certified speech therapists, occupational therapists, or physical therapists.

m. "Treatment of autism spectrum disorders" will include the following care prescribed, provided, or ordered for an individual diagnosed with one of the autism spectrum disorders by a licensed physician or a licensed psychologist who determines the care to be medically necessary:

1. habilitative or rehabilitative care;
2. pharmacy care;
3. psychiatric care;
4. psychological care; and
5. therapeutic care.

6. Any care for individuals with autism spectrum disorders determined medically necessary by a licensed physician or licensed psychologist, based upon their review of evidence-based research, and that care is defined by the department of health by rule. Any such care, treatment, intervention, service, or item that was not previously covered will be included in any health insurance policy delivered, executed, issued, amended, adjusted, or renewed on or after 90 days following the adoption of a rule by the department of health specifying the care, treatment, intervention, service, or item.

n. Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer will have the right to request a review of that treatment not more than once every 6 months unless the insurer and the individual's licensed physician or licensed psychologist agrees that a more frequent review is necessary. The cost of obtaining any review will be borne by the insurer.

o. The state health department will establish standards to be utilized by health plans for the credentialing of autism service providers. The department may require that a health plan grant credentials to any autism services provider whom the department determines meets or exceeds the department's credentialing standards.

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## APPENDIX D

### Submission from Health Care Authority



### Sunrise Review for Mandated Autism Benefit – HCA Fiscal Analysis

#### Proposal Summary

Senator Karen Kaiser provided proposed legislation to the Department of Health and asked that a sunrise review be conducted related to mandating coverage in health plans for services relating to diagnosis and treatment of autism spectrum disorders in individuals less than 21 years of age. The mandate would apply to most health plans regulated by Title 48 RCW and self-insured medical plans<sup>47</sup> offered to Public Employees Benefits Board (PEBB) enrollees. It does not apply to Basic Health.

This analysis is limited to the impact on the PEBB self-insured medical plans and PEBB health plans underwritten by health carriers. Due to time and budget constraints, this analysis has not been reviewed by the Health Care Authority's (HCA) contracted actuary (Milliman, Inc.). We acknowledge that such a review could revise the estimated cost for the proposed mandated autism benefits.

A new section is added to chapter 41.05 RCW. Selected excerpts follow:

Subsection 1 is added that states [PEBB] shall include coverage for the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders in individuals less than twenty-one years of age.

Subsection 2 is added to state that coverage under this section will not be subject to any limits on the number of visits an individual may make to an autism services provider. This section will not be construed as limiting benefits that are otherwise available to an individual under a health plan. Coverage under this section will be subject to a maximum benefit of \$50,000 per year. [It will be adjusted annually by the Office of the Insurance Commissioner using the medical care component of the United States Department of Labor Consumer Price Index for all urban consumers].

Subsection 3 adds definitions including:

- (a) "Applied behavior analysis" means the design, implementation and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement and functional analysis of the relations between environment and behavior.
- (b) "Autism services provider" means any person, entity, or group that provides treatment of autism spectrum disorders.

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<sup>47</sup> Currently, PEBB offers two self-insured plans; the Uniform Medical Plan (UMP) and the Aetna Public Employees Plan (Aetna).

- (c) “Autism spectrum disorders” means any of the pervasive development disorders as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders including Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified.
- (m) “Treatment of autism spectrum disorders” will include the following care prescribed, provided, or ordered for an individual diagnosed with one of the autism spectrum disorders by a licensed physician or a licensed psychologist who determines the care to be medically necessary:
  1. habilitative or rehabilitative care;
  2. pharmacy care;
  3. psychiatric care;
  4. psychological care; and
  5. therapeutic care.
  6. Any care for individuals with autism spectrum disorders determined medically necessary by a licensed physician or licensed psychologist, based upon their review of evidence-based research, and that care is defined by the department of health by rule. Any such care, treatment, intervention, service, or item that was not previously covered will be included in any health insurance policy delivered, executed, issued amended, adjusted, or renewed on or after 90 days following the adoption of a rule by the department of health specifying the care, treatment, intervention, service, or item
- (n) Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer will have the right to request a review of that treatment not more than once every six months unless the insurer and the individual’s licensed physician or licensed psychologist agrees that a more frequent review is necessary. The cost of obtaining any review will be borne by the insurer.
- (o) The state health department will establish standards to be utilized by health plans for the credentialing of autism service providers. The department may require that a health plan grant credentials to any autism services provider whom the department determines meets or exceeds the department’s credentialing standards.

A new section is added to chapter 48.43 RCW that sets out the same criteria as described above for health plans regulated under chapters 48.21 RCW, 48.44 RCW and 48.46 RCW.

**Proposal Impact and Consideration for the PEBB program**

- Currently the PEBB self-insured medical programs and health carriers establish a set of evidence-based criteria for determining a standard of care based on peer-reviewed literature, effectiveness, quality outcomes, safety, and cost. The proposal as drafted includes numerous provisions that limit the ability for the PEBB self-insured medical programs and PEBB health carriers to establish and utilize such criteria.
- Specific benefits are set out in statute and are to be further clarified in rule by the Department of Health. There is no distinction between medical and educational services which could require health benefit plans to include benefits for educational services. Generally, applied behavior analysis is targeted to behavior outcomes and falls in the educational domain.
- Medical necessity is to be determined by a licensed physician or licensed psychologist (presumably the patient’s provider, not the PEBB self-insured medical programs’ or health carrier’s medical experts) based on their review of literature and the Department of Health rules. Depending on how department rules are developed, the PEBB health

benefit plans may be required to include coverage for experimental, investigational, or unproven services.

- Standards for credentialing of autism services providers will be developed by Department of Health and must be used by health carriers including PEBB self-insured medical programs. The department may require PEBB self-insured medical programs and health carriers to grant credentials to any autism services provider who meets the standards. This could include a large population of provider types as autism treatment services are within the scope of practice of several provider types. For example, educators could be included in the credentialing with reimbursement for services required by the “autism services provider” definition in the proposal.
- The proposal carries a statement that “autism is widely regarded erroneously as a mental illness.” Autism spectrum disorders are included in the Diagnostic and Statistical Manual of Mental Disorders and the mental health parity law will provide parity in coverage for many of the proposed services not later than 2010. However, there appear to be services mandated in the proposed law that would require a greater scope of coverage than parity. For example, some health benefit plans include visit and age limits on some services such as speech, physical, occupational and neurodevelopmental therapy. Under this proposal visit limits will not be allowed.
- The law permits a \$50,000 per year maximum (subject to an annual inflation adjustment) for autism diagnosis and treatment, but also states that “this section will not be construed as limiting benefits that are otherwise available to an individual under a health plan.” Thus, we assume this means that PEBB health benefit plans would need to provide \$50,000 above what is available under the Mental Health Parity law. This includes the services provided in excess of mental health coverage (visit) limits and the additional services such as the applied behavior analysis services not otherwise covered as a benefit.

## **Cost Approach**

The fiscal impact of this proposal on the PEBB health benefit plans can be quantified in two major categories. The first, and largest, impact is the cost of medical claims or benefit costs. This occurs as a result of the proposal’s \$50,000 per year limit on the treatment of autism spectrum disorders. Based on the language of Section 1 – Subsection 2, HCA assumes this proposal would allow up to \$50,000 per year of autism-related services in addition to the services already provided by PEBB health benefit plans. The second category of costs is related to the proposal’s impact on the number of service providers credentialed by PEBB self-insured medical programs and health carriers. HCA assumes this proposal would increase the categories of service providers and thus increase credentialing costs.

## **Assumptions**

This fiscal analysis makes the following assumptions:

- The scope of the fiscal analysis is limited to HCA’s PEBB self-insured medical programs and PEBB health carriers.
- The mandated autism benefit becomes effective January 2010 for the PEBB health benefit plans.
- This proposal does not impact the incidence rate of childhood autism diagnosis currently experienced by the PEBB health benefit plans. The current diagnosis rate is assumed to be approximately 343 members per year.

- The \$50,000 annual limit for autism benefits is in addition to current autism services provided.
- The \$50,000 annual limit increases by 3.5 percent each year.
- Increased costs impact the PEBB non-Medicare risk pool and do not impact the Medicare risk pool.

Different assumptions would result in different costs projections.

### **Impact on Benefit Costs**

HCA staff ran enrollment queries to identify the number of PEBB members under age 21. Additional analysis was conducted to quantify the number of Uniform Medical Plan's (UMP) members under age 21 who had claims submitted with the International Classification Code of Diseases (ICD-9) number 299.0 (Childhood Autism). The query identified 175 UMP members with childhood autism - or approximately 0.4 percent of all under age 21 UMP members. We applied that percentage to all non-UMP PEBB members under age 21 to quantify the estimated number of PEBB members we assume to have a diagnosis of childhood autism. The result of this analysis is 343 PEBB members are assumed to have a diagnosis of childhood autism.

We then multiplied the number of impacted members by \$50,000 to identify the increased benefits cost in calendar year (CY 2010). We assume an annual cost of \$17,150,000 for CY 2010 for the mandated autism benefit services.

### **Impact on Plan Credentialing Costs**

Further, each PEBB self-insured medical program and PEBB health carrier is assumed to have increased credentialing costs amounting to \$36,400 annually. HCA used information related to UMP and adjusted it for the entire PEBB portfolio. The proposal will likely expand the number of professionals eligible to provide covered services. The proposal does not distinguish between medical and educational autism-related services. Thus, previously non-covered services (and service providers) would be covered. As a result, the number of providers who must be credentialed would increase. For purposes of this fiscal analysis, the HCA assumes an additional 400 professionals would apply to the UMP for credentialing. UMP pays \$91.00 per provider for the initial credentialing service report. We assume the same cost for other health carriers. Thus, the total cost for all PEBB self-insured medical programs and PEBB health carriers is \$218,400. We added the annual benefit cost to the increased cost for credentialing to arrive at the final benefit cost of \$17,368,400 for CY 2010.

### **Operational Impacts**

In addition to the increased benefits and credentialing costs, we identified the following operational impacts:

- 1.3 FTE's - Health Insurance Benefits Specialist (HIBS) 2: on-going at HCA's Seattle office beginning July 2009. A HIBS 2 spends about 6.5 hours, per provider, to complete the credentialing process. The work includes taking the call from the interested provider's office, sending the application, reviewing the application, sending information to the credentialing service, reviewing the service report, following up, if required (mainly as to malpractice claim history), getting the contract finalized, and mailing. The additional UMP program costs for 1.3 FTE's will be \$115,553 in fiscal year 2010 and \$104,436 every year thereafter. Costs include salaries and benefits, goods and services, travel and equipment start-up costs. HCA's Seattle office HIBS positions receive a 15 percent cost differential due to the geographic location.

- HCA should participate as a stakeholder as part of the Department of Health rule-making process to provide clarity on the benefits to be provided to assure there is no conflict with the Mental Health Parity law requirements. This can be accomplished within current resources.
- Benefit language will need to be developed and approved by the PEB Board to reflect the intent of the statute. This can be accomplished within current resources.
- Certificates of coverage will need to incorporate the new benefit and any other clarifying instructions or exclusions. This can be accomplished within current resources.
- The various claims payments systems will need to track claims related to the \$50,000 ceiling. We believe this can be accomplished within health plan rates.

The following chart converts the calendar year costs to a fiscal year (FY) basis and shows the estimated increased costs for the 2009-2011 biennium. Please note: the benefit costs in FY 2010 reflect six months of the benefits cost effective January 2010 and twelve months administrative costs for the additional staffing required in the self-insured medical plans. Thereafter, twelve months costs are reflected.

<b>Autism Mandated Benefit Cost</b>	
<b>FY 2010</b>	
Fund 721 Benefits Costs	\$ 8,684,200
Fund 418 Admin Costs	\$ 115,553
<b>FY 2010 Total</b>	<b>\$ 8,799,753</b>
<b>FY 2011</b>	
Fund 721 Benefits Costs	\$ 17,750,250
Fund 418 Admin Costs	\$ 104,436
<b>FY 2011 Total</b>	<b>\$ 17,854,686</b>
<b>09-11 Biennium Total</b>	<b>\$ 26,654,439</b>

### ***Cash Receipts Impact***

The mandated autism benefits proposal will increase the overall cost of providing PEBB benefits.

The following chart shows the expected increased revenues from FY 2010 through FY 2015.

<b>Cash Receipts</b>	<b>FY 10</b>	<b>FY 11</b>	<b>FY 12</b>	<b>FY 13</b>	<b>FY 14</b>	<b>FY 15</b>
721 Benefits	\$ 8,684,200	\$ 17,750,250	\$ 18,371,509	\$ 19,014,512	\$ 19,680,019	\$ 20,368,820
418 Administration	115,553	104,436	104,436	104,436	104,436	104,436
<b>Total</b>	<b>\$ 8,799,753</b>	<b>\$ 17,854,686</b>	<b>\$ 18,475,945</b>	<b>\$ 19,118,947</b>	<b>\$ 19,784,455</b>	<b>\$ 20,473,256</b>

### **Expenditures Impact**

The table below shows the estimate of the increased cost for each group that participates in the PEBB non-Medicare risk pool. FY 2010 includes start-up administrative expenditures. FY 2010 shows the increased administrative costs and six months of mandated autism costs beginning January 2010. Thereafter, full fiscal year expenditures are shown.

<b>Expenditures</b>	<b>FY 10</b>	<b>FY 11</b>	<b>FY 12</b>	<b>FY 13</b>	<b>FY 14</b>	<b>FY 15</b>
State Share	\$ 6,706,116	\$ 13,606,699	\$ 14,080,149	\$ 14,570,167	\$ 15,077,337	\$ 15,602,259
Employee Share	914,470	1,855,459	1,920,020	1,986,841	2,056,001	2,127,581
Other Enrollment	721,580	1,464,084	1,515,027	1,567,754	1,622,325	1,678,807
Non Medicare Retirees	457,587	928,444	960,749	994,185	1,028,792	1,064,609
<b>Total</b>	<b>\$ 8,799,753</b>	<b>\$ 17,854,686</b>	<b>\$ 18,475,945</b>	<b>\$ 19,118,947</b>	<b>\$ 19,784,455</b>	<b>\$ 20,473,256</b>

The next table shows the source of funding for the state share of the increased expenditures.

<b>State Share Revenue Source</b>	<b>FY 10</b>	<b>FY 11</b>	<b>FY 12</b>	<b>FY 13</b>	<b>FY 14</b>	<b>FY 15</b>
46.5% GF-State	\$ 3,118,344	\$ 6,327,116	\$ 6,547,269	\$ 6,775,128	\$ 7,010,961	\$ 7,255,051
6.1% GF-Federal	409,073	830,009	858,889	888,780	919,718	951,738
0.5% GF-Local	33,531	68,033	70,401	72,851	75,387	78,011
17.5% Other Appropriated	1,173,570	2,381,172	2,464,026	2,549,779	2,638,534	2,730,395
29.4% Non Appropriated	1,971,598	4,000,369	4,139,564	4,283,629	4,432,737	4,587,064
100.0% Total Active revenue	\$ 6,706,116	\$ 13,606,699	\$ 14,080,149	\$ 14,570,167	\$ 15,077,337	\$ 15,602,259

The last table shows the expected increase to the employer funding rate.

<b>Employer Funding Rate</b>	<b>FY 10</b>	<b>FY 11</b>	<b>FY 12</b>	<b>FY 13</b>	<b>FY 14</b>	<b>FY 15</b>
Change	\$ 4.83	\$ 9.80	\$ 10.14	\$ 10.49	\$ 10.86	\$ 11.24



## MEMORANDUM

**To:** Sherry Thomas, Policy Coordinator, Health Systems Quality Assurance, Office of the Assistant Secretary, Department of Health  
**From:** Dennis Martin, Director of Policy and Legislative Relations, Health Care Authority  
**Re:** Health Care Authority Analysis of the Sunrise Review of Proposed Mandated Health Care Coverage for Diagnosis and Treatment of Autism Spectrum Disorders  
**Date:** September 15, 2008

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### Proposal for Review:

- ❖ The proposal submitted by Washington Autism Advocacy requests mandating coverage in health plans for services related to diagnosis and treatment of autism spectrum disorders in individuals under 21 years of age.

### Scope of the Review:

- ❖ The Health Care Authority (HCA) has completed an initial analysis of the Sunrise Review proposal. As directed by RCW 48.47.030(5), the HCA completed a preliminary cost analysis of the proposal. The attached staff fiscal analysis includes input from insurers and is limited to the assumed impact to the state of Washington for the Public Employees Benefits Board (PEBB) program.

### Analysis of Social Impacts:

#### The proposal as submitted does not apply to:

- ❖ The Medicaid Fee-For-Service program, Healthy Options, or other health care programs provided through the Department of Social and Health Services, Health and Recovery Services Administration.
- ❖ The Basic Health Plan administered by the Health Care Authority.
- ❖ Self-insured or self-funded employer health insurance programs subject to the federal Employee Retirement Income Security Act (ERISA). This includes health coverage for a number of large employers in the state.
- ❖ Dental and long-term care benefit plans.

#### The proposal applies to:

- ❖ Individual and group medical insurance plans offered by health maintenance organizations and health care service contractors regulated by the Office of the Insurance Commissioner.
- ❖ Group medical insurance plans offered by disability insurers regulated by the Office of the Insurance Commissioner. However, there is no mandate for individual health plans offered by disability insurers.

### Impact of the proposal on PEBB:

- ❖ We assume the proposal is intended to cover all medical insurance options provided through the PEBB program, including the Uniform Medical Plan (UMP) and Aetna self-insured options currently provided to PEBB members. While there are technical issues/conflicts with the language used in Section 1 of the proposal that need to be resolved to clearly achieve this intent, our attached fiscal analysis assumed that the proposed mandate would apply to all medical insurance options provided to PEBB active employees and their dependents.
- ❖ There is a difference in terminology between Section 1 and Section 2 that creates a disparity in coverage requirements between self-insured and OIC-regulated medical coverage offered to PEBB retirees and their dependents (children and grandchildren). Section 1 of the proposed bill is specific to public *employees* and their covered dependents and does not require coverage for retirees and their dependents. Section 2 applies to every OIC regulated medical plan offered to the public including coverage for retirees and their dependents.

### **Analysis of Financial Impacts:**

#### Overview:

- ❖ The attached fiscal analysis estimates the cost of the proposal to the PEBB program. The fiscal analysis conducted to date is a staff analysis which included input from participating insurers and does not include a review from our actuary. We have not conducted a fiscal analysis of the overall state insurance costs as HCA does not currently have the available financial resources to conduct such an actuarial evaluation.
- ❖ HCA staff conducted analysis on the proposal as submitted. We have not conducted an analytic comparison of this proposal with the proposals adopted or proposed in other states.

#### PEBB Cost Estimate:

- ❖ Based on analysis of the proposal, as written, our cost estimate of the impact on the PEBB programs exceed the assumptions made in the analysis provided by advocates for the proposal. In a document provided by Washington Autism Advocacy, the cost impact is estimated at 0.0023% to less than 1% based on the effect in other states. HCA estimates the annual cost increase to PEBB would be 1% or slightly greater than 1%. This equates to a per member per month increase of over \$5.00. HCA estimates the impact of the proposal on the monthly employer funding rate for PEBB benefits would be a \$9.80 per employee increase for FY 2011.
- ❖ HCA assumed a lower ratio of children diagnosed with an autism spectrum disorders than the ratio of 1 to 150 children noted in the materials provided by the advocates. HCA used a ratio of 1 to 231 members under age 21 based on UMP data that identified the number of members currently diagnosed with autism. If HCA used the higher ratio of 1 to 150 children, our fiscal analysis would increase.
- ❖ We assumed the cost of this proposal would be \$50,000 per person utilizing autism spectrum disorder services not otherwise covered as an insured benefit.
- ❖ While the proposal carries a statement that “autism is widely regarded erroneously as a mental illness”, we assume that certain services for autism spectrum disorders would be provided under the mental health benefit. The mental health parity mandate is required to be fully implemented by 2010.
- ❖ HCA cost analysis is based on the proposal as written. The specifics of the proposal raise a number of questions and concerns regarding the ability of health carriers and PEBB to manage the care and cost of care for autism spectrum disorders. While HCA did not conduct an analysis

of the statewide costs, we assume that health carriers will make similar assumptions regarding the proposal.

Expansion of covered benefits:

- ❖ The benefit mandate is substantial. HCA analysis could not fully define the extent and breadth of the mandated benefit expansion.
- ❖ The proposal expands covered benefits to include applied behavior analysis which is targeted to behavior, rather than medical outcomes. Thus, the proposal would mandate coverage by health carriers and PEBB for services traditionally defined as educational, rather than medical.
- ❖ Specific benefits are set out in statute and are to be further clarified in rule by the Department of Health. This is counter to how other benefits are determined and limits the ability of health carriers and the PEBB program to develop benefits based on current evidence-based standards.
- ❖ Currently PEBB and health carriers establish a set of evidence-based criteria for determining a standard of care based on peer-reviewed literature, effectiveness, quality outcomes, safety, and cost. Depending on how department rules are developed, the PEBB and health carriers may be required to provide coverage for experimental, investigational, or unproven services.
- ❖ The mandate will require contracts to add benefits for autism spectrum disorders services that may not be covered for other conditions. For example, a bare-bones contract in the commercial market may not cover prescription drugs. However, the contract would be required to provide prescription drug coverage if prescribed to treat an autistic spectrum disorder because prescription drugs are included as a mandated benefit under this proposal.
- ❖ The proposal will very likely increase the number of provider types that could receive reimbursement for services. Autism treatment services are within the scope of practice of several provider types. Department of Health may require health carriers to grant credentials to any autism services provider who meets the standards. Educators would likely be included in the credentialing with reimbursement for services under the “autism services provider” definition in the proposal.

Limitations on Health Carrier / PEBB Management of Health Care Quality / Costs:

- ❖ The proposal restricts health carriers from including limitations on benefits for services provided for autism spectrum disorders. For example, some health carrier contracts include visit or age limits on services such as speech, physical, occupational and neurodevelopmental therapy. Service limits would not apply for a child with autism, but the same services are limited for children with other conditions or diagnoses.
- ❖ The proposal states that medical necessity is to be determined by a licensed physician or licensed psychologist based on their review of literature. This effectively limits the ability for a health carrier or PEBB self-insured program to manage services based on best evidence as the provider determines whether the services are medical necessity.
- ❖ Carriers and PEBB self-insured programs may not request a review of outpatient treatment more often than once every six months. This limit in conjunction with the provider determining medical necessity significantly limits what a carrier or PEBB self-insured program can do to assure that appropriate care is being provided to their enrollees.
- ❖ It is unclear what Department of Health rules regarding medical necessity would actually do. Medical necessity is a clinical process to determine if the covered services are appropriate for an individual patient, not a process to define covered services. It is assumed that such a rulemaking process will further limit a health carrier or PEBB self-insured program from reviewing or managing the services provided to children with autism spectrum disorders.
- ❖ Standards for credentialing autism services providers will be developed by Department of Health and must be used by health carriers including PEBB self-insured programs. Health carriers would

not be able to require a higher standard for providers than the minimum standards established by the department.

- ❖ Department of Health may require health carriers to grant credentials to any provider meeting the department's credentialing standards, but the proposal does not require health carriers or PEBB self-insured programs to contract with all credentialed providers. The distinction between credentialing and contracting may allow health carriers and PEBB self-insured programs to establish networks and a payment differential based on contractual terms. However, the proposal requires carriers and PEBB self-insured programs to pay any credentialed provider for autism spectrum disorder services, whether or not the provider is part of the network. HCA assumes the Department of Health credentialing process in conjunction with the "any willing provider" environment created by the proposal will limit and further complicate the ability of a health carrier or PEBB self insured program to utilize their provider networks to manage care.

## APPENDIX E

### Participant list for September 5, 2008 public hearing

<b>Name</b>	<b>Organization</b>
Arzu Forough, Proponent	Autism Speaks
Mark Gjurasic	Autism Speaks
Ronnie Thibault	Parent
Cynthia Allen-Wessing	Parent
Jennifer Castillo	Parent
Adam Burns	Parent
Robert Ott	Parent
Diana Stadden	ARC of Washington State, Parent, Autism Society of Washington
Charles Cowan, MD	Physician
Katrina K. Davis	Parent, ASTAR Center
Jenny Cochrane	Parent
Susan Malmquist	BCBA Consultant
Lisa Barker	Parent
Michael Fabrizio	FEAT of Washington
Senator Marilyn Rasmussen	Grandparent
Denise Fulton	TACA Washington
Don Burbank	TACA Washington
Renaew Lewandowski	OT – Private Practice
Jianchun Dong, Yi Cao	Parents
Beverly Jacobson	CHILD
Cathy Deleon	CHILD
Jackie Kettman-Thomas	Parent
Patty Solano-Fah	Parent
Cliff Finch	Unknown
Susan Eidenschink	League of Women Voters of Washington
Jessica Solano	Family/Care Provider
Beverlee Boe	Grandparent
Sue Kaplan	Parent
Carl Cecka	Innovative Services NW
Marcelline Love	Parent
Marijean Holland	Office of the Insurance Commissioner
Dennis Martin	Health Care Authority
Ethan Pruett	Parent
Larry Post	Parent
Ken Cole	Parent
Mel Sorenson	America's Health Insurance Plans
Beth Schubert	Parent
Bryan King, MD	Professional
Brandelyn Bergstedt	Parent
Denise Mino	Parent
Chelsi Dailey Coate	Parent
Alicia Liston	Parent
Karen A. Stemwell	Parent
Diana Burke	Parent



## APPENDIX F

### Hearing Summary September 5, 2008

#### Arzu Forough, Proponent, Presentation of Sunrise Proposal

Everyone in this room has exhausted every financial resource we have to get our children into therapies that will make them productive members of our community. Several other states have passed autism insurance mandates recently for families like ours on the brink of financial disaster: Indiana, South Carolina, Texas, Arizona, Florida, and Pennsylvania. Minnesota provides a similar level of coverage as a result of a lawsuit. I trust you have read my proposal and through my proposal you can see that current insurance laws are not providing adequate insurance coverage for medically necessary treatments of autism. I'd like to stop here and speak about what autism is.

Autism and autism spectrum disorders are complex neurological, biological, medical conditions. The severity of these disorders varies along a continuum with some individuals having more profound problems in one key diagnostic area than others and is associated with a full range of cognitive abilities. As is true with any other biomedical disorder there is currently no cure for autism. Rather, autism care is focused on controlling diminishing systems and associated impairment. In this way it does not differ from numerous other chronic medical disorders whose treatments are covered by insurance. A lack of insurance coverage heavily burdens families with children with autism. Many families will speak to this so I will move past this point and allow other families to share that with you. I also provided in my submission information on how private insurance coverage will increase appropriate use of autism services. For the people in the room I wanted to share with you what autism treatments are and what services we are requesting as a part of this legislation.

I also want to share that part of our presentation goes into how private insurance coverage will increase appropriate uses of autism services. I'm not going to go in depth on these points I'm bringing up because they are part of my submission.

We also believe that coverage of autism services will decrease the cost of autism services. Autism insurance benefits will benefit thousands of Washington children at minimal cost and will decrease the long-term costs for caring for children with autism. Again, as part of my submission, I provided incremental societal costs of autism. I talked about what the differences are over a person's lifetime with effective interventions versus a person who does not get remediation. Washington state is nationally recognized for its pioneering spirit and commitment to innovation. We hope that it is one day known as a state with insurance coverage for medically necessary treatments for autism as well.

#### Questions from the panel to Arzu

**Michael Ellsworth:** The maximum is \$50,000 per year that you are seeking, right?

**Arzu:** I first of all want to say that I am a mom and I am the one who proposed that and wrote it and it is a work in progress. The reason we sought that dollar figure is based on the states that have passed legislation and also based on the maximum out-of-pocket amounts that have come through studies. There is an interactive autism network that collects data from families on how much out-of-pocket they are spending per capita. We found that \$50,000 was right for the severe cases for early intervention.

**Michael:** This is definitely a very exhaustive report and is very impressive. I just saw a discounted lifetime cost you cited for behavioral therapies is \$200,000. I guess, based on what you are saying, you are talking about the extreme range of autism that would require this maximum amount.

**Arzu:** I'm really glad you brought that up. One of the things I want everybody to recognize is that autism is a spectrum disorder. When a child is first diagnosed with autism or when families first notice that something is awry, there are children whose severity in the way they are impacted is such that they require intensive services. At the same time, there are individuals on the spectrum that will be successful and will be supported with minimal services. The \$50,000 is not indicative of what every family will need. There is a lot of information I could provide separately on what percentage of the population falls into the more severe, profound range.

**Michael:** One more question. California has autism as a mandatory coverage, right?

**Arzu:** They do not.

**Michael:** When I was looking around at other states, they talked about the Pennsylvania bill that was just passed and they mentioned California and said that in 2000 they passed some sort of mandatory autism coverage and one of the...

**Arzu:** Are you talking about AB88? There are about 25 states that have enacted various levels of coverage, but the type of coverage will cover the bulk of therapies that are for the core symptoms of autism. As of right now there are only eight states.

**Michael:** I think you've just addressed the issue that in the other states there has been a lot of litigation around what should be covered.

**Barbara Hawks:** As a mom of two boys that have autism, who made the diagnosis on your boys? What level of licensure? And I would be interested in hearing this from some of the other moms as well.

**Arzu:** We were in the state of Texas and initially it took a neurologist, a team of neurologists, a developmental pediatrician, a speech-language pathologist, and an educational specialist that together made the diagnosis of our oldest son. I also want to point out that we moved here from Texas and we had treatment covered in Texas for both of our kids and had state-supported services. Our ruinous situation occurred after we moved to Washington. To answer your original question, it was a team of a developmental pediatrician, a neuropsychologist, a speech-language pathologist, and an educational specialist who looked at him in different settings to make that determination.

**Barbara:** If I had a child that had symptoms of autism, I wouldn't go through a primary physician? I would need to see a neurologist?

**Arzu:** No, you would go through... in fact one of the things we want to stress is that a primary care physician should be involved in the care and treatment of children. You would absolutely go through your primary care physician who would make the determination that they are seeing enough of those signs and symptoms to refer you to a neuropsychologist.

**Ronnie Thibault:** I would like to address your question about diagnosis. My son who is seven was diagnosed by a neurologist and he is also a neuropsychologist. He had his secondary diagnosis through UW Autism Research Center. He has gone to multiple places for services where the diagnosis was backed up when he was evaluated.

## **Public testimony**

### **Parents who testified**

- Ronnie Thibault, mother of a seven year old son has autism
- Adam Burns, father of a seven year old son who has autism
- Robert Ott, father of six year old Aaron who has autism
- Diana Stadden, past executive director and current vice president of the Autism Society of Washington and does policy and advocacy for ARC of Washington, and mother of a 15 year old son who has autism
- Edward DeWitt, veteran of the Iraq war and Hurricane Katrina, and father of Jack who has autism (his letter to the Governor was read during the hearing)
- Katrina Davis, mother of 11 year daughter, typically-developing and Arthur who has autism
- Jenny Cochrane, mother of one-year old son with ASD
- Lisa Barker, works for an insurance company, and mother of an eight year old with autism
- Don Burbank, volunteer at non-profit autism organization, and father of four children, including five year old son, Dawson, who has autism
- Jianchun Dong and Yi Cao, researcher with an M.D. and Ph.D., and parents of a three and a half year old son with autism
- Jackie Ketman-Thomas, mother of a seven year old son who has autism
- Sue Kaplan, mother of a son who has autism
- Marcelline Love, mother of a son with Asperger Syndrome
- Jackie Kettman-Thomas, mother of a child who has autism
- Ethan Pruitt, father of a nine year old boy who has autism, wife in military
- Beth Schubert, mother of six year old, Cole, who has autism
- Brandelyn Burkstedt, mother of Claren who has autism
- Denise Mino, mother of two sons, a nine year old typically developing, and a nine and a half year old, Giovanni, who has autism
- Diana Burke, mother of two sons who have autism

There were 23 people who testified, as well as two letters that were read. Nineteen of those who testified or had letters read were parents of children with autism. These parents told impassioned, difficult stories, often through tears, of the challenges they face trying to provide treatment for their children with autism.

Unfortunately, we cannot relate their individual comments in this summary because of the need to provide a brief report to the legislature. We have summarized the common elements from all of the parents' comments and tried to highlight their key points. We in no way intend to diminish their testimony or the value of individual statements.

### **The symptoms of autism spectrum disorder**

Many parents shared the multiple symptoms of autism. These include:

- Struggles with social issues
- Speech and language issues
- Difficulty tolerating noises and light
- Inability to speak, including only being able to squeak one tone
- Preference for isolation
- Trouble with other executive-level functions, such as difficulty carrying on a conversation, difficulty describing things, and difficulty figuring out a sequence of steps for an activity

- Inability to make eye contact
- Feeding or eating issues
- Inability to follow more than one instruction at a time
- Rejection of transitions, need of warnings and countdowns to events such as leaving the house
- Fearlessness or poor judgment, resulting in parents needing to be extra vigilant and even having to install extra locks on doors to keep them from hurting themselves
- Sudden regression, suddenly becoming non-verbal at two years old or hiding in closets to isolate themselves
- Sensory dysfunction, including things like sensitivity to certain textures
- Self-regulation and decision-making problems
- Delayed toilet training, many delayed until the age of five
- The need to make constant noise or move all the time
- Struggles with basic endeavors such as walking through the grocery store
- Struggles to get dressed, eat meals, brush teeth, or sit in a chair during class
- Violent behaviors
- Being “unreachable”
- Extreme diarrhea
- Severe digestive problems
- Severe allergies
- Sleeplessness
- General immune dysfunction
- Very high rate of infection
- Poor reaction to antibiotics
- Inability to detoxify
- Failure to thrive
- Problems with vision. One example given is that sometimes a child with ASD has problems with his or her eyes not tracking together, which causes double vision or issues such as seeing rivers down the page

Many of these children are at normal and even gifted intelligence levels. One mother said her daughter with ASD knows the difference between Monet and Picasso but cannot answer simple questions.

### **Treatments for autism spectrum disorder**

Parents spoke about many effective therapies for their children. These include:

- Intensive early intervention, such as Applied Behavior Analysis (ABA)
- Physical and occupational therapy
- Water therapy
- Chelation therapy (removes heavy metals from the body)
- Speech-language therapy
- The Handle Method
- Relationship Development Intervention (RDI)
- Floor Time (the parent or therapist follows the child's lead, with playful positive attention and tuning in to the child's interests)
- Hippotherapy (utilizes equine movement to help with balance and control)

### **Paying for autism treatment**

Most of the parents who testified spoke of severe financial problems because of the high cost of treatment for their children with ASD. These treatments are very expensive. We heard many say they paid \$40,000 to \$50,000 per year. Some even paid up to \$100,000 in one year for treatments. Here are the ways we heard parents say they paid for autism treatments:

- Second mortgage
- Cashed in retirement
- Cashed in other family members' retirement, such as grandparents
- Sacrificed college funds
- Maxed-out credit cards
- Held fundraisers in their community
- Gave up dental and vision care
- Took on second and sometimes third jobs
- No vacations

There were a few parents who called themselves lucky because their insurance covered many of their children's therapies. Or some felt lucky they did not have to file bankruptcy or lose their homes to foreclosure in order to pay for therapies. On this topic, one mother testified about how good Microsoft's insurance coverage is. She was able to receive occupational and physical therapy four times a week and it was fully covered without her having to fight for the treatment to be covered.

Many said they were beginning to see great improvements in their children until certain age cut-offs when they were forced to stop or cut back on therapy because they couldn't afford it on their own. Age cut-offs we heard about were:

- Age four: Birth to Three Program, through the Infant Toddler Early Intervention Program (ITEIP). This program ends at age four.
- Age seven: Neurodevelopmental Therapies Mandate. This covers services for occupational, physical, and speech therapy. The insurance mandate only requires it through age six.

Many also told about neurodevelopmental therapies being covered by their insurance, but these therapies are capped at such a low visit limit or monetary limit, making it completely inadequate to treat autism spectrum disorders.

### **The financial affects on families**

In order to pay for needed treatments, many of the families are now in financial ruin. Here are the financial affects on families that we heard about:

- Forced to file for bankruptcy
- Forced to sell their homes and rent apartments
- Lost their homes to foreclosure
- Siblings have had to sacrifice dental and vision care, sports and other opportunities
- Lost life savings
- Received constant calls from creditors because they couldn't afford to pay the bills for the credit cards they maxed out
- Had to quit jobs to devote full-time care to child with ASD in order to meet his/her needs

### **Lack of early intervention may lead to institutionalization**

Diana Stadden told the story about her son being on a state waiver that supplies most of their medical needs. She stated they had to be in crisis for that to happen. She was a single mom and was almost to the point of institutionalizing her son.

She also stated that there are a large number of children institutionalized in our state. Over half of them have autism. The other half have behavioral issues. Last year, legislation was passed approving almost \$2 million to start a new program to meet this crisis. This is almost unheard of in a supplemental budget

year. Many families can't deal with their children on their own because there aren't enough services to help them.

### **Intensive early intervention is crucial**

Intensive early intervention is the key to helping these children reach their full potential. There seemed to be agreement between the participants that most children on the spectrum require 20 – 30 hours per week of intensive intervention, such as applied behavior analysis (ABA), and many need weekly sessions of occupational and physical therapy, as well as speech-language therapy.

### **Questions asked by panel regarding institutionalized children**

**Michael:** How many children under 21 do you estimate have autism in Washington state?

**Diana:** We have been using the Autism Outreach Projects, within Office of Superintendent of Public Instruction (OSPI), for tracking numbers. OSPI sends out a survey every year to school districts asking for their numbers. I can get that data from them. That's as close as we can come. Not all the kids are accounted for, because instead of being labeled as autistic, they may be labeled as health-impaired and may not show up in that category.

**Michael:** Say we estimated, would you think 10,000?

**Arzu:** Some numbers say about 6,025. Those are children in school. Birth to three children are not included. But those in institutions are included.

**Michael:** You mentioned you were able to get \$2 million for children institutionalized.

**Diana:** No, that is to prevent institutionalization. If a parent is going into crisis, we have 100 slots for that money. The Division of Developmental Disabilities has already identified 300 families. It would provide a team of experts to go into the home, evaluate behaviors, and put together a team to help parents figure out how to provide support to the family to keep the child at home.

**Michael:** So that would help 100 kids. Where I was going was, if you have 6,000 kids who use half the maximum, that is \$150 million.

**Arzu:** If you look at the Interactive Autism Network and look at the numbers, there is a range of out-of-pocket dollar amounts families are spending. The average for Washington is \$6,000. That averages out for families with highly functioning kids. There are studies that show this for the entire spectrum. Two things I've submitted are actuarial reports that have looked at the numbers from the states that have had similar levels of legislation enacted. The first was Indiana that has had legislation since 2001. Actuarial reports from 2005 stated that autism claims impact was 0.0023 percent. That's less than 2/100<sup>th</sup> of a percent of claims impact. To put it in perspective, these 100 or 200 individuals are those identified at the highest level on the autism spectrum, which is the most severe. It has taken years and years of not having access to treatment to get into the states they've gotten in. We are hoping to put in place preventative measures so that families and children can get services ahead of time. That way their children don't get into crisis situations or develop debilitating behaviors that force them into more restrictive environments.

**Michael:** I'm hearing that the folks who showed up today are families with kids with very serious needs. So it sounds so dire sitting up here and doing the math that I couldn't figure out how .0023 could be the case. Thank you for that explanation.

## **Additional messages from parents**

We heard that the divorce rate among families dealing with autism may be as high as 85 percent.

The parents want this mandate so they can give their children the best chance at become functioning members of society. They want their children to become independent. They feel that the evidence-based treatments being discussed during the hearing are necessary and effective. All families deserve this, not just those who can afford it or those with extraordinary insurance coverage.

It is not just the children who receive these services. It is a whole family. They help the families understand how to cope, what is triggering the issues, why the kids are struggling. Services for the children are therapy for the whole family, and in the long run, for the community.

Many parents told great success stories about the difference early intervention like applied behavioral analysis (ABA) has made in their kids' lives. Many of these children who were so unreachable and could not perform simple tasks like getting dressed for school or going to the grocery store before receiving early intervention treatments are now mainstreamed in regular classrooms and are on their way to reaching their full potential.

We heard stories about it taking many months, even years, for a child to be diagnosed. Parents testified that this is due to things like very long waiting lists to see specialists, and family practitioners and pediatricians who are not trained to recognize the signs of autism. One father told us it took 13 months to get any treatment between getting diagnosed and finding someone to provide the therapy.

A few parents were told by their pediatricians when their sons stopped talking that boys develop slower than girls and that everything would be fine.

We heard stories about families only getting insurance coverage if the diagnosis was stated to be something other than autism. Some stated that insurance companies deny everything once autism is mentioned because it is considered a mental health issue. Insurance companies only cover psychotropic medications, which do not work. The insurers randomly deny services and parents often have to appeal the denial before insurers will pay.

One father said two doctors looked at his son's test measuring heavy metal toxicity and both said they'd never seen anybody measure so high. (Individuals with ASD seem to lack the ability to rid themselves of heavy metal toxins such as mercury.) This father had about \$200,000 saved from various IRAs, etc., and it is now completely gone. Parents said that anything that sounds like a developmental disability will not be covered by insurance companies.

One father spoke of his three year old who could not speak, could only squeak one tone, and who could hardly stand to be near any noise at all. His insurance denied all treatment, even an augmentative speaking device that would enable his son to communicate with teachers, friends, and family.

Diagnosis is often covered because a neurologist does it.

It is documented that intense physical and neurological therapy will help those with autism grow out of this affliction. Yet the support system is not in place. Lack of health insurance coverage inhibits the medical industry from filling the holes in the support system to make breakthroughs possible.

There is a large burden on public schools. This issue should be addressed by insurance before they get to schools—early intervention would help the burden on public funds. Many schools don't have proper

programs or properly trained staff to care for kids with autism spectrum disorder (ASD). If a child's needs are not severe enough, they cannot receive benefits in school. Schools cannot devote enough time to make a real difference.

Autism was likened to someone who has had a stroke in which something happened to their brain and they could not function. Stroke victims' therapies would be covered. Saying that kids with autism who have something wrong with their brains do not deserve the same treatment is wrong. This should be covered as any other medical condition. The behavior issues need to be addressed in addition to the occupational and physical therapy.

Some parents who testified admitted they will not benefit from this mandate because they have self-insured plans, but they want to see it pass for the benefit of others.

One parent shared a short video clip of her son showing that he was unreachable at 18 months just after being diagnosed with autism. The clip then moved forward two years showing the large difference in the child's behavior that intensive therapy made.

Additional costs many people don't think about are the cost of special foods, vitamins, and safety locks on doors because children with ASD often have no fear.

There should be an autism management plan. Many parents and health care providers compared autism treatment to treatment for diabetes. They stated that insurance companies have diabetes management plans. Insurance companies established these plans to save money.

Most children are not diagnosed until they are four years old.

One parent asked whether the state of Washington is prepared to support these kids when they turn 21... not for 10 years but for 60 or 70 years. Mandating coverage now will save the state a lot of money in the future.

One mother stated she wants the following:

- Allow children over six to be eligible for neurodevelopmental therapies.
- Do not discriminate by age, but assess by need.
- Cover parent education. Just like a diagnosis of diabetes, parents should be provided with informational packets and educational opportunities.

Please consider other therapies like music therapy and the Handle Method.

How can we tell our children we won't sacrifice to get them what they need to lead a good life?

We are all advocates for our kids, but we are representing a much larger group.

We must share the burden of the cost of autism across families, society, and private insurers.

Kids don't grow out of autism, they grow into it.

This is discrimination against people with disabilities who don't have self-advocacy skills and don't receive basic human rights.

A Spokane father wrote his story to Gov. Gregoire, stating that he is a veteran of the Iraq war. He was deployed from 2004-2005, and was also deployed to New Orleans during Hurricane Katrina. His son,

Jack, was born while he was deployed in Iraq, and thoughts of his son kept him going during missions in Baghdad. Now that he has returned home, he has different problems. His son, who is now four years old, has been diagnosed with autism. Very few of Jack's treatments are covered, yet his parents are continuing them.

**Sen. Marilyn Rasmussen:**

As you know, I have a grandson with autism who is eight years old. He is over the threshold of being able to get help. What he gets is at school and is wonderful since we changed schools. But that's not true with all of our children. We need to keep pressure on the insurance companies to allow help for these children after age seven. I can't tell you the difference it has made in this one child to be able to get better training and better treatment. He may be a success. We hope so. But for the children who don't get these opportunities, we all lose. We can't afford to do that. I'm hoping you'll listen to the needs of all these parents and grandmas that this is tremendously important.

I was with Senator Hobbs and his wife recently and their child is over the age of seven and lost all of his benefits. They are very concerned. I've watched my grandson go from a child that at age six, the school said he was unmanageable, unable to educate, and they wanted him out of the school. In two months at a different school, he was reading at 61 words per minute out loud with no disruptions and fully mainstreamed.

What did that save that school--a whole lot of money. And what did that bring to that child — a whole lot of self-esteem and self-worth. What did it bring to his parents and grandma--tremendous happiness. I want that for every child. We cannot afford to lose one child. We have an epidemic. We can mandate training and we have tried to do all kinds of things, but if we can't get the help for them in our schools and in the private sector, we all lose. I implore you to keep working for these children. There are so many who care so much. And we can save down the road. It is a win-win.

## **Questions from panel members asked during public testimony**

**Michael:** (Requested clarification on the difficulty of finding professionals who have had training to treat autism.)

**Response:** There are two problems. One is getting the diagnosis. The other is getting on waiting lists for services. For one kind of occupational therapy, we waited four years.

**Michael:** It sounds like it wasn't as much the resources as there weren't enough professionals out there who specialize in treating children with autism?

**Response:** Obviously if insurance companies aren't covering it, there is going to be a much lower market for professionals who go into the field. Also, we are in a crisis now because of the numbers in this state. I believe we are higher than the national average of one in 166. I believe we are around one in 150. That means something like one in 95 boys. We have an epidemic of autism in this country. I don't think there is anywhere in the country where there isn't an under-supply of professionals.

**Michael:** Did I hear you correctly that there are one in 100 boys in Washington?

**Response:** Autism affects three boys in four, which would mean three times as many boys. That is something like one in 94 boys.

**Barbara:** Is there a standardized therapy these children would all need? I've heard water therapy, speech therapy, occupational therapy.

**Response:** Speech therapy is a common one because so many are non-verbal and we need to give them language of some kind. Speech therapy is often one of the first therapies they provide, depending on what type of behaviors that child has and what they're caused by. Even though you can generalize these, you can't generalize the therapy because it's different depending on the child.

**Barbara:** When a child is diagnosed with autism, does the neurologist or neuropsychologist set up a standardized treatment, therapies?

**Response:** No. When you get a diagnosis, you don't know. My son wasn't diagnosed until he was five. My doctor really didn't know what autism was. In fact, it wasn't until we switched doctors and went to Mary Bridge Children's Hospital in Tacoma that he was diagnosed. Often when a child is diagnosed, especially with a primary care physician, they don't know what to do. They do the assessment and send you on for an evaluation. First of all, they know if you don't have insurance, you can't pay for anything. So they don't refer you. A lot of families leave with that diagnosis and end up getting their information from the Internet.

**Barbara:** Who sets the treatment plan if you have insurance?

**Diana:** As Ronnie talked about, Microsoft has physicians with knowledge of autism in their system.

**Michael:** (Asked a mother of a son with Asperger syndrome.) Does your son work? Or have friends? You said you had to go all the way to Kirkland to get services? Was that because there were not any services locally? How about now?

**Response:** No, he does not work or have friends. I went to Kirkland because that is where the doctor my pediatrician recommended was located. That was in the 1980s. They had recommended some psychological appointments. After three visits the psychologist told me there was nothing more he could do because my son wouldn't talk to him.

**Michael:** (Asked the audience whether they have services available in their areas.)

**Response:** Many stated they are from all around western Washington and have trouble finding services. A woman from Mason County stated there are no services there.

## **Testimony from health care providers**

### **Dr. Gary Stobbe, MD (This is his letter that was read by Arzu Forough, the proponent during her initial presentation)**

I am a Board Certified Neurologist sub-specializing in the field of cognitive and behavioral neurology. I earned my BS in psychobiology from UCLA in 1985, and my MD from Albany Medical College in 1989, before completing my neurology residency at UCLA-West LA VA Medical Center in 1993. Currently, I am Assistant Professor of both Psychiatry and Neurology at University of Washington, specializing in autism spectrum disorders, multiple sclerosis, and traumatic brain injury. I serve on the Board of Directors of ASTAR Center, as well as the Professional Advisory Boards of the Autism Society of Washington and the Brain Injury Association of Washington.

In 1993, I began private practice as a neurologist in Washington State. I had an interest in autism

spectrum disorders, and my interest along with the dramatic rise in prevalence of the disorder during the 90s led me to work with a large number of individuals and families impacted by the disorder.

I quickly became aware of a severe misunderstanding that existed in the medical field regarding autism. There existed the belief that autism was not treatable. This belief seemed to stem from the lack of traditional double-blind, placebo-controlled, pharmacological therapies to which most physicians (and third party payers) are so accustomed.

Although progress is being made into pharmacological therapies for autism, the core and platform of therapy for autism surrounds “hands-on” interventions provided by behavioral psychologists, education specialists, speech therapists, occupational therapists, and social workers. These are not glamorous services. In general, they do not involve advances in technology or medical procedures. They challenge researchers in their ability to prove efficacy through blinded trials (as is true of so many behaviorally-based conditions). However, prospective case-study data does exist and clearly supports benefit of a variety of therapy types for autism.

In 2003 we founded ASTAR (Autism Spectrum Treatment and Research). Dedicated to partnering with families impacted by autism, regardless of age, severity, or ability to pay, ASTAR is a non-profit organization and has served over 2000 families in just five years. As Medical Director of ASTAR, I have had the pleasure and responsibility of helping design treatment plans for individuals of all ages and severity. Due to the current inadequate insurance coverage of treatments for autism, I have the “not-so-good” fortune of seeing the impact and benefit of treatment for individuals (whose) families can afford to pay for the optimized treatment plan services privately as compared to the lack of treatment for individuals who’s families cannot afford these same services.

The differences in outcomes due to lack of equitable access to services are dramatic and sadden me deeply as a physician and human. I was brought up in an American household and trained in a U.S. medical school and residency. Naturally my training taught me that treatments should be available for all people, especially children. Currently this could not be further from the truth for families and individuals impacted by autism.

I wish everyone could experience what I experience everyday at ASTAR. I am faced with explaining to families that effective treatments are available, but we will not be able to use them due to cost and/or availability. I feel like I am practicing in a third world country. When families get to experience this firsthand, they are shocked and outraged. How could this be? How could this exist in a state as progressive and resourceful as ours?

In my 15 year career as a neurologist, I have treated numerous neurological conditions, the majority of which do not have cures. Out of all of these conditions, autism stands out as the condition with the greatest disparity between the “haves” and the “have-nots.” Implementation of an optimal treatment plan occurs with the lucky few that have finances able to afford services or that have an insurance plan that covers these services (currently only a few self-insured companies, like Microsoft).

**Scientific evidence as well as clinical experience supports the efficacy of autism treatment.**

Autism is not unique in that most neurological disorders I treat will have a small percentage of individuals that cannot access services and treatments due to a variety of reasons. What is unique is the large percentage of individuals with autism that currently cannot access basic and vital services and treatments due to insurance not covering these services.

A direct result of this absence of insurance coverage for autism-related therapies is the resultant shortage of service providers. Since services are generally not covered, it becomes very difficult to recruit

providers from geographical areas that do cover services. As a result, most treatment providers have long waitlists, creating a further barrier to access these services. Currently ASTAR has a 10-month waitlist just to get in for a diagnosis! Precious time is passing while families wait for these diagnostic services in addition to the great difficulties in accessing treatment services. **This would change if services were broadly covered.**

The impact of autism on a family is great, not just financially but emotionally as well. The divorce rates among families impacted by autism exceed 70 percent. This further blocks our ability to effectively treat autism, and creates an even greater burden to society down the road. Our lack of broad access to treatment services has created greater need for social and welfare services for families and individuals impacted by autism. Our shortsightedness in choosing not to cover autism-related treatment services has backfired and has created a greater burden to our tax payers.

Insurance parity for autism related services is a crucial and necessary step toward increasing access to these services for all. The impact on outcomes for families and individuals will be dramatic. Functional levels such as inclusion in typical education settings, independent and supported employment, and independent and supported living will improve as we are already seeing for families that are currently accessing services. Reduced social stressors as measured by lowering divorce rates and improving employment status of parents will be measurable.

*With passage of an insurance parity law, it will be the responsibility of providers and clinical researchers such as myself to collect and provide the data to payors that proves the effectiveness of these therapies over time. Data generated not just in the lab, but in the real world. I wholeheartedly accept this commitment in partnership with families and those responsible enough to pass this law.*

Autism spectrum treatment and research

### **Dr. Charles Cowen**

I am Charles Cowen. I'm a clinical professor at the University of Washington in the department of pediatrics. I'm a board certified developmental and behavioral pediatrician and medical director of the autism program at Seattle Children's Hospital. I'm also a member of the State Interagency Coordinating Council which supervises the early intervention programs in Washington.

In the early 1990s, while working as a general developmental pediatrician we started to see an increasing number of kids at Children's that we didn't really understand what was going on with them. As time passed, we began to get more sophisticated and recognized that this population of children with autism was a disorder that most of us had read about in our training but had very little experience with. The numbers continued to grow. It was not a local phenomenon, but an international one.

The first international autism research meeting occurred in 2001. This is similar to other health crises that have happened such as the HIV epidemic: A new phenomenon that takes the medical community a long time to understand and develop treatment strategies. Autism, early on, was thought to be a behavioral disorder due to family interaction. In fact, that was the understanding in the early 1950s and as science has proceeded, we have recognized that autism does not have to do with how a child is reared, but is due to a complicated genetic and biologic phenomenon that we don't understand. In my 40 years as a pediatrician, I don't think I've dealt with a more challenging and confusing problem...one that has taxed the medical community to its ultimate extent, and one that continues to have fewer answers than we feel we need to know.

To put this in perspective, this is also true of a lot of problems related to emotional disorders, bipolar disease, schizophrenia, Alzheimer's. In fact, most of those disorders are increasing in prevalence. It is a disturbing phenomenon. One of the realities in the health insurance arena is that things that are considered mental health problems have always received under-reimbursement compared to those considered medical. But there is no rationality to this. The mind is a biological structure. Just because it behaves abnormally, it doesn't mean it's not a biological phenomenon. We just don't understand it because the brain is a very hard organ to understand. I certainly want to reiterate what all the parents have said, but I don't want to belabor any of their experiences or add anything to what Arzu has said or what my friend Gary Stobbe has said.

Let me tell you a story about a three-year-old kid I saw recently in my clinic. We made a diagnosis and a few days ago his mother called our staff in tears saying her insurance company refused to pay for services and she didn't know what to do. That was just an evaluation, a half-day visit with a psychologist and a speech therapist, and my services. We worked this through and it turns out I'm fortunate to work at Children's, because Children's Hospital is a very generous organization and when families cannot get their insurance companies to pay we have ways to help them out. We then told her she had an appointment scheduled for additional evaluations and as our staff person talked to her, the mom said she wasn't sure she was going to be able to come. And I don't know why. I didn't speak to her and I don't know why she declined our services. But the economic barrier -- and you all recognize the economic state right now. To add those additional burdens, or to have to ask for charity, is something that people will decline to do.

Autism services are provided in many, many ways in our community. Public school systems are a key component of providing services. It is not just a medical problem. There are services that need to be provided through the mental health system. All of these systems are under enormous stress, have inadequate staff, and inadequate funding, so let's not kid ourselves that the health insurance system is going to provide all the services. It's going to provide a critical piece of it and make it possible for more folks getting trained, more folks being willing to enter this very under-reimbursed field so they can take care of these kids. Many, many of these kids, and I've seen probably thousands in my 15-17 years, have shown enormous changes over time with therapy. Unfortunately a significant number of these kids have not made improvements despite all of our efforts. These kids constitute a very high risk population for severe behavioral problems, institutionalization, etc. So let's not pretend we have all the answers because we don't.

This year the international autism research meeting in London in May had the largest showing, and they had to close the meeting with over 1,500 people from all over the world. This is a serious problem. Everybody is spending a lot of time and money on it. The research has substantially increased.

What I think I would like to suggest that the legislature has to do, and the public has to do, is work on combining a whole lot of resources. This includes more services through the health insurance industry and health providers, more services in the public sector through schools, and more services in the mental health system to help these families. It is going to take a concerted effort of a whole lot of folks to make some impact. But we have an increasing number of families who are incredibly stressed.

And I want to make a couple of other points. Autism does not hit any particular socio-economic class or racial group. The national Center for Disease Control did a study, which showed the prevalence rates in people with Hispanic background, or African-Americans or Asian-Americans, are all the same. And this is true all over the world, so we are pretty confident this increase is an international phenomenon. This is a huge public health issue. I'm strongly encouraging that this bill move forward as one of the many pieces that has to occur to help these children.

## **Dr. Susan Malmquist**

I am a Board Certified Behavior Analyst in Seattle. I believe it is common values we share as a society that should drive our public policies. When we recognize that a system we have designed no longer meets the needs of society and our greater good, it is our obligation to change that system. We can do it. Unfortunately, there seems to be little incentive for insurance companies to change these unfair practices on their own. I would like to believe that with what we know about autism and the effective therapies such as ABA, that if they all felt it was the best way to care for their consumers and the community as a whole, they would provide coverage. But the evidence, to date, does not bear that out. Let's not forget that we are talking about a system of risk management. That is what insurance is. They are more than happy to take our insurance premiums and in return they have agreed to pay for medically necessary services that are critical to the well-being of their consumers.

After all, we are not suggesting that a treatment approach that can make the difference in whether or not a child can learn to talk is a luxury, are we? If it were your child, would you think it was no big deal if your child could not tell you, "mommy, my tummy hurts," but instead, you sat by helplessly as they screamed in distress. There is nothing closer to our hearts or more precious than our children, and we now know better.

How is it possible that Uniform Medical will approve psychotherapy, CPT code 90806, for a three year old girl with autism who is non-verbal, but they won't cover services for one of the most effective treatment approaches, Applied Behavior Analysis? There is not a CPT code for that. Do they really not know that psychotherapy is useless in this situation? Or is this a symptom of a much larger problem in insurance coverage?

In fact, this has been studied and is being looked at. In February 2008, New York Attorney General Andrew Cuomo announced that he is conducting an industry-wide investigation into the fraudulent reimbursement schemes by the nation's largest provider of health care billing information. The president of the American Medical Association, Nancy Nielsen said, "The investigation lost today by New York Attorney General Andrew Cuomo calls into question the validity of a system that health insurers have used for years to reimburse physicians and their enrolled members. Patients have a right to expect fair and accurate payment for services promised by health insurers."

It is only with an insurance mandate that these policies that allow psychotherapy but not Applied Behavior Analysis for a child with autism will change. In fact, the only real argument that I have heard against it, is that Applied Behavior Analysis is being provided in our schools. I'm here to testify as someone who has worked as a consultant and advocate for families in Washington State for the past 13 years, that it is simply not true. It goes beyond the scope of what I can discuss today to go into detail. But suffice it to say that if the entire burden continues to be placed solely on the schools and directly on families, the entire system is going to collapse. The federal government does not provide enough funding through the Individuals with Disabilities Education Act to cover these services. Nor do we have the educational funding on a state or local level to support this. The health care system must take ownership as well. Until we get a better system, we need to continue to work to fix the system we have. This is not an educational problem. It is not a psychological problem. It is a medical condition as you have heard. It is neurological in basis. The treatments do lie in multi-disciplinary fields though. And it is very complex as you are hearing. I urge the Department of Health to work together with the Attorney General's Office, OSPI, and the Washington State Legislature to reform autism insurance coverage for children and families in the state of Washington.

## **Panel questions**

**Michael:** Is there coverage for someone diagnosed with bipolar disorder or schizophrenia?

**Dr. Malmquist:** The mental health benefits, are typically about 50 percent reimbursement. But the system is becoming more and more restrictive by laws being passed from special interest groups and insurance companies. It really is a matter of concern about this cutting into the bottom line and I think that's a problem we need to address. So I appreciate your questions about how we get the number right. We need to look carefully at that. I've been looking at the bills that have been approved by Autism Speaks and there is standardization there. If you look at the Autism Speaks' Web site, there are models that are working in the eight states that have passed this legislation. But it is going to require some problem-solving to figure out how to do this in a way that is cost-effective. I don't think there is anyone saying we don't need to change this in some way. It is a critical problem.

**Michael:** Mental health is reimbursed at 50 percent?

**Dr. Malmquist:** Typically, though it varies by plan. It is not standardized. And I am not an expert in insurance.

**Michael:** Isn't autism a mental health disorder?

**Dr. Malmquist:** No. It is not. There is often a line-item exclusion in policies for autism. It is completely unfair and I'm not sure how that happened. I'm not sure how the insurance companies are dictating to the government and consumers and what is driving these laws that don't make sense.

**Arzu:** That is a really good question and I'm really glad you brought it up. I apologize for jumping in like this and this will be brief. But part of what the task force did for 18 months was try to identify what the obstacles are for families like us to have treatments covered. The number one problem was this exact question. Is autism a mental health problem? It is not, so the biggest obstacle is that autism is a medical condition that should be covered under the medical portion of benefits. It is not a mental health problem and is not covered under the mental health parity.

**Dr. Cowen:** I don't want to belabor this, but for some strange reason, autism is covered as a neurological condition in some health plans but not all. I want to clarify that it is not just Microsoft. They are the ones who will pay for behavior analysis. But some companies regard this as an exception. The issue of the 50 percent is that many individuals get health plans that provide less services for mental health, just as an employer will decide to sign up for vision benefits or emergency room benefits. Every health plan is different. There is a bottom line that is mandated by the State Insurance Commissioner. Basically, what we are trying to say, is that autism should be included in that bottom line and not excluded. I think that's a really important principle. Certainly we're also seeing in the United States a continued trend to recognize that physical and mental health are not separate issues. Mental health problems have been more difficult to treat than some types of cancer, but there are treatments and evidence of benefits for those treatments continues to exist. The problem is that the insurance companies are lagging far behind in recognizing those changes that have happened.

## **Dr. Brian King**

I am a professor and vice-chair of the Dept. of Psychiatry at the University of Washington, Director at the Division of Child and Adolescent Psychiatry, and Director of Child and Adolescent Psychiatry at Seattle Children's Hospital. I am a lifelong researcher on autism. As a clinician in the field for two decades, these are the stories we hear every day in our clinics all over our state. This is a very small representation of the families affected. To manage a child with ASD who has many special needs requires a lot of effort.

Traveling is an extraordinary example of the will of these parents to end the discrimination around the diagnosis of coverage for autism. Imagine what the discussion would be like if we were talking about diabetes, having the same debate on what should be covered, whether we should cover insulin. It's really not different. A diagnosis of autism is as secure as a diagnosis of diabetes. It is very reliable. The criteria are very common and commonly applied. There are treatments that are clearly effective.

We can introduce something we know works over night and is not different than insulin being available for diabetes. In actuarial constructs, it will be hard. There are the cost savings down the road and all the consequences we might avoid in terms of additive expenses. That will be hard to see in the calculus. Please take the bold step forward with this legislation and in the words of Senator Rasmussen, this is unquestionably a win-win situation for the citizens of the state of Washington and for children and families affected by autism.

**Dr. Malmquist:** Also, the individuals I have talked with in the insurance companies actually appear helpless in many cases and say they wish they could do this. They can't just do it. There is a box they check. It's a system made up by individuals who in most cases have good intentions. It's a system that is broken though and it needs to be addressed. I don't see it changing on its own. The example with Uniform is startling. Can't Uniform figure out that psychotherapy is not appropriate for a child with autism and that the approaches that work should be covered? I think it is going to take more than that and I urge the Department of Health to do this.

### **Michael Fabrezio**

I am a Board Certified Behavior Analyst. I spend half of my professional clinical time as the Clinical Services Director for Families for Effective Autism Treatment, or FEAT of Washington. FEAT is an organization that advocates for science-based, or evidence-based interventions for people with autism. We currently have over 500 member families and have been in the state of Washington for just over 10 years. I want to make a few corrections to some things you might have heard.

One is that Microsoft through Premera is the only insurance company that pays for ABA services for kids with autism. That is untrue. Another major insurance company is Tri-Care, our military service provider. Some other companies are Duke Engineering and some others. It is becoming more and more common. That is important because it wasn't until the creation and researching of Early Intensive Behavioral Intervention (EIBI) that researched an entire history of autism since it was first diagnosed in 1943--that we saw significant, robust, enduring, positive outcomes for children with autism.

Children should receive the right mix of services which appears to be 25 to 40 hours a week of early intensive behavioral intervention, intensive speech therapy, occupational therapy as needed, as well as early childhood special education. Those are different things. If children receive these services from the time they are diagnosed, and for approximately two to three years, they have significantly better outcomes. They learn to talk, to be much more independent, to socialize with their family members, and their cognitive abilities are developed. And it is estimated that they will save the state hundreds of thousands to millions of dollars per child, depending on how well they do with the intervention, in future services that are not used. Future services are not needed because of the early intervention.

As you look at the numbers, I have worked with children with autism for about 16 years across the U.S. and parts of Canada. In my experience, somewhere between \$40,000 and \$60,000 per year would provide a very adequate, strong array of appropriate services for most families. Is it going to be enough for all families? No. Will some require less? Yes. But I think we have to pick a number and I think your number is pretty strong.

## **Ken Cole**

I am a physical therapist at Olympic Physical Therapy. I have three children. My second child (son) was diagnosed with autism at age two (about nine months ago). The cost for therapy alone is approximately \$28,000 per year.

We need to systematically choose which therapies and services. You have codes like 90808 and 90806 that are reimbursed for autism, which are administered by PhDs. Autism is under mental health, but is a neurodevelopmental issue. Neurodevelopmental codes are only used for PTs, OTs, speech therapists, and physicians. Under Microsoft, they have been able to use those codes and get reimbursed because they have money to pay for those services and write that contract. It's not fair to everyone else in this state. It should be equal across the board. The law on who can provide these codes needs to be looked at. ABA therapy is one of the most evidence-based therapies I have seen in my many years of experience. The research speaks for itself. My son went from speaking five words to being able to give us answers to our questions because of ABA and other therapies. Our insurance only covered a certain number of mental health visits but it wasn't nearly enough.

This is also a problem in muscular-skeletal conditions, like Alzheimer's. You take a three or five year old, and they are no different than an 85-year old with a muscle tear. This therapy is muscle control, the brain. When you use behavior therapy, you show pictures so a person learns how to interpret data. It is no different than what we pay for any other condition or disease. It's perceived as different because it's been re-written as a mental health disorder. That is the sad part. It is poorly defined in federal and state laws as to who can use what CPT codes. Most insurance won't cover it because they cannot legally use certain codes. It has to be a PT, OT, or a speech therapist in order to use any of the neurological codes.

I have one question. Is this mandate going to help the self-insured?

**Kristi Weeks:** No.

**Ken:** Is that ok? Is it something you can address or are planning to address?

**Kristi:** We don't come up with these. A legislator drafted a bill and asked us to review this proposal.

## **Other testimony**

### **Dennis Martin, Health Care Authority**

The Health Care Authority is directed to look at cost projections and policy issues with the proposal during the sunrise review. We will not likely complete a full actuarial evaluation because we do not have the potential \$100,000 to do that for this proposal.

I anticipate we will have information for you in writing next week, our initial fiscal analysis on impact to the Public Employee Benefits Board (PEBB) program, section one of the bill. We will include background and a detailed policy analysis.

We do not see this bill as applying to:

- Medicaid or DSHS services
- The Basic Health Plan which the HCA administers
- Large employers operating under the federal ERISA law

We are not sure whether Microsoft or others mentioned today are under ERISA. We are also unclear whether our retirees are covered under the bill.

It does apply to:

- Most of the regulated insurance market including those offered by Health Maintenance Organizations and health care service contractors.
- Only group coverage of disability insurers, not any individual coverage (the way we read this bill)

Section One looks to be intended to cover Public Employee Benefits Board, including our self-insured products such as Uniform Medical Plan and AETNA.

We have concerns with the language in that section and would like to work with the proponents on this to make sure it meets the intent of the bill.

We also have information regarding financial impacts of this legislation. We are likely to be more conservative than the information in the materials you received today. One difficulty without a lot more work is looking at what has been happening in other states and what are the parameters we are working with because it is unclear.

There may be some services under mental health parity when fully implemented in the year 2010 that would be covered.

There are other concerns we see with the bill. We see some provisions in the bill that would work differently than how insurers currently operate in their plans today. We talked about evidence-based care and managed care. There are issues in the bill that may affect purchasers' ability to really manage care and work with families to manage their care:

1. The bill prevents visit limitations, which is standard on medical benefits.
2. The bill would mandate coverage for certain types of services that otherwise might not be covered by an insurance policy. For example, pharmacy is specifically covered in this legislation. There are products sold today that do not cover a pharmacy benefit
3. The benefits are set out in statute and clarified by Department of Health rule. This creates uncertainty and could be perceived as limiting the ability to make changes rapidly from an evidence-based perspective. It limits the ability of health plans to utilize that information as it evolves.
4. Medical necessity would be determined by licensed providers and department rules, not the health plans or purchasers. I'm not even sure how that would work having medical necessity defined by rule. It is not a benefit. It is a determination about whether or not the covered benefits are medically provided under the insurance policy and are applicable for the individual and for the individual circumstances.

Those decisions would be made in rule and made by a provider. This bill does not require the provider to be a specialist in any way. This is going to limit the ability of looking at criteria for best practices and making decisions based on that.

Credentialing standards would be developed by Department of Health and must be used by health plans. So, if UMP wanted more specific criteria for an individual to participate, it is questionable whether they would be able to do that under this language. I'm not sure whether providers could have a provider network for autism. I'm not sure whether they would be eligible for reimbursement.

Plans would be limited to review outpatient treatment every six months. This is also different than how health plans are managing their businesses. This will likely increase the cost estimates.

## **Mel Sorenson, American's Health Insurance Plans**

I am with America's Health Insurance Plans (AHIP), a national trade association of insurers, managed care, disability insurers, and health care service contractors, many of whom do business in Washington State. I want to make it clear that AHIP members doing business in Washington are very mindful of the realities families deal with every day with respect to autism-related difficulties, and other health care issues that are equally grave for families dealing with these issues and the financial consequences. At the same time, our members have to balance cost and cost-management issues. We want to address a number of issues with this proposal.

Cost issues are not insignificant and I know you have received a letter from the Association of Washington Healthcare Plans (AWHP), a separate organization. AHIP would associate itself with a number of the observations in the letter AWHP submitted. Cost considerations are not a new issue, but consider this:

- Small employers particularly are struggling with costs of health care.
- Premium costs are significant reflection of the cost to which the coverage is exposed. Health insurance is a reflection of this.
- To the extent mandated benefits come forward increasing the array of services, the cost of those services and overall magnitude of the costs, will absolutely flow through in premium costs.
- Data has clearly shown that as premium costs have gone up, many small employers find themselves not able to afford coverage.
- One of the sad ironies of the mandated benefit debate is that as we address one at-need group, costs go up, and a block of the population ceases to have coverage.
- Are we doing a net service or are people without any insurance a consequence?
- I'm not saying one specific proposal has that impact, but certainly the collective impact does. We ask Department of Health to be mindful that the services, however worthy, are not free.

Washington State has two mandated benefits that cover some autism-related services. I want to clarify some things:

- The neurodevelopmental therapies mandate covers children through age six for OT, PT, and speech therapy. In many cases those services are billed for autism.
- The mental health benefits are frequently billed and paid for depending on the circumstances. Washington State has passed a mental health parity law which requires that mental health benefits track exactly with those available for medical conditions. It is being phased in and I believe the last phase is phasing in now, or by 2010.

Details matter greatly. When we talk about a new array of services and therapies to be paid for, it matters:

- Who is delivering those services?
- How much of those services we are talking about?
- Which segment of the population will be eligible for those services?

If there aren't decisions made on clarifying each of those points, you have an issue that becomes unmanageable from an insurance standpoint.

There are some particularly troubling parts of the proposal that make it very unclear who can bill for services. A prescriber, a physician can order services, but doesn't indicate a particular level of licensee or regulated health professional has to deliver the services. It indicates anyone who delivers those services is an authorized provider.

I also want to note that some of the discussion today has been in the context of education, or socially-oriented issues. Are we going to start moving health insurance away from being directed by health insurance structures towards supplementing our education system? If that is the move and it is appropriate for autism services, why wouldn't it be appropriate for other services that funding is difficult for in the public health system?

It is not unreasonable to ask a question related to the overall parity of the reimbursement system. A substantial portion of the population is covered through self-insured employers, etc. Those programs are expressly preempted by federal law of having accountability to mandated benefits. Perhaps nearly 50 percent with employer-oriented policies meet this. If we are going to have a mandated benefit that affects the regulated marketplace, are we kidding ourselves in respect to the segments of the public it does not reach?

And what about the public programs? Would this fit within the Basic Health Plan, Uniform, Healthy Options, Medicaid? Why would a child with needs who is under Health Options not benefit from this same sort of structure under the commercial plans?

As Department of Health grapples with this issue, please consider the pragmatic realities such as procedure codes that show the service clearly, and how does the carrier administer it? They need a structure to follow with clear direction. We want to make sure costs are figured by actuarial analysis to make sure the proposal is not too low or too high. That doesn't do anybody any good. The consequences are related to how the bill is put together. We are willing to work with the proponent, the state health department, etc., to make sure this is addressed.

## APPENDIX G

### Summary of written comments

The department received letters and emails from over 60 family members and a number of health care providers in support of an autism insurance mandate. As in the public hearing, the letters and emails from parents and family members testified about the challenges they are facing trying to find and pay for treatment for autism treatment disorder (ASD). In order to keep this report brief, we will summarize the comments provided by family members into key messages.

#### Common messages

“In my mind, the question of insurance coverage for autism presents the classic ‘pay me now or pay me later’ conundrum. If we can get these kids early and with intensive treatment, they have every chance of becoming contributing members of society. Without this early intervention and ongoing treatment to sustain their gains, they don’t have a chance and the ‘collective we’ end up paying for it in a multitude of ways.” Many families wrote this opinion citing much greater future costs to society if we don’t provide treatment now. We either treat these kids now so many can become productive members of society or we institutionalize them down the road for much higher costs.

Some parents stated that the alternative to no treatment is that children will not improve. Often they will actually get worse because their inability to connect and communicate with the outside world builds frustration and anger, resulting in more profound behavior issues. In time, these children can pose a danger to themselves, their family, and others. If these behavior issues cannot be dealt with effectively, these children are moved into institutional settings, requiring significant public funding subsidies. One parent wrote, “From a purely economic perspective, an investment in early intensive intervention will pay huge dividends later in life as these children are able to reach their full potential.”

Many who commented stated this is an insurance industry problem. The whole premise behind insurance is to spread the cost risks of some individual health issues across the financial contributions of many people.

Multiple families wrote about the incredibly positive results they have seen in their children after intensive intervention, especially those that started treatment early. They told of children who were “unreachable,” non-verbal, and very delayed in their development before treatment, who eventually entered school in mainstream classrooms and became participating members of their families after treatment. These families cited literature and research showing that early intensive intervention of 25-30 hours per week is the key to helping children with autism reach their full potential. Many parents and health care providers stated the earlier treatment is started, the better. These are not experimental treatments. The experts know that intensive early intervention is critical to treating ASD.

Many families wrote about the emotional impact of having a diagnosis of ASD. Upon hearing this devastating diagnosis, they are then told that extensive early intervention is crucial to their child’s development; however most insurance won’t cover the \$20,000 to \$50,000 per year it takes for intensive treatments. This is followed by the news that there are huge waiting lists and a shortage of qualified professionals to provide the needed therapy.

One mother wrote, “Having a child on the [autism] spectrum affects every portion of your life. It drains all your resources, all your time; it even steals your career. My family has tried everything. I have sent my husband as a civilian contractor to work in Iraq dodging bullets for \$12,000 a month, sent him to DC and Houston providing personal protection for other people and even *their* children so that we could teach our child to eat, sleep and speak. I have worked 100 hours a week as a retail manager where 100% of my paycheck went straight back to my son and his medical bills. I have brought my mother in law to live with us solely to care for my child and see to his therapies while my husband and I worked in two different states to cover the bills my son had already acquired. Eventually our marriage suffered so greatly that I gave up my career to stay home with my son while my husband continued to work 3000 miles away.”

Many families wrote stories like the one above of the tremendous financial burden of paying for autism treatment. They told stories about losing everything, filing for bankruptcy, and losing their homes because the costs of therapy are so high. Some have medical bills of over \$100,000 per year. Some families held fundraisers in their communities to raise money for their autistic children’s treatments. Many families have been forced to discontinue services that are working for their autistic child’s treatment because they couldn’t afford it.

Many told about their neurodevelopmental therapy coverage only allowing for a maximum benefit of \$1,000 per year. They exhaust this amount in just a few months and are forced to pay out-of-pocket for the remainder of the year. In addition, once these children turn seven, they are no longer eligible for the neurodevelopmental therapy benefit (the mandate only requires it be covered through age six.) Many stated the benefit should be extended well beyond seven years old because children with ASD require those services far beyond that age.

Many families wrote that insurance companies currently group ASD incorrectly under mental illness. One family wrote, “This is not only scientifically incorrect and inconsistent with the DSM Manual, it significantly misrepresents both the cause and treatments necessary to help those afflicted by it. The physiological fact that these children’s brains are not developing in a typical fashion is a biological issue, not an emotional one. The fact that these brain development issues can cause emotional regulation and attachment issues in these children is a *symptom* of ASD, not the cause. All we are asking for is that insurance companies cover ‘broken brains’ in the same way ‘broken bones’ are covered.”

Families wrote that public school special education does not provide consistent and appropriate educational intervention for children with autism. Districts and schools vary in their ability to adequately handle the influx of children with autism. Schools have a one-size fits all approach to special education. Schools are overburdened already and parents have to advocate for everything they get for their children with ASD.

Many told of the effects on the whole family when dealing with autism. They told how their typically developing children don’t get the attention they deserve because their affected child’s needs are so great. They stated that the divorce rate is extremely high in families dealing with autism.

Some parents wrote on behalf of the people who cannot afford intensive therapy. Many, like those who work for Microsoft, told their success stories. They told about children who were at first unable to perform even simple tasks without struggles, and after two or three years of intensive behavior therapy are now performing normally in many areas. They wrote in support of a mandate so other parents can have the success they have had.

Some families told about the University of Washington Autism Research Center. They are taking part in an early intervention study that provides children at risk for autism with 20 hours of ABA in their homes at no cost. They told success stories based on the help they obtained from the Autism Research Center.

Many families wrote about the long waiting lists, often waiting six to eight months just to be evaluated or begin treatment. They wrote that coverage for treatments and more service providers would make it easier to get into treatments more quickly after diagnosis, which will improve outcomes. They wrote that coverage will increase efficiency of health care service.

## **One example of intensive intervention**

One family provided the following example of their son's schedule and costs:

**Education**--Kindering Center offers four to six hours per week of support. This includes classroom hours, integrated speech, and occupational therapy. What is not paid by our insurance first (against our maximum visit allowances) is paid by the state or uncompensated Kindering support.

**Speech**--One hour per week privately supplied. Supplemental speech therapy is needed due to the lack of available speech therapists at Kindering to provide private. Insurance pays \$1000 per year for combined for Speech, OT, and PT. We met this maximum within 30 days. The remaining expense is paid out-of-pocket. We are fortunate to have found a therapist willing to charge us 60 percent of the in office rate but we still pay all of this as insurance maximums have been met. *Monthly expense was \$300. Out-of-pocket estimate--\$3,300 per year.*

**Occupational therapy** – Four hours per month to support his weakness in feeding, writing, dressing, etc. (See above for insurance coverage) *Monthly expense - \$560 Out-of-pocket estimate - \$6,160 per year.*

**Physical therapy**--Four hours per month. At 2 ½ years of age, he still struggles with stairs, running and jumping. (See above for insurance coverage) *Monthly expense - \$560. Out-of-pocket estimate - \$6,160 per year.*

**Applied behavioral therapy**--Although there is no known cure for autism, specialized behavioral therapy is the only treatment proven to help children with autism reach their full potential. It is expensive and difficult to find this help. We have hired Northwest Behavioral Associates to program manage our son's ABA therapy. Our son sees his Board Certified Behavioral Analyst (BCBA) weekly for two hours and then is supplemented by home therapy for eight hours per week. In addition, the program manager supports training of the tutors, school reviews and in home consultations. It is very hard to find trained tutors to come to our home--but impossible for us to afford to pay a certified behavioral analyst for all the hours. In addition, I do not think we could find someone with the hours to give. Unfortunately, many insurance plans do not cover BCBA's because they are not licensed in the state. Worse, almost none will cover home tutors. Regence pays 50 percent of the allowed 20 office visits per year and no coverage for home tutors. We exhaust the office visit coverage in less than five months. *Monthly expense--\$1,000 for CBA, \$860 for home tutor. Out-of-pocket estimate--\$19,200 per year.*

**“Total out-of-pocket estimate--\$34,820. And we have excellent insurance coverage--or so we thought.”**

## **Commenters' issues with the current proposal**

Many questioned why ABA is the only therapy specifically mentioned in the proposal. They state that it is only one treatment method for ASD and that it should be left to the medical professionals to determine what should be covered.

Some asked why this proposal doesn't include coverage for other disabilities, and whether under the proposal there will be more coverage for ASD than for kids with other disabilities.

A mental health counselor wrote with a concern that psychotherapy by a licensed mental health counselor or clinical social worker is not covered under the proposal. She requests MA-level therapists be added to the proposal unless there is a compelling public policy reason to exclude them.

The Washington Speech & Hearing Association (WSHA) requested the mandate cover other communication disorders as well.

## **Additional messages from parents**

One parent wrote questioning why this proposal only covers early interventions. She asked why treatments are not being proposed that would help her 19-year-old with autism. She stated that these kids grow up into adults and still need services.

One parent questioned why this does not apply to all insurance companies that provide coverage for people in Washington state.

One commenter wrote she thinks this legislation is needed; however, she questions why we address issues one illness at a time, rather than addressing insurance companies' denials of coverage for many other diseases and disorders.

One parent asked how she can tell her child that she won't sacrifice to give him what he needs to lead a good life.

One parent asked about insurance for her adult child who is unable to hold a full-time job and cannot maneuver the health care system on her own. Once her daughter graduated from high school, she could no longer be on her parent's insurance. She suggested it would be wonderful if parents of children with disabilities were able to carry their adult children on their insurance.

One parent stated that providers of behavior therapies are not licensed in Washington. She stated it is important that BCBAs be recognized by insurance companies. She suggested they look to Microsoft's insurance plan for examples of criteria for recognition of these providers.

One mother told of her despair while reading in her insurance booklet about the very limited insurance coverage available for neurodevelopmental therapies while on the facing page seeing the almost unlimited coverage for inpatient drug and alcohol rehabilitation. She stated that she watched her father go through alcohol treatment four times and die young as a practicing alcoholic. She asked what the logic is of covering something with such a high recidivism rate while not covering ASD. Her father made choices in his life, while her son has no choice.

One mother stated she plays "Mama Bear" to protect her two children who have ASD from all the people who cast judgment on them. She stated that she is scared to let anyone know about her sons'

challenges because people pass judgment based on them. She is frustrated with so many people turning their backs on them and it seems to her that the older her children get, the harder it becomes.

One mother stated that insurance companies still often consider ABA to be experimental. She stated this is surprising given how long ABA has been used successfully and the wealth of studies proving its effectiveness.

One parent stated that funding through the State Department of Developmental Disabilities is frozen: 13,000 families languish on waitlists.

One mother wrote that because of financial constraints, she chose school-funded services for her son with ASD. He is now 20 and only says occasional words, can draw only lines, and cannot write his name. He needs constant one-on-one supervision.

One commenter who states she is an advocate for children with autism stated that the mandate should also include expedited claim review and no life-time caps. She stated that if we cap the program, we are not using it to the full potential. Expedited claim review will ensure insurance companies comply with the required coverage and do not delay payment to parents of providers.

One family wrote that their wish for their son is no longer that he attends college, but that he simply has a good life and a job that makes him a contributor to the values of their community and the tax base.

One commenter disagrees with the assertion in the proposal that autism is not a mental illness. He provides the following definition taken from a draft mental health briefing document presented to the Governor's Interagency Council on Health Disparities May 23, 2007: "Mental health means healthy mental function, which is characterized by the ability to perform productive activities, to have fulfilling relationships with other people, to adapt to change, and to cope with adversity. Mental illness refers to conditions generally characterized by alterations in thinking, mood, or behavior that are associated with distress or impaired function." He states that this definition would seem to apply to autism. He questioned whether Department of Health has a standard definition of mental illness.

One commenter suggested insurance companies should cover treatments recommended by the National Institute of Child Health and Human Development and the American Academy of Pediatrics. She stated they should cover Applied Behavior Analysis, Occupational Therapy, Relationship Development Intervention, Sensory Integration Therapy, Speech Therapy, and Floortime.

Other treatments commenters requested be included in coverage:

Neurobiological Learning Therapy (NBLT)

Social skills training

Vision therapy

Speech therapy

Occupational therapy

Physical therapy

Floortime

Handle Program

Son-Rise Program

## **Written comments from health care providers**

A number of health care providers wrote in support of this proposal.

One provider wrote that she hopes the bill will not mandate a particular therapy.

A speech language pathologist wrote about working with many students and families impacted by autism for 13 years. While early intervention is extremely important in all aspects of child development, people do not stop developing or learning at age six or seven years. In fact, most typically developing students are just beginning their formal learning careers at that age. It is without merit or research to arbitrarily cut out therapies and other services from children with autism at age six or seven years.

She also wrote that as children move into their adolescent years, they require continually changing therapies with a stronger focus on reinstating missing social skills, understanding others' perspectives, or in some cases, significant augmentative/alternative communication help.

She stated that children with autism don't stop learning, growing, or changing at seven years old and their insurance coverage shouldn't stop either. No one would consider discontinuing coverage at seven for medical services like X-rays, blood work, or surgery.

A parent and professional treating autism wrote that research backs up the wisdom of this investment, showing that dollars spent on early intervention saves many thousands of dollars later in avoided institutionalization costs. Medical and therapy services are in short supply and high demand, and when available (after a long wait list) are often hard to get covered by insurance. Many plans exclude autism services. She stated that insurance companies have tricky ways to deny claims or make it frustrating for providers to participate.

She wrote about her six to nine month wait list. She has been dropping companies because she cannot make a living on what they are willing to pay. She has tried negotiating with insurance companies. She wrote of the endless paperwork insurance companies require, while being notorious for denying claims for no apparent reason. She related conversations with provider relations representatives where the responses regarding their subscribers with autism are that they don't track the autism specialty, clients need to call and inquire with each therapist on the list about their training in that area, they don't offer specialty services...

She also wrote that there is a reimbursement issue with the rate for group therapy, which is set at around \$20 per session, the fee for standard groups of six to eight adults. Therapy groups for individuals with autism are three to four children with one to two adults, which is a completely unrealistic rate.

In addition, she wrote that insurance won't cover the costs necessary for conducting assessments for families who visit from greater distances. Typically, these families lack access to services in their local areas and stay in a hotel, receiving intensive services over a two to three day period; however, insurance will only cover one session per day, at best. Some will only cover one session per week. She sees them for six hours per day, in order to make use of their time. In addition, the cost of writing the report and treatment plan, necessary for the family to carry out the plan independently at home is consistently denied by insurance. Records review by professionals is consistently denied reimbursement by insurance, yet any child with autism usually comes with a pile of previous reports

that takes at least an hour to read. Any session conducted via telephone or webcam is not covered, yet the clients who live in remote areas where services are unavailable find it extremely difficult to travel with their child with ASD for an in person session.

She further wrote that any mental health therapist who specializes in treating autism has spent thousands of dollars on workshops, clinical supervision and additional training, and has experience that deserves to be compensated at a higher rate than the average therapist. If insurance companies are not compensating for that specialty, given the short supply and high demand, they will have no autism specialists on their panel. Currently, most insurance companies do not care. It is up to legislation to mandate that they care.

An occupational therapist specializing in early intervention wrote representing the Washington Occupational Therapy Association in support of the proposal. She is a research coordinator at Boyer Children's Clinic in Seattle and Clinical Assistant Professor in the Department of Rehabilitation Medicine at the University of Washington.

She wrote, "At best, the current health care coverage in Washington State for this diagnosis includes children up to seven years of age and sometimes, but not always, includes medically necessary therapies such as speech, occupational, and physical therapy. In early intervention programs funded by Part C, Individual with Disabilities Education Act for children age birth to three years, reimbursement for these therapies by health care insurance is used before Part C monies are allowed to reimburse these services. In other words, Part C is a payer of last resort."

She also indicated that occupational therapy is provided in the public school system in order to meet the educational, rather than the health needs of the children with disabilities. Occupational therapy is a healthcare profession, but the focus in the schools is on helping children participate in their education. Occupational therapy may address eating, sleeping, and other self-care issues these children and their families face. She wrote that if not addressed, these issues will significantly impair the child's ability to participate in everyday activities.

She recommended policy makers look to the interagency coordination efforts of the early intervention system as a model for less fragmented and more comprehensive services.

A speech-language pathologist wrote that she sees the incredible difference intervention makes in the lives of children with autism. Autism is a medical disorder that persists into adulthood, thus coverage is needed beyond age seven (developmental delay cutoff age). Since there is currently no cure, management is the appropriate treatment. This includes the main deficit areas of social and communication skills. She wrote the department to please mandate insurance coverage of autism at a level appropriate to most patients' needs, ie., at least once per week of SLP, OT, PT.

The Physical Therapy Association of Washington wrote in support of the diagnosis and treatment of autism spectrum disorders being added as a mandated benefit in Washington State.

They state there are challenges finding the appropriate care for children with autism. They said that treatment in schools is impractical and in some cases impossible due to staffing shortages, lack of trained professional staff, and tightened school district budgets.

They wrote that insurance benefits for necessary treatment are limited for most families. In some, the \$1000 per year and high deductibles that most carriers offer do not even begin to provide coverage for the services necessary for these children and their families. The proposed mandated benefit legislation

will ensure that children with ASD will receive the care they need to become actively engaged in their communities.

The Washington Speech & Hearing Association (WSHA) wrote in support of the proposal. They stated that, “As an association of professionals in the speech, language, and hearing fields, WSHA supports early intervention and insurance coverage for disorders that impact the ability to communicate and access education. Because autism is such a disorder, WSHA supports a mandated insurance benefit for this treatment.” They also stated that they recognize the need for insurance coverage; however, they believe that many persons with communication disorders would benefit from early and intense therapy. They requested the mandate cover other communication disorders as well.

WSHA also stated they do not want coverage of only one mode of therapy. Therapists and the families they treat need the autonomy to choose the most effective therapy for their individual needs.

One ABA provider wrote that she has been doing ABA home therapy for children with autism for a year and sees the need for government help and regulation especially in regard to insurance policies. She told about the large number of parents that contact her weekly to see if she is available to do ABA therapy for their children. She stated that this therapy is proven effective by scientific research to help improve the lives of people with autism and questioned why it isn’t covered. She compared it to denying someone with bad eyesight the aid for prescription glasses. “Legislation needs to show that we as a society value these kids and that these kids can and will do great for our society.”

Another ABA provider, who is a BCBA, wrote that she has worked with children with autism for seven years. She stated that ABA works. She has seen many success stories. She wrote that success for one child may be to communicate their needs for the first time, which lowers their frustration and aggression. For another child, it may be having a conversation with a friend, a meaningful interaction. ABA is very individualized, with each program tailored to their strengths and weaknesses. It is not a one-size fits all approach. It is custom-made and flexible. It is also closely monitored and changed based on the progress of the child.

The Children’s Institute for Learning Differences (CHILD) wrote in support of the proposed legislation. CHILD is a not for profit therapeutic day school serving children who have a variety of learning, language, sensory and behavior differences, with 62% on the spectrum. In addition, they wrote that two-thirds of the children on the waiting list for their summer program were on the spectrum and were not able to access needed therapy because of financial constraints.

They stated they support the proposed legislation because it will:

- Provide continued critical medically-necessary services for all children on the autism spectrum. Many insurance providers specifically decline coverage for services to children who have a diagnosis of autism or deny coverage beyond the seventh birthday. Evidence-based research demonstrates that children continue to make significant and necessary progress past the age of seven when provided with appropriate therapeutic interventions. Insurance coverage for this neurobiological condition should continue based on identified medical necessity, a resulting plan of care and the patient’s continued progress.
- Eliminate the specific exclusion clause for the diagnosis of autism in a medical/health insurance policy. Autism is a complex neurobiological medical condition. As such, it must be considered a “covered” diagnostic code and all exclusions for the diagnosis be removed by insurers in order to grant full access to health benefits and necessary care provided by professional therapists.

- Allow all professional fees to be covered when providing services for children with a diagnosis on the autism spectrum.
- Allow the treating licensed physician along with families, to determine the treatment plan; not the health plan.
- Allow the full extent of “medical necessity” needs of children on the autism spectrum to be in the purview of the health plans. It is not within the scope of the educational system in Washington State to provide for and meet the full extent of needs of persons with autism. Routinely, school districts deny therapeutic services if it is found to be of “medical necessity”.

CHILD wrote that they repeatedly experience families being informed by their school districts that they will not provide therapeutic interventions that fall beyond the scope of special education services mandated in the current RCW. Often this leaves the child lacking access to the critical services that have been identified in the medical care plan by the child’s primary care physician because there is no financial support for the therapies. Allowing all providers to be financially supported for providing the needed therapy assures children receive needed services, both early intervention and continued throughout childhood. In the end, this will result in decreased costs for the family and the community, as the individual learns new skills to be successful in school, at home, and in life.

CHILD also reinforced the fact that autism is a “neuro-biological medical condition” and the individuals with this diagnosis deserve the same type of support as any other medical condition with financial coverage from health plans. They acknowledged that the proposed legislation will not cover all children; yet wrote that they believe it is a great beginning to help many families who otherwise face insurmountable barriers because of the lack of resources.

## Written comments from the insurance industry

The Association of Washington Healthcare Plans (AWHP’s) submitted the following comments about the proposal:

“Our members, too, are concerned about the challenges faced by children with autism and their families. We want to approach this issue in a manner that is in their best interest, as well as that of all those we serve. Accordingly, we offer the following input for your consideration.

- **ABA Therapy is generally recognized as being more educational and school-based, rather than medical/mental health in nature.** A major focus of the proposed benefit mandate is ABA therapy, which consists of intensive behavior modification services designed to help improve school readiness and developmental functioning. Accordingly, private insurers should not be solely responsible for providing and covering these services. It is our understanding that the federal Individuals with Disabilities in Education Act (IDEA) guarantees ‘free and appropriate public education’. As part of that requirement, school districts must conduct outreach to pre-school children ages 0 – 3 who may be disabled and need special early intervention services. In addition to identifying children with autism spectrum disorder through this process, the district is expected to supply services to these children and set-up an “individual education program” for disabled children aged 3 – 21. The district must also submit compliance reports to the U.S. Department of Education<sup>48</sup>.
- **Development of a best practice intervention model with special focus on diagnosis and evaluation is needed.** This model should make use of evidence based research and include a comprehensive evaluation or re-evaluation of the child consistent with recommendations of the American Academy of Pediatrics. The treatment plan should be individualized and developed

with input and collaboration from a myriad of different disciplines. The model should also allow for utilization review, case management, medical necessity review, and other care coordination techniques, as appropriate. Additionally, to prevent inappropriate cost-shifting, the model should allow for close coordination with schools and other resources. We want to ensure appropriate optimization and utilization of existing resources and seamless delivery of care across the spectrum of services for the individual.

- **Treatment should be limited to licensed and/or certified providers.** To ensure quality treatment and patient safety, any person or entity providing treatment of autism spectrum disorders should be licensed or certified, and health plans should have the tools necessary to credential those providers. Additionally, we recommend that ABA therapy be provided by behavior specialists that are board certified, such as by the Behavior Analyst Certification Board.
- **Proposed legislation should maintain consistency with the mental health parity statute of 2005; for which autism is one of the covered mental health conditions.** This should include maintaining consistency with all medical necessity and certificate of coverage requirements. Washington's current mental health parity law allows healthcare plans to manage utilization, make medical necessity decisions regarding treatment, and exclude coverage for experimental/investigational treatment – as with any other disease or disorder.
- **Requiring carriers to provide for the coverage of autism care will increase the cost of healthcare and insurance premiums.** Each benefit mandate adds to the overall cost of healthcare and insurance premiums. And, in a time when we are collectively looking to make healthcare more affordable, we believe employers should be able to determine their own benefit plans without additional state mandates. Financial impacts must be strongly considered for any benefit mandate proposal, especially given current economic conditions in our state and the fact that many families and employers are already struggling to afford coverage.
- **Washington already has mandates in place that cover services for individuals diagnosed with autism spectrum disorders** --- including the mental health parity statute of 2005, and the neurodevelopmental benefit mandate. We note that some states with new autism mandates, like Arizona, did not previously have such mandates.

In addition to offering the above input, we would also like to request clarification regarding which populations the proposed legislation would cover.”

## **Comments in opposition to proposal**

(These comments appear as written)

“It appears that the goal is to make health insurance increasingly expensive, until almost no one can afford it. Then, the nanny-state can intervene and impose socialized medicine "in our best interest", along with all its mandates and intrusions into our lives. The reason so many insurance companies already refuse to write health coverage in Washington State is because of the level of bureaucracy. It would be much better to allow the free market to work.

The proposed system will only create one more expensive, cumbersome, monstrous bureaucracy.

There is no perfect solution to all problems. There is a lot of erroneous thinking. It appears some individuals live in a fantasy world where they believe government can solve all their problems. They do not understand that dollars are a finite quantity. Every dollar spent on one purchase may not be available for a higher priority purchase. Some people seem to believe that if they cannot afford to pay their bills that I can afford to pay mine and theirs, too. Another fallacy is that health is directly proportional to the amount of access and health care coverage an individual has. Possibly with the

exception of accidents, nothing could be further from the truth. More depends on diet, exercise, sanitation, righteous thinking, and environmental exposures. *The physician cannot undo what the patient will not do.*

I suspect the special interests will be organized to make a showing on this issue. The truth is that most working taxpayers are far too busy with responsibilities to show up at hearings. Nor are they notified of hearings. They do not have the expense accounts or get time off work to contribute. Often hearings are held simply because they are mandated, but there is never any intent to take the input of citizens seriously if it runs counter to the proposed agenda.

I predict that if this goes as other proposed changes, most of the citizens of WA will be railroaded into paying an increased premium for coverage they do not want or need. I am tired of hearing increased costs compared to slices of take-out pizza. The truth is that many families can no longer afford pizza.

I will trust families to make the best decisions about how their health care dollars are spent rather than relegating their responsibilities to the state. If the people of Washington want autism coverage, the free market will provide it... but apparently, most do not. A government mandate is never necessary when it some thing most of the people want to do anyway.”

“I do not want or need this coverage on my health insurance policy. It will increase my premiums over time. We need a free market system where those who want it can buy it... and those who do not want it are not forced to buy it.

In general, I suspect that most of the people who respond to this request for commentary will be individuals who stand to benefit... such as health care workers who accept reimbursement and parents of autistic children. It is unlikely this is representative of the opinions of the Washington taxpayers who will foot the bill. For example, I would not have known about it had I not been specifically contacted and asked for input. Most people are too busy working to keep up with this sort of thing.

What we need to do is get government out of the health care business and let people be responsible for themselves and their families.”

## **Comments in response to hearing testimony**

One parent wrote that her child is one of the millions of American children without proper health insurance. She related that her husband’s company doesn’t provide dependent coverage. Her child suffers from a spectrum disorder and other major neurological conditions including a neuromuscular disorder and seizure disorder, and is considered uninsurable by one of the very companies who sent a representative to the hearing. This representative spoke of the fallout due to the increases in the premiums that would take place should this bill pass.

She wrote that she has her own private insurance policy, which increased by \$36 a month or approximately 18 percent, following the passage of the recent mental health parity bill. She didn’t care about the increase because it reflected an increase in coverage. She told of fighting insurance companies who incorrectly denied claims under ICD-9 code 299.00 (Autism Spectrum Disorders) as a Mental Health Nervous Condition not covered under the policy. She stated that many families not on the spectrum who are impacted by the increase in premiums will also benefit from an increase in coverage when their children or grandchildren are diagnosed.

One father wrote that he found the testimony of the insurance industry representative to be condescending and rambling. He stated that the representative admonished the committee that these changes wouldn't be free, which was ironic because there had just been over three hours of testimony on how costly the treatments are. He wrote that they have submitted their best estimate on the overall impact on premiums, which are backed up by similar economic impact research in at least eight states. "The insurance industry representative couldn't even give a ball-park figure to refute our numbers."

This father disagreed with the insurance representative in his suggestion that the Mental Health Parity law already addresses autism treatment. He reiterated that autism is not a mental health issue, but a medical issue, and hoped we had heard Dr. Susan Malmstein's testimony about trying to treat an individual with ASD using psychotherapy. "The confusion that is caused by trying to use mental health CPT codes to treat these individuals needs to be cleared up once and for all."

The father reiterated that he feels they have provided significant documentation that the evidence-based therapies are medical interventions. He agrees that the non-coverage for ASD is a form of discrimination. He further stated that if you weighed the cost of insurance premiums on other major medical epidemics, such as diabetes, obesity or thyroid disease, they would dwarf the fraction of one percent they estimate for this bill.

He wrote that the insurance lobby seems to realize that the argument that autism treatments are unproven is being discredited. He wrote this will result in more and more claims about the market for insurance becoming "uncompetitive." He further stated that the insurance companies won't be able to use a threat to pull out of Washington because fewer and fewer states will be allowing them to continue to "gouge the public and continue to earn the huge margins they have enjoyed up till now".

"We urge you to ignore the smokescreens put up by the insurance industry and recommend the Autism Insurance Parity bill for legislative debate."

One mother wrote in response to testimony at the hearing by the representative of American Health Insurance Plans' comment about the quality of providers if this proposal passes. She responded that the current providers her family has encountered in Washington are staffed by licensed and regulated therapists "of singular courage, devotion and abilities. Autism is a marathon, not a sprint." The therapists help kids on the autism spectrum because they care deeply and are devoted to the work. This type of work is a calling, not a get rich quick job. "Attracting more people like this to Washington State can only be a blessing and a benefit."

Another mother wrote in response to the hearing that there is so much the panel did not hear about autism. She wrote urging the panel to hear a short story from "Day to Day," a program on National Public Radio. In addition, she wrote that she is a member of a support group hosted by the Parent-to-Parent program of Thurston County, where she hears stories from other parents. She told of many children who suffer from symptoms of fecal smearing and gastro-intestinal output. She stated that there is no child care or respite care available for these children. The parents of these children do not have time to appeal insurance coverage denials, attend public hearings, or write their legislators, which is why she chose to write to us to speak up for them. She further wrote that as far as she knows, no school districts offer therapies to address the GI distresses afflicting many children with ASD. In addition, she stated that testing for these conditions is not covered.

## APPENDIX H

### Comments and rebuttals to draft report

(These comments appear as written)

#### Arzu Forough, Proponent of Proposal

Thank you for your thorough review and thoughtful comments on the proposed autism insurance legislation. After careful consideration of your October 2008 draft report, we have revised the proposed legislation to address your concerns.

Your first concern on page 14 relates primarily to vagueness. Specifically, the report states that the bill “does not specify what treatments will be covered.” In response, we have revised section (3)(m) – which is now renumbered as section (6)(k) – to specify “Applied Behavior Analysis” as a covered treatment instead of the more broad “habilitative and rehabilitative care.” We assume that this revision addresses the vagueness concern; if not, we would appreciate the opportunity to refine the language further.

Note that in listing covered treatments, we use the phrase “Applied Behavior Analysis and other structured behavior programs” as opposed to merely “Applied Behavior Analysis.” This phrasing is consistent with the wording in Microsoft’s health insurance plan.

Your second concern relates to providers. The report states that the bill “does not specify what providers could be compensated.” In response, we have added a third section to the bill to provide for the creation of a professional credential in Washington for providers of Applied Behavior Analysis (“behavior specialists”). We based the structure of this section, which amends Title 18, on a recent certification bill passed in Washington state. We are flexible on the exact terms of the certification and believe that reference to the standards established by the national Behavior Analyst Certification Board would be appropriate.

If there are other concerns that remain, please let us know. We appreciate your understanding of the issues and feel confident that we can make appropriate modifications to ensure a clear and meaningful bill.

We strongly disagree with the cost projection by the Health Care Authority, the group that are in charge of Public Employees Benefits Board (PEBB) and other state employee insurance plans.

Their calculation assumes that every child with autism will generate \$50,000 of new claims. That is simply not correct as evidenced by several of the families who provided written as well as oral testimony. Please bear in mind the families taking the time to write and to come in to testify in person represent those in the state with highest out-of-pocket medical costs. I’ve outlined below some of the out-of-pocket expenses reported to the Department of Health by families and documented on your Web site.

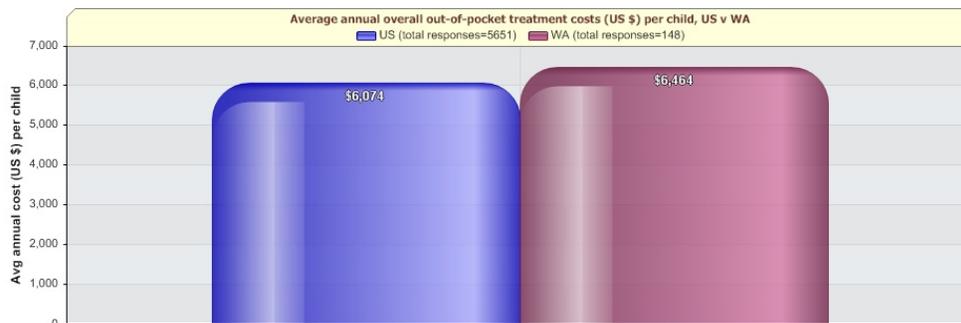
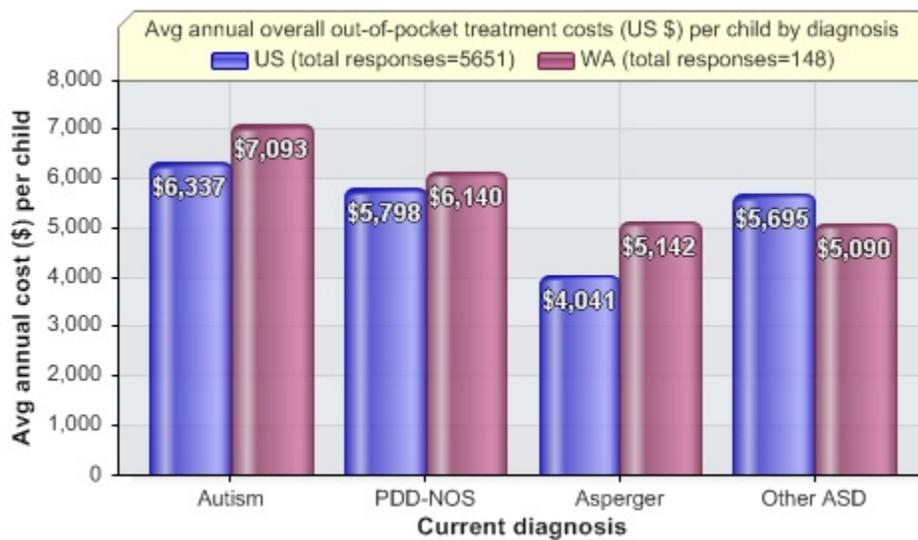
Scott & Rachel Schreffler	\$15,000.00
Teresa Mundel	\$3,333.00
Danielle Olsen	\$15,000.00
Gayle Warden	\$9,090.00
Connie Opedal	\$12,500.00
Aris Kihara	\$14,400.00
Carrie Sheppard	\$14,000.00
Christa Colouzis,	\$12,500.00
Susan Jones	\$13,000.00
Tara Wilson	\$13,333.00

Corey Oroshiba \$10,000.00

In our family, we have two children both diagnosed with forms of Autism. In 2007, we spent \$3224.25 in out of pocket medical expenses for our younger son (diagnosed with Asperger's Syndrome) and 40,139.24 for our oldest son, the majority of which was spent on Applied Behavior Analysis.

Please keep in mind that not every child diagnosed with autism will use the maximum annual benefit. Autism is a spectrum disorder, ranging from mild to severe. Those on the mild-moderate end will most likely use a much smaller percentage of the amount available to them, over a much shorter period of time.

In absence of a survey and correct calculations based on average out-of-pocket expenses in Washington, we will be using the published data & report prepared by Interactive Autism Network Kennedy Krieger (<http://dashboard.ianexchange.org/statestats.aspx>), based on surveys completed by Washington State parents of children with Autism Spectrum Disorders.



We disagree with the assertion that our proposed bill will raise premiums by \$5 and project the impact will be about \$0.65 cents per member per month and an impact on the monthly employer funding rate of \$1.27 per employee increase for fiscal year 2011.

According to the Harvard School of Public Health, the average societal costs of caring for **1** person with autism is **\$3.2 million** over their lifespan.



Now, **5** quarters will change that!

We know hard you've worked to provide a balanced and fair system of review and we commend you for acknowledging all the information that was presented.

Thank you very much for your continued support and we hope that you consider the above and make changes to the draft to reflect the additional information.

<http://www.WashingtonAutismAdvocacy.org>

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**Kris Meilahn, CCC-SLP, Speech-Language Pathologist**

Thanks for sending me a copy of the Mandate. I have been meaning to send some comments to my legislators for quite some time now.

I am a speech-language pathologist with 27 years of work experience here in Washington State. I have been in private practice for the past 20 years so I have worked with many insurance companies and have clearly seen a gradual decline in benefits offered (with the exception of a few insurance groups) over the years. While group insurance plans have offered neurodevelopmental benefits the dollar or visit cap per year has become very limited. Many children with disabilities are not getting their needs met. Also, I have served 100s of children with autism over the past many years. As the statistics show, there has been a sharp increase of children diagnosed with autism on my caseload over the recent 8-10 years. I also see children with a variety of other types of diagnosis as well.

**I am strongly concerned about the ramifications that the proposed autism bill may have on children with other types of disabilities.** I think the reality is that if group insurance companies within Washington State are required to offer an autism benefit they are bound to reduce benefits for children with other types of disabilities who also need intervention services. I have seen that over the years several insurance companies have consistently reduced the state mandated neurodevelopmental benefit that they offer. It is not uncommon for group insurance plans to now offer subscribers a benefit of \$1000/year for all types of therapy intervention services. This is highly inadequate for many, many families.

Children with autism are not the only group of children that need better funding. What safe guards are in place so that insurance companies can not further reduce funding for children with other types of disabilities to meet the budgeting needs of providing funds for ABA services for children with autism. I am not sure that those who have created this bill have looked at this bigger issue of overall funding deficits or have just focused on the needs of children with autism.

I can not support this bill unless there is clear mandate that provides families of other disabled children access to similar but less intense services. As a health care provider I care deeply that we take greater responsibility at providing improved guidelines for all children with disabilities. I know there is much support for the passage of this bill and I too believe the mandate is and necessary services for children with autism **BUT** without safe guards we will see reductions in available funds for other children and I know that is not the intent of this mandate. Please consider putting reasonable financial caps on any state

mandate requiring insurance companies to provide improved funding for children with autism. While the ABA services per year may be as much as \$50,00 as reported in autism document I think insurance companies should be able to cap the benefit at a much lower number. This mandate is a needed socially conscious step to impose in Washington state, but not at the expense of funding cuts for other children who have similar but less intense needs. That will be the direction insurance companies take.

Thank you for letting me share my perspective.

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### **Kate O'Leary**

Per the Autism Insurance Bill legislation, as a parent of a child with Down Syndrome, I would love to see this benefit include more than children with autism. Unfortunately, I don't have the time to do the research myself, but it saddens me that because the medical, therapeutic, and educational community have not advocated for the same intensive treatments for all children with pervasive developmental delays and other disabilities like DS. I realize that the rise of autism is frightening, but as new research and therapies are developed, why are they not extended to others?

We have cobbled together such treatments ourselves, but what I wouldn't give to have a behavioralist work for 1-3 hours with my child every day to address his sensory integration issues, his learning issues, his social issues, etc – and have it paid for by my insurance (as my coworkers with children with autism do). I find it horribly discriminatory. I am fighting the same discrimination in our school district as we have “autism” inclusion programs but little other real inclusion. Again, I don't have time to fight this particular fight, nor do I have the stamina. I can't begin to bring it up with parents of children with autism for fear of insulting them – the last thing I wish to do is lay a burden on the parent of a child with a disability. I can only hope that others like me bring up the same point and that someone is more energetic and brave than I. The result could be that we see children with Down Syndrome live past age 50 and that a higher percentage attend college. This benefit would give them a fighting chance, just as heart surgeries (previously withheld because their lives were not worth the expense) have afforded them a life past early childhood. I know that there are many other types of children with a variety of disabilities that would greatly benefit from treatments today reserved for those with autism. Why we exclude them, I cannot fathom...

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### **Lisa Fitch**

I support the Autism Insurance Bill. I have a 13-year old son with Asperger's Syndrome. He is doing well and has benefited from several years of private occupational therapy and group social therapy sessions. We are fortunate in that our medical insurance covered some of these costs, unfortunately it did not cover speech therapy for him. It would have been beneficial for him to receive speech therapy services but we were not able to afford this.

We are fortunate in that we are middle class people with good health insurance. I cannot help but think of how difficult it must be for people who do not have health insurance and who cannot afford these services. All children affected by autism have a right to services.

Please support the autism insurance bill. Thank you.

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### **Shelly Nomura**

Thank for all your very thoughtful, fair, and balanced review of the Autism Parity bill. I appreciate this opportunity to respond to the findings in the report.

Our family considers ourselves one of the lucky ones. Our son was diagnosed with mild to moderate autism at the age of 4. Because of this, his level of need for therapies has not matched what is necessary for a child that falls on the more severe end of the spectrum.

After his diagnosis, he spent a year in a 12-15 hour per week ABA program, along with private speech therapy once per week. Because of the significant amount of progress he made during this time, we were able to stop the ABA program after that year. Although my husband and I have a good insurance coverage through our employer, the plan did not cover any of the ABA treatments, and only paid for 24 speech therapy visits annually (with a \$50 co-pay). We paid \$12,000 out-of-pocket for the ABA therapy. This came from my evening and weekend part-time job. We paid an additional \$3,000 over the course of 2 years for his speech therapy (which consisted primarily of our \$50 per visit co-pay).

I disagree with projection by the Health Care Authority, the group in charge of Public Employees Benefits Board (PEBB) and other state employee insurance plans. Their calculation assumes that every child with autism will generate \$50,000 of new claims. That is simply not correct as evidenced by our experience. Over the course of 2 years we paid out-of-pocket \$15,000 for my son's therapies. He was fully mainstreamed in Kindergarten as a result of the early intervention he received, and now as a first grader is thriving. He continues to receive some support services through the school district, but they are minimal. This \$15,000 investment we made during the early years has more than likely saved the state a significant amount of money for services he would need otherwise as he ages.

Please keep in mind that not every child diagnosed with autism will use the maximum annual benefit. Autism is a spectrum disorder, ranging from mild to severe. Those on the mild-moderate end will most likely use a much smaller percentage of the amount available to them, over a much shorter period of time. We made some significant sacrifices over that two-year period to pay for my son's therapies, and I feel fortunate we were able to do so. Every child should have the same advantages as my son, regardless of their income level.

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### **Deborah Skalabrin, MSW, Year for Change LLC**

I am writing about the Autism Parity Bill. Approximately 90% of my therapy practice in Spokane, Washington involves working with children who have Autism, Asperger Syndrome, or PDD, and their families. Families who hope for the most improvements often choose very intensive therapies which are typically used for up to three years early in life. Because therapy takes advantage of this early window of opportunity, I have seen some remarkable successes in some cases, and improvements in many cases, so I am a firm believer in early interventions.

But this takes resources. Unfortunately, the cost can be \$25,000 or more per year, necessitating draining of retirement accounts, wiping out of college funds, help from already low-income grandparents, second mortgages, cars being sold, drastic credit card debt, and in some cases even bankruptcy or divorce. I have seen many family struggling in financial or emotional ruin, and it's heartbreaking.

This is unacceptable, and I applaud the proposal of this bill. To be effective, I believe the following needs to be ensured, either in the bill itself or in its later implementation:

1. No "one way" to treat. Most practitioners, myself included, use many techniques, which may include behavior modification (but not necessarily ABA) and many other effective elements. Every child and family is unique and will respond differently - the best interventions are individualized and flexible to meet those needs.
2. Family involvement and support as integral to effectiveness. As one example of how this is currently not encouraged: Right now, insurance companies have no time specification on codes involving work

with families (such as 90847) but the reimbursement rate means only 1 hour per week is covered. Sessions also must be at least a week apart. No allowance is made for current significant issues which require more time, or for families coming from a distance who may need more help over a several-day stay. When families receive the time to learn how to interact with their child and fold "therapy" into their daily lives, therapy dollars are multiplied, family relationships improve, and impacts of the therapies are often drastically increased, necessitating far few dollars at a later time. The goal of this kind of intervention is to do what is needed now, to potentially avoid or minimize spending much more over many years, later. Periodic and reasonable provider justification of results or a similar control could be part of this process to prevent abuses.

3. Wide variety of health professionals involved. It will be important when this law is implemented, to ensure that "qualified health professionals" is not defined narrowly (i.e., Psychologist, Psychiatrist, Physician). Others such as Licensed Independent Clinical Social Workers (a designation I will test for shortly) should be approved practitioners as well. Those of us who have been deeply interested in this field have pursued substantial education and experience which continues to benefit our clients and improve their outcomes. The field of Autism is a complex one, and requires many disciplines working in collaboration.

I understand that objections could be raised to this bill on my fronts. One level of compromise may be to offer graduated benefits, with birth-to-five at a higher level, and ages five and over at a lower level. I believe the intensive programs make more sense and have the potential to yield better results when pursued earlier. Older children still have needs, but in my experience not at the same intensive levels needed at younger ages, especially if they did receive the earliest interventions. This compromise would require more effective early screenings and referrals for services, so that all families would have the option of earliest interventions before their child aged into the later category.

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### **Jai Jeffery**

I am writing in support of the insurance bill for autism treatment. Autism treatment is lost in a void between our educational and medical institutions and this bill is regrettably necessary so that several thousand children in our state will learn to speak and become functional members of society.

Our son was diagnosed with autism just prior to his second birthday. I remember thinking that I might never speak with him. We visited many experts and went about securing the therapies that were unanimously recommended. "It's important that you get started right away," they said; all evidence being that earlier intervention yields better outcomes.

I guess that's when all the fighting started. I used to think we took care of these vulnerable people but what I discovered was surreal. The schools, you see, said they lacked funding and teacher resources, and pointed us to the health care industry. But our insurance-mediated health care system pointed right back to the schools, saying these treatments were educational. Our health insurance carrier shotgunned denials once they learned he was autistic, once even denying a common, inexpensive test for anemia. Wait-listed with several providers, it seemed that the clock was ticking.

We were lucky to navigate our way, and found both providers and funding for behavioral therapies. Today, we have a joyous 8-year-old attending his neighborhood school who lights up the room with his positive energy. I love talking with him about Calvin, chameleons, and crickets (apparently, crickets have three predators).

Securing treatment has been physically, emotionally, and financially taxing. I'm tired of all the fighting. But we'd do it again. We're still doing it. There isn't really a choice, now, is there? He's the best kid a father could

ever ask for and there's nothing I wouldn't do for him. But what of the Moms and Dads that simply can't afford similar treatments? How must that feel? I can't even begin to imagine.

The Surgeon General, National Academy of Sciences, and American Academy of Pediatrics, among others, have issued statements supporting autism treatments like the ABA therapies that helped our family. It's folly to pretend that these are experimental, or that lack of precise agreement over model treatment and clinical practices justifies refusal of insurers to finance proper treatment. Similarly, it's unreasonable to hide behind arguments that each child has individual needs and that program "Brand Names" are improper, and therefore best practices and proven interventions aren't valid, useful, or legitimate as an ASD treatment or program model.

If I were brain-injured in an auto accident today and had to relearn to speak, I wouldn't be sent back to college and I wouldn't be denied therapy because it's "experimental" or because different providers do things a bit differently. Therapists would come to my home or be centrally located at a clinic or hospital and my medical insurance would cover a therapy program that *looks* a lot like education.

Washington has a demonstrable shortage of qualified providers. That's because most families can't afford to pay them. Until autism is recognized as a medical condition and insurers provide therapy coverage, proper treatments will largely remain the province of wealthy families or a few insured Redmond families, and they still have to somehow find providers. Our society doesn't fund or require autism treatment at the school, and few young parents stash away the equivalent of four full UW educations for an infant on the off chance that the child will be autistic. I submit to you that autism is a medical condition, that autism is treatable, and that insurance is purchased by consumers for exactly this type of catastrophic medical event.

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**Susan K. Malmquist, Ph.D., BCBA**

Re: SUMMARY OF INFORMATION

- Page 5, paragraph five: please change "thirty-five hours per week" to "forty hours per week".

Re: DETAILED RECOMMENDATIONS TO LEGISLATURE

- Neurodevelopmental Therapy - It is recommended that the following treatments be specified for coverage: ABA, Occupational Therapy, Physical Therapy, and Speech and Language therapy.
- Neurodevelopmental Therapy - It is recommended that the following service providers be compensated: Speech Language Pathologists, Occupational Therapists, Physical Therapists, and Board Certified Behavior Analysts.
- It appears that coverage of these critical services could be met through an expansion of the neurodevelopmental therapy mandate and expansion/clarification of the mental health parity mandate as outlined in the DETAILED RECOMMENDATIONS TO LEGISLATURE.
- Creation of a professional credential in Washington relating to the provision of ABA is needed.

Thank you for your attention to this important matter. Please do not hesitate to contact me if I can be of assistance in any way.

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**Sydney Smith Zvara, Executive Director**

On behalf of the Association of Washington Healthcare Plans' (AWHP's) members, thank you for the opportunity to provide comments regarding the draft Autism Spectrum Disorders (ASD) Mandated Benefit Sunrise Review report. We appreciate the Department of Health's efforts.

As stated in our earlier letter, we too are concerned about the challenges faced by children with autism  
Autism Spectrum Disorder Mandated Benefit Sunrise

and their families. We want to approach this issue in a manner that is in their best interest, as well as that of all those we serve.

It is our understanding that the Department of Health is recommending the Legislature not enact the proposed bill because the language is too vague to allow the department to determine whether the benefits outweigh the costs, and, it fails to offer meaningful guidance to insurers, providers, and the department. We share the department's concerns and offer the following additional reasons for why the proposed mandate should not be enacted.

Of serious concern is the cost impact for employers and families already struggling to continue to afford healthcare coverage. Healthcare plan actuaries project a financial impact of at least 2 %. This is higher than the 1% cost increase estimated by the Health Care Authority (HCA) for PEBB because 1) PEBB already provides richer benefits than most employer sponsored plans, thus it would experience a proportionately smaller increase, and, 2) HCA assumed 1 of 231 children affected by ASD, rather than 1 of 150 as cited in the department's report. We also note that ASD is the fastest growing developmental disability with a 10 -17% growth in cases each year. Individual states are reporting increases in the number of autistic children enrolled in school, with an average annual increase of more than 800% since 1992. Many factors may contribute to the seemingly higher prevalence of ASD, such as changes in diagnostic criteria and increasing awareness of ASD over time.

Every benefit mandate adds to the overall cost of healthcare and insurance premiums. And, in a time when we are collectively looking to make healthcare more affordable, we believe employers should be able to determine their own benefit plans without additional state mandates. Financial impacts must be strongly considered for any benefit mandate proposal, especially given current economic conditions in our state and the fact that many families and employers are already struggling to afford coverage.

The proposed mandate would certainly provide some financial relief to ASD affected families whose employers can continue to afford coverage --- however an unfortunate trade-off would be that other families (likely including some with ASD affected children) would no longer have any medical coverage at all --- as employers are forced to drop coverage because they can no longer afford it.

Also of particular concern is potentially requiring medical plan coverage for services that are essentially educational in nature, such as Applied Behavior Analysis (ABA) therapy. These services are provided by individuals with backgrounds and training in the field of education, not medical or mental health. The proposed mandate would require establishment of an entirely new and different category of healthcare providers. We also question the appropriateness of mandating that educational services designed to assist with behaviors like getting dressed, eating meals, brushing teeth, or sitting still during classes" --- be included as part of medical program coverage. This would establish an inappropriate and troubling precedence.

To ensure quality treatment and patient safety, it is important that any person or entity providing treatment of autism spectrum disorders be licensed or certified, and health plans should have the tools necessary to credential those providers. Additionally, we recommend that ABA therapy be provided by behavior specialists that are board certified, such as by the Behavior Analyst Certification Board.

We also continue to recommend development of a best practice intervention model with special focus on diagnosis and evaluation. This model should make use of evidence based research. (We note that some of the therapies mentioned in the report, such as Water or Aquatic Therapy, Hippotherapy, and Chelation Therapy have no evidence-based study to support their use for ASD.) It should also include a comprehensive evaluation or re-evaluation of the child consistent with recommendations of the American Academy of Pediatrics --- as well as allow for utilization review, case management, medical necessity review, and other care coordination techniques, as appropriate.

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**Denise Fulton**

Thank for all your consideration of the Autism Parity bill. I appreciate this opportunity to respond to the findings in the report.

Our family has witnessed first-hand the benefits of early intervention. Our son was referred for evaluation at 15 months when he showed the early signs of autism. Our concerns were confirmed and we started preliminary interventions immediately (speech, occupational therapy, Birth-to-3 services) and he made some good strides. He was diagnosed with autism at the University of Washington just prior to his third birthday. At that point, on UW's recommendation, we added Applied Behavioral Analysis (ABA) to his treatment plan. He has benefitted measurably from this approach.

We have done the best we could, hiring therapists with ABA experience to help provide what we could afford - 15-20 hours per week of ABA program, along with private sessions of occupational therapy and speech therapy once per week.

Our family is fortunate to have good insurance coverage through our employer, but it has not covered these crucial ABA treatments.

That said, I disagree with the Health Care Authority's assumption that every child with autism will necessarily generate \$50,000 of new claims. Costs of providing effective early intervention - like the care our son has received - will vary significantly depending on each child's needs, the services available, their location, etc. I am confident you will consider these - and all relevant factors - as you move forward on behalf of our children.