

Governor's Task Force on Autism Spectrum Disorders
Costs of Autism Committee
Conference Call
October 21, 2008
11:00 a.m. – 5:00 p.m.
Summary of Minutes

Committee Members

Benson, Holly	non-voting delegate sent on her behalf (Shachi Mankodi)
DeBeaugrine, Jim	
Emken, Elizabeth	
Hill, Kimberly	
Kanjian, Bob (Co-Chair)	absent
La Belle, Rich	
Sequenzia, Ven (Co-Chair)	

Department of Health Staff

Demko, Tamara
Howard, Catherine

Call began at 11:01 a.m.

Ms. Demko provided an overview of the meeting and explained the format of the recommendations the group will be formulating during the conference call.

Mr. Sequenzia suggested that the committee first address a plan for funding the Statewide Autism Website.

There was some discussion about this and how the committee should organize its time for the day.

Mr. La Belle suggested that the group draft an outline to guide them in crafting their recommendations. Following this suggestion, the group decided to address the following topics:

- 1) Breakdown of costs by age groups
- 2) Costs of early screening and diagnosis
- 3) Breakdown of costs by school-age and beyond

Mr. DeBeaugrine suggested that the committee recommend that a state agency or other group be charged with monitoring ongoing and future costs of autism spectrum disorders. There was discussion among the members as to whether or not this should be done by a state agency, by a non-profit, or by another committee or council yet to be created.

The group discussed the idea of establishing an ongoing coordinating council for Autism Spectrum Disorders (ASD). Ms. Demko stated that other committees have suggested

this as well. Mr. La Belle stated that the proposed coordinating group, however it is organized, should include entities from state government, private and non-profit groups.

Ms. Demko added the idea of regional collaboratives from the Putting the Pieces Together Committee and further shared that at least one other committee may recommend that the Task Force continue past its charter. This is an option instead of recommending the creation of a new group.

Ms. Demko reviewed recommendations made by other committees so the group had the opportunity to combine or build on work from other committees.

Following the outline for the meeting, Mr. Sequenzia began a discussion on the costs of early screening and diagnosis. The group used information provided by Task Force Member, Dr. Jeff Brosco [Appendices 1 and 2].

There were questions regarding the information provided. Ms. Demko suggested that the group wait until Dr. Brosco joined the call after lunch to continue the discussion on early screening and diagnosis. The group agreed.

After some discussion about exact figures and costs, Ms. Emken stated that the numbers will never be completely accurate, and suggested that they focus more on what they will do with the cost data rather than try to identify precise numbers. Ms. Emken stated that she believes solid recommendations can be made with estimates of cost.

Mr. DeBeaugrine stated that there should be better coordination between school districts to assist families in securing as many resources as possible. He stated that there are several funding streams available however, most sources do not provide complete funding and coordination between sources could help families maximize the various resources available to them. The group discussed whether this should be the sole responsibility of the school districts.

The group discussed information provided by Ms. Emken on prevalence data. The group used the following excerpt from Ms. Emken to facilitate discussion on this topic.

Population-based studies conducted worldwide before 1985 indicated that the prevalence of autism was .4-.5 per 1000 children under the age of eighteen. Findings from the first multisite study to monitor the prevalence of autism spectrum disorders nationwide showed a prevalence rate of 6.7 per 1000 children aged eight years. Researchers at the Centers for Disease Control interpreted this data as indicating that autism spectrum disorders are more common than previously believed.

Number of Eligible Beneficiaries of HB 1291 and SB 2654

According to estimates provided by the U.S. Census Bureau, there are approximately 4,260,000 Floridians between the ages of two and twenty who satisfy the age criteria for the benefits proposed in HB 1291 and SB 2654. A recent source indicates that approximately 15.1% of Floridians under the age of 18 are uninsured. The number of insured Floridians, therefore, between the ages of two and twenty is approximately 3,616,000.

Based on information published by the Medical Expenditure Panel Survey (MEPS), 68.1% of private-sector enrollees in Florida businesses with over fifty employees are enrolled in self-insured plans. In addition, the proposed bills note that the term "Health Insurance Plan" does not include "any health insurance plan offered in the individual

market, any health insurance plan that is individually underwritten, or any health insurance plan provided to a small employer.” Florida law defines small employers as those having fewer of fifty employees. According to the Florida Office of Insurance Regulation 2006 Annual Report, employers in Florida with more than fifty employees that also offer fully regulated major medical plans comprise approximately 64.40% of the fully regulated market. The potential pool of beneficiaries between the ages of two and twenty, therefore, after accounting for ERISA and small business exemptions and the uninsured, is approximately 742,856.

Number of Potential Eligible Beneficiaries with Autism in Florida

The prevalence of autism is estimated by the CDC to be approximately 1 in 150. Given this additional data, we estimate the total number of potential beneficiaries with an Autistic Spectrum Disorder to be 4,952.

The full document was also forwarded to the group by Ms. Demko [See Appendix 3].

At 12:15 p.m. the group adjourned for lunch. They reconvened at 1:00 p.m.

The group continued the discussion regarding the information sent from Ms. Emken above and in Appendix 3.

The group next discussed costs of serving the current ASD population. Mr. Sequenzia asked if figures on vocational rehabilitation in the state had been received. Ms. Demko responded that the information has not been received.

The group moved onto discussions about the Agency for Persons with Disabilities expenditures from fiscal years 06/07 and 07/08 for individuals with a primary diagnosis of autism [Appendices 4 and 5].

Dr. Brosco joined the call. In response to questions from the committee he explained how he came up with the numbers presented in his notes [Appendices 1 and 2]. Based on his statements the group discussed the barriers to universal screening. They also discussed the need to find other options beyond Early Steps.

Dr. Brosco stated that psychologists are the most important entity in diagnosing autism, and that in most cases they are not reimbursed by insurance companies or Medicaid/Medicare. He suggested that the group work a solution to this barrier into their recommendations.

Mr. DeBeaugrine asked if the group had any advice for Secretary Benson with the Agency for Health Care Administration (AHCA) as they move forward with waiver modifications mandated by Senate Bill 2654. Ms. Mankodi shared that AHCA is looking at the type of waiver to use and what services will need to be covered. She stated that the primary problem with the federal waiver is that it is limited to only a required institutional level of care. This limitation places federal waiver benefits in direct conflict with the new state mandate which is inclusive of all individuals on the spectrum; not just severe cases that require institutionalization.

The group discussed potential technical amendments to the Senate Bill 2654.

The group requested information on the funding sources and amount for the Early Steps Program. In response to this request the numbers were provided [Appendix 6].

Ms. Demko reviewed recommendations from other committees that are likely to have financial impacts. The group discussed these recommendations.

The group requested that Ms. Demko petition the Governor's Office for assistance with drafting fiscal notes to their proposed recommendations.

Mr. Sequenzia suggested that the group explore collaborative efforts as additional resources for potential sources of funding.

Ms. Emken stated that the committee should note that the Developmental Disabilities Compact Workgroup [Compact Workgroup] recommendations will be released after the Task Force's preliminary report and before the Task Force's final report. She recommended that the Task Force note in their preliminary report that the recommendations from the Compact Workgroup may impact the Task Force's final report.

Mr. La Belle asked if any of the committees within the Task Force has addressed the various definitions of autism and autism spectrum disorders. He sees this as a cost issue. The group discussed the definitions in the Florida Statutes that they were aware of. They discussed potential problems with this and the need to standardize the definition.

Based on the deliberations throughout the day, Ms. Demko drafted recommendations and read them to the group. The group approved the draft recommendations and as follows:

Recommendation 1

Create a Florida autism awareness license plate to support public awareness and the statewide autism website.

Recommendation 2

For this recommendation the committee added a place holder for the topic of insurance benefit expansion. At this time, they could not reach consensus on the recommendation.

Recommendation 3

Design the statewide autism website to include periodically updated cost data.

Recommendation 4

Task a state-level entity to maintain and periodically update autism-specific cost data.

OR

Task a subcommittee of the recommended *Florida Autism Coordinating Council* to maintain and periodically review autism-specific cost data.

Recommendation 5

Request that state agencies track and compile autism-specific cost data for the individuals that they serve.

Recommendation 6

Explore financial incentives for health care providers to conduct early screenings for autism spectrum disorder in accordance with American Academy of Pediatrics recommended guidelines.

Recommendation 7

Increase funding for Early Steps: Florida's early intervention program within Children's Medical Services.

- Ensure Early Steps meets compliance requirements and certification through Individuals with Disabilities Education Act (IDEA)
- Explore ways to accomplish this: legislative appropriation,

Recommendation 8

Consider options for amending Senate Bill 2654 to expand Agency for Health Care Administration's ability to comply with the intent of the statute through a Medicaid state plan and/or waiver.

Recommendation 9

Increase funding for Florida's Centers for Autism and Related Disabilities.

Recommendation 10

Improve identification and coordination in the use of resources available to individuals with autism spectrum disorders.

Task the (and increase funding for) Florida's Centers for Autism and Related Disabilities to maintain and periodically update state-level autism-specific data.

Recommendation 11

Tap into existing local and community resources to explore collaborations

Recommendation 12

Request a Memorial to Congress asking for additional flexibility in Medicaid.

Recommendation 13

Explore new options under Florida KidCare and Healthy Kids to fund autism services.

Task Force Report Note

The Task Force --- set of recommendations to carry forward part of compact provisions in the final report....note that compact recommendations are coming prior to final report

Recommendation 14

Standardize the definition of autism spectrum disorder across state agencies and within Florida statutes.

Call concluded at 4:13 p.m.

Taken By: Catherine Howard

Appendix 1

Dr. Jeff Brosco: Some Thoughts on Costs of Care for Children with Autism

- this is a first draft, and should be amended by folks with more expertise and experience
- these ideas only concern children, as I know little about adults with developmental disabilities

1. The costs of **early identification** of all children with autism are not part of current budgets for child health and development—but should be.
 - a. Bright Futures and American Academy of Pediatrics guidelines for primary care pediatric health providers require universal screening for autism to all children at ages 18 months and 24 months. This cost is not generally reimbursed by health insurance, and it is critical to understand that this is just one of many “unfunded mandates.”
 - b. It is estimated to cost \$10-15 dollars/child for general developmental screening using a caregiver report measure.¹ Most of this cost is physician time to interpret and explain results. It is likely that screening for autism would be similar if using the MCHAT, a caregiver-report measure which is available free. If the average pediatric health provider has approximately 100 children per age cohort, it costs the average physician \$2000-\$3000 per year to follow AAP guidelines for screening for autism, and an additional \$3000 - \$4500 per year to follow AAP guidelines for screening for developmental delay.
 - c. There are state and local requirements (and recommendations) for developmental screening by child care providers. There is no consistent financial support for these activities.
2. The costs of **secondary screening** of all children suspected to have autism are not part of the current Early Steps/Part C (ES) budget for child health and development—but should be.
 - a. Universal screening for autism may lead to as many as 20,000 referrals to ES per year, of whom approximately 1000 will actually have an ASD. (See document, “Autism Estimates 10-17-08jpb.” [Included under Appendix 1]) The most appropriate approach for ES would be to perform a “secondary screen,” to determine which children are truly at risk for an ASD. One approach is to use the MCHAT follow-up interview, which takes 5 -20 minutes and can be administered by a paraprofessional. If it takes 30 minutes per family for test/discussion = 10,000 hours (5 FTE), the cost to ES would be approximately 5 x \$50,000 = **\$250,000/year.**
3. Children in whom an ASD is suspected, whether because of screening results or parental/professional concern, need an assessment to determine intervention needs and goals. The cost of an autism **assessment** (“evaluation” or “diagnosis”) is generally the responsibility of individual families—but shouldn’t be.
 - a. Health insurance will sometimes pay for an assessment by a physician, but not consistently. Unfortunately, when physicians alone try to diagnose autism, it often leads to misdiagnosis. Physicians rely on history and physical examination; they rarely conduct measures of cognitive function, consider teacher input, or use standardized autism diagnostic tools. In some cases, a well-trained and experienced physician can make a correct diagnosis, but this is risky in the absence of standardized measures and team input.
 - b. Developmental psychologists do measure cognitive function, consider teacher input, and used standardized tools to diagnose autism. They are typically NOT reimbursed by health insurers (particularly Medicaid), however, and families pay approximately \$1500-\$3000 for this service.

- c. Best practices for diagnosing autism is for an interdisciplinary team to assess each child. The team should include a developmental psychologist, speech and language pathologist, and an occupational therapist. Many other professionals can be helpful in both making the diagnosis and developing a coordinated treatment plan: physical therapist, education specialist, nutritionist, social worker, pediatric neurologist, clinical geneticist, child psychiatrist, and developmental pediatrician. Although most of these professionals are reimbursed by health insurance, no health insurance covers the costs of the interdisciplinary team meetings and coordinating care, which are critical to successful team functioning.
- d. Both Part C/Early Steps (Birth to third birthday) and Part B/Child Find (public school system for children after 3rd birthday) provide interdisciplinary team assessments under the federal law IDEA. However, both programs are designed NOT to make a specific diagnosis, but rather to identify areas that the family and team agree a child needs assistance (Part C) or to determine how best to provide an appropriate education in the least restrictive environment (Part B).
 - i. The current CMS Work Group on Autism is preparing final recommendations that will include ensuring that each local Early Steps program has some mechanism for assessing and diagnosing autism. If Early Steps programs continue current practice and do not rule in or rule out autism, many families would be in the difficult position of not having the financial means to determine whether their child has autism. Since most of these children will NOT meet criteria for autism, there may be as many as 20,000 families of children less than 3 years of age worrying about autism but not knowing whether their child needs treatment (See "Autism Estimates").
 - ii. The potential cost implications to Early Steps of assessing children with ASDs is enormous. A full diagnostic evaluation by a psychologist (e.g. ADOS, etc.) is estimate to cost at least \$1000/child (and as noted above can cost as much as \$3000/child). Assuming the lower estimate of \$1000 is possible, and if 3300 children need a diagnostic evaluation, then the potential cost to ES could be as high as **\$3.3 million/year**.
 - 1. Note that ES does NOT typically provide a "diagnosis," but rather an assessment that leads to measurable outcomes; the new recommendations of the CMS Workgroup on Autism are that every child who screens positive for an ASD should have a sufficient assessment to design an appropriate intervention plan and measurable outcomes that may include communication, social development, etc.
- 4. The costs of providing intensive **intervention** for children with autism can overwhelm current budgets for child health and development.
 - a. Children less than 3 years old
 - i. It would cost approximately **\$50 million/year** to provide 25 hours/week of individual services to the 1500 children with autism under three years of age who live in Florida (1500 children X \$35,000/year).
 - ii. The entire budget for the 37,000 children in Early Steps is approximately \$47 million (\$1261/child). Note that ES does NOT typically provide services; rather ES coordinates the provision of services through a service plan ("Family Support Plan") that indicates the needed interventions, the payer source, and who will provide it. In some instances, services are covered through insurance/other sources, and in some cases, ES is responsible for paying; but in all instances, the service coordinator navigates the system with the family to locate the provider
 - b. Children more than 3 years old

- i. I do not have access to information on special education budgets, but there are likely to be similar issues: many children referred to the school system (Child Find/FDLRS/Part B) who would need some sort of assessment if autism is suspected. Current budgets do not take this into account. Children with an ASD would constitute a very small proportion of the children needing special education services, but may require higher levels of staff attention and educational resources.
 - ii. It is critical to remember that individual interventions for children with autism are NOT the only evidence-based approaches. School-based interventions such as LEAP and TEEACH can be as effective and may even lead to greater generalization of new skills. These interventions may be less expensive and can sometimes be obtained through the public school system (e.g. Miami-Dade County Public Schools), but there are limited slots available.
- 5. It is very unlikely that any **new money** will be available at the state or federal level to fund new autism programs. We will need to find ways to use current funds more efficiently if we are to begin to meet the needs of children with autism.
 - a. There is evidence that early intervention for children with autism can reduce later costs, so the most efficient use of limited resources would suggest focusing on screening, assessment, and early, intensive intervention
 - b. Autism advocates can increase the funds available for children with autism by advocating for early intervention for children with other developmental and behavioral conditions. For example, the majority of children receiving special education services in the public schools have a diagnosis of a learning disorder. There is strong evidence that early identification and treatment of reading disorders can dramatically reduce the need for special education services in the future. In theory, cost-savings from such programs could increase the education budget for children with other disabilities.
- 1. Glascoe FP, Foster EM, Wolraich ML. An Economic Analysis of Developmental Detection Methods. Vol 99; 1997:830-837.

Appendix 2

Dr. Jeff Brosco: Autism Estimates: Implications for Early Steps, Florida

Estimated prevalence of all autism spectrum disorders = 1 per 150 children¹

If this estimated prevalence holds for all age groups in Florida, then overall there are approximately 26,700 children < 18 years old in Florida with an ASD (Autistic disorder, Asperger disorder, or PDD, NOS).

$$4,000,000 \text{ children (2004 census)} / 150 = 26,666$$

There are approximately 200,000 children per birth cohort in Florida
2004 Census = 218,000 births in Florida

Number of children per birth cohort with an ASD
 $200,000 / 150 = \mathbf{1300 \text{ children}}$

If approximately 80% of children with an ASD will have symptoms before age 3 years,² then approximately **1000** children per year should be referred to Early Steps (ES) each year, **if** every child with autism is identified, referred, and comes to ES for evaluation.

One of the few autism screening tools that has been tested on a general population is the MCHAT, which has a sensitivity = 0.85 and specificity = 0.93 for ASDs. However, autism is a relatively low prevalence condition, and even the best screening tool will yield many false positives when used on a low-risk population (i.e., all 18- and 24-month old children). If the pretest probability of a child having an ASD is 1/150 and the MCHAT is used as a screening test, the post-test probability of any one child who screens positive actually having an ASD is 8% (or a 92% chance that that child does not have an ASD). Overall, we can expect approximately **11 false positives for every true positive** if the MCHAT is used to screen for autism in all 18- and 24-month old children in Florida. In practice, there have been even more false positives for every case of autism (see Robins, D. below).

We do not know how many primary care pediatric providers in Florida will follow AAP/Bright Futures Guidelines and use the MCHAT (or other test) to screen for ASD in all 18- and 24-month old children. Recent studies suggest that about 20% of pediatric providers currently do formal screening for general developmental delay, but if ASD screening becomes one way that Medicaid and other health insurers measure PCP performance, compliance with AAP guidelines may be much higher. The immense public interest in autism and the new Florida law mandating health insurance coverage for autism treatment may also increase the likelihood that PCPs screen universally for ASDs per the AAP/Bright Futures recommendations. Therefore, two estimates of

¹ "Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000" MMWR February 9, 2007 / 56(SS01);1-11.

² "Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000" MMWR February 9, 2007 / 56(SS01);1-11

physician compliance are provided: 20% and 80%. (In an informal survey on the AAP's SOAPM listserv, less than 40% were willing to do this screening)

Estimated referrals to ES each year

If 20% compliance with universal screening by PCPs:

- 200 children with an ASD would be referred to ES each year
- 2200 children without an ASD (false positive on MCHAT) referred to ES

If 80% compliance with universal screening by PCPs:

- 800 children with an ASD would be referred to ES each year
- 8800 children without an ASD (false positive on the MCHAT) referred to ES

We do not know what percentage of the children with an ASD are currently referred to ES, but since the majority of children with an ASD presenting before age 3 years have language delay, most should already be in the ES system. It is much less likely that a child with a false positive result on the MCHAT is already in the ES system, because there are many items on the MCHAT that are not tested by most developmental screening tools (e.g. joint attention). We also do not know how many children with a false positive result on the MCHAT will meet ES criteria for intervention because of some other disorder, in which case the referral to ES was appropriate even if the child does not have an ASD.

In the worst-case scenario of children with false positive results entering the system, the Florida ES system may have as many as **10,000 new referrals** per year for children who do not have a developmental disability.

There are other methods of primary screening besides the M-CHAT, but it is the best studied in a general population. Based on a very recent study by Robins, we can estimate what state-wide screening for autism using the MCHAT as a primary screening tool (by pediatrician or ES) and the MCHAT follow-up interview (by ES) might look like.

Recent study using MCHAT for universal screening

Robins Diana L. Screening for autism spectrum disorders in primary care settings. Autism 12; 2008:537-556.

Abstract: The need for autism-specific screening during pediatric well-child visits has been established. However, additional support for specific screening instruments is needed. The current study used the Modified Checklist for Autism in Toddlers (M-CHAT) and the M-CHAT Follow-Up Interview to screen 4797 children during toddler checkups. Of the 4797 cases, 466 screened positive on the M-CHAT; of the 362 who completed the follow-up interview, 61 continued to show risk for autism spectrum disorders (ASDs). A total of 41 children have been evaluated; 21 children have been diagnosed with ASD, 17 were classified with non-ASD delays, and three were typically developing. The PPV of M-CHAT plus interview was .57. It is notable that only four of the 21 cases of ASD were flagged by their pediatrician. These findings suggest that the M-CHAT is effective in identifying ASD in primary care settings. Future research will follow this sample longitudinally.

If Robins data were applied to Florida/ES:

If there are 200,000 children per birth cohort in FL, then

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- 19,400 would screen (+) on MCHAT (9.7% of all children screened)
 - o 21 ASD/466 MCHAT (+) = 22 FP for every TP (double the above estimates)
- 3298 would screen (+) on “MCHAT follow-up interview” (17% of those + on MCHAT)

Of the 3298 who would need a full evaluation (ADOS, etc.), we would expect these diagnoses:

- ASD = 1681 (51%)
 - o PDD = 1286 (39% of 3298)
 - o Autism = 395 (12% of 3298)
- Language delay = 884 (27%)
- “Broad ASD phenotype” = 321 (9.7%)
- Within normal limits = 230 (7%)
- Global delay = 80 (2.5%)
- “non – ASD” developmental delay = 80 (2.5%)

Cost implications of the above “worst case scenario”

1. MCHAT follow-up interview or other secondary screen
 - a. 5 -20 minutes, can be administered by a paraprofessional
 - b. Assume 20,000 children/year would need secondary screen
 - c. If 30 minutes per family for test/discussion = 10,000 hours (5 FTE)
2. Full diagnostic evaluation by a psychologist (e.g. ADOS, etc.)
 - a. Estimated cost = \$1000
 - b. If 3300 children need a diagnostic evaluation, then \$3.3 million/year
 - c. Note that ES does NOT typically provide a “diagnosis,” but rather an assessment that leads to measurable outcomes; the new recommendations of the CMS Workgroup on Autism are that every child who screens positive for an ASD should have a sufficient assessment to design an appropriate intervention plan and measurable outcomes that may include communication, social development, etc.
3. If “full services” provided to every child with autism
 - a. Estimated cost of 25 hrs/wk of intensive intervention (\$35,000/child)
 - b. All 2 year-olds (1681) and 50% of 1 year-olds (840) = 2521 children with an ASD in ES at any one time
 - c. $\$35,000 \times 2521 = \58.8 million
 - d. Current total ES budget for all 37,000 children in ES is \$47.5 million (\$1261/child)
 - e. Note that ES does NOT typically provide services; rather ES coordinates the provision of services through a service plan (“Family Support Plan”) that indicates the needed interventions, the payer source, and who will provide it. In some instances, services are covered through insurance/other sources, and in some cases, ES is responsible for paying; but in all instances, the service coordinator navigates the system with the family to locate the provider

Appendix 3

Letter from Elizabeth Emken to State Representative Ari Porth, March 17, 2008



March 17, 2008

State Representative Ari Abraham Porth
1301 The Capitol
402 South Monroe Street
Tallahassee, FL 32399

Re: Report Under § 624.215(2), Fla. Stat. (2007), Assessing the Social and Financial Impacts of House Bill 1291 and Senate Bill 2654

Dear Representative Porth:

Autism Speaks writes in support of two bills pending in the Florida legislature, House Bill 1291 ("HB 1291") and Senate Bill 2654 ("SB 2654"). Autism Speaks is the world's largest autism advocacy organization. We are dedicated to increasing awareness of autism spectrum disorders, to funding research into the causes, prevention, treatments of, and a cure for, autism, and to advocating for the needs of affected families.

Summary of Report

Thousands of Florida children with autism use and depend upon the treatments and services required by HB 1291 and SB 2654. Florida health insurance plans do not generally provide this care. This lack of coverage results in persons avoiding necessary health care treatment and places unreasonable financial hardship on families. There is great public demand for autism treatment services, with families looking to their health insurance for help. The level of interest of collective bargaining agents in including this coverage in group contracts is not known. The coverage required by HB 1291 and SB 2654 is likely to decrease the cost of autism treatment and to increase the appropriate uses of this treatment. The required treatment is not a substitute for more expensive treatment or services. HB 1291 and SB 2654 will likely result in very modest premium increases -- significantly less than 1 percent per policy -- and will reduce the total cost of health care by improving outcomes for children with autism.

Justification for Report

Section 624.215 of the Florida Statutes requires a proponent of a bill that would mandate health benefits to submit a report that assesses the social and financial impacts of the proposed coverage. The statute in full reads as follows:

§ 624.215. Proposals for legislation which mandates health benefit coverage; review by Legislature

(1) *LEGISLATIVE INTENT.* --The Legislature finds that there is an increasing number of proposals which mandate that certain health benefits be provided by insurers and health maintenance organizations as components of individual and group policies. The Legislature further finds that many of these benefits provide beneficial social and health consequences which may be in the public interest. However, the Legislature also recognizes that most mandated benefits contribute to the increasing cost of health insurance premiums. Therefore, it is the intent of the Legislature to conduct a systematic review of current and proposed mandated or mandatorily offered health coverages and to establish guidelines for such a review. This review will assist the Legislature in determining whether mandating a particular coverage is in the public interest.

(2) *MANDATED HEALTH COVERAGE; REPORT TO AGENCY FOR HEALTH CARE ADMINISTRATION AND LEGISLATIVE COMMITTEES; GUIDELINES FOR ASSESSING IMPACT.* --Every person or organization seeking consideration of a legislative proposal which would mandate a health coverage or the offering of a health coverage by an insurance carrier, health care service contractor, or health maintenance organization as a component of individual or group policies, shall submit to the Agency for Health Care Administration and the legislative committees having jurisdiction a report which assesses the social and financial impacts of the proposed coverage. Guidelines for assessing the impact of a proposed mandated or mandatorily offered health coverage, to the extent that information is available, shall include:

- (a) To what extent is the treatment or service generally used by a significant portion of the population.
- (b) To what extent is the insurance coverage generally available.
- (c) If the insurance coverage is not generally available, to what extent does the lack of coverage result in persons avoiding necessary health care treatment.
- (d) If the coverage is not generally available, to what extent does the lack of coverage result in unreasonable financial hardship.
- (e) The level of public demand for the treatment or service.
- (f) The level of public demand for insurance coverage of the treatment

or service.

(g) The level of interest of collective bargaining agents in negotiating for the inclusion of this coverage in group contracts.

(h) To what extent will the coverage increase or decrease the cost of the treatment or service.

(i) To what extent will the coverage increase the appropriate uses of the treatment or service.

(j) To what extent will the mandated treatment or service be a substitute for a more expensive treatment or service.

(k) To what extent will the coverage increase or decrease the administrative expenses of insurance companies and the premium and administrative expenses of policyholders.

(l) The impact of this coverage on the total cost of health care.

Autism Speaks is a proponent of HB 1291 and SB 2654. These measures would require health insurance plans to provide coverage for screening, diagnosis, intervention, and treatment of autism spectrum disorder in children. This report is our submission in favor of those measures.

Guidelines for Assessing the Impact of the Proposed Health Coverage

Extent to Which the Treatment or Service is Generally Used by a Significant Portion of the Population

HB 1291 and SB 2654 would affect Florida children with autism. Both bills require health insurance plans to provide coverage for "autism spectrum disorder," a condition that the bills define as follows:

"Autism spectrum disorder" means any of the following disorders as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association:

1. Autistic disorder.
2. Asperger's syndrome.
3. Pervasive developmental disorder not otherwise specified.

The terms "autism," "autistic spectrum disorder," "autistic disorder," "Asperger's syndrome," and "pervasive developmental disorder not otherwise specified" merit further description. All of these terms refer to a disorder that in recent years has received far greater attention than ever before.

What is autism? Autism is a general term used to describe a group of complex developmental brain disorders known as pervasive developmental disorders. The pervasive developmental disorders are autistic disorder, the most severe common form of the disorders; Asperger's Syndrome, a milder form of the condition; pervasive developmental disorder not otherwise specified, a descriptor used for a child who has symptoms of autistic disorder and Asperger's Syndrome but does not meet the specific

criteria for either; and two rare conditions, Rett Syndrome and Childhood Disintegrative Disorder. Many refer to the pervasive developmental disorders as autism spectrum disorders.

As the National Institute of Mental Health points out³, all children with autism spectrum disorders demonstrate deficits in social interaction and in communication, and show repetitive behaviors or interests. They will often have unusual responses to sensory experiences, such as certain sounds or the way objects look. Each of these symptoms runs the gamut from mild to severe. They will present in each individual child differently. For instance, a child may have little trouble learning to read but exhibit extremely poor social interaction. Each child will display communication, social, and behavioral patterns that are individual but fit into the overall diagnosis of an autism spectrum disorder.

Today, it is estimated that one in every 150 children is diagnosed with autism.⁴ Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to five times more frequently.⁵ Current estimates are that one out of 94 boys in the United States is diagnosed with autism.⁶ With an estimated population of approximately 4,475,000 people age nineteen and younger,⁷ Florida may have as many as 30,000 boys and girls with autism.

In Florida and elsewhere, families of children with autism have sought out treatment for their children. No one treatment is perfect for every child, but speech therapy, occupational therapy, and physical therapy have produced gains. Children with autism have also benefitted from psychological and psychiatric services, as well as pharmacological interventions. The American Academy of Pediatrics has recognized the role of physicians – the gatekeepers for services under HB 1291 and SB 2654 -- in recognizing, evaluating, and managing autism spectrum disorders in children:

Pediatricians have an important role not only in early recognition and evaluation of autism spectrum disorders but also in chronic management of these disorders. The primary goals of treatment are to maximize the child's ultimate functional independence and quality of life by minimizing the core autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviors, and educating and supporting families. . . . Optimization of health care is likely to have a positive effect on habilitative progress, functional outcome, and quality of life⁸

With the right interventions, children with autism can make remarkable progress.

³ <http://www.nimh.nih.gov/health/publications/autism/symptoms.shtml>

⁴ http://www.cdc.gov/ncbddd/autism/faq_prevalence.htm

⁵ <http://www.cdc.gov/ncbddd/dd/addmprevalence.htm>

⁶ See Department of Health and Human Services Centers for Disease Control and Prevention, "Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000," 56/SS-1 *Morbidity and Mortality Weekly Report* 8 (Feb. 9, 2007).

⁷ U.S. Bureau of the Census, "American Community Survey Demographic and Housing Estimates for Florida: 2006." http://factfinder.census.gov/servlet/ADPTable?_bm=y&-geo_id=04000US12&-qr_name=ACS_2006_EST_G00_DP5&-ds_name=ACS_2006_EST_G00_&-_lang=en&-_sse=on

⁸ Scott M. Myers, Chris Plauche Johnson, the Council on Children with Disabilities, "Management of Children with Autism Spectrum Disorders," 120 *Pediatrics* 1162 (2007).

Applied behavior analysis (“ABA”) is the treatment of choice for many children with autism. HB 1291 and SB 2654 define “applied behavior analysis” as “the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including, but not limited to, the use of direct observation, measurement, and functional analysis of the relations between environment and behavior.” ABA is used to increase adaptive behaviors and to decrease maladaptive ones. Most ABA programs are highly structured. Targeted skills and behaviors are based on an established curriculum. Each skill is broken down into small steps and taught using prompts, which are gradually eliminated as the steps are mastered. The child is given repeated opportunities to learn and practice each step in a variety of settings.

ABA is neither new nor investigational. The recent American Academy of Pediatrics clinical report on the medical management of children with autism spectrum disorders noted its decades-long record of efficacy:

The effectiveness of ABA-based intervention in ASDs [autism spectrum disorders] has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.⁹

The Academy’s findings mirrored conclusions of the Surgeon General of the United States: “Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”¹⁰

Autism is a treatable condition. Thousands of Floridians depend upon the treatments and services required by HB 1291 and SB 2654.

Extent to Which the Insurance Coverage is Generally Available

Very few health insurance plans in Florida or elsewhere cover applied behavior analysis. ABA is often dismissed as investigational or experimental, notwithstanding the scientific evidence of its efficacy and its endorsement by the nation’s leading health authorities. Interventions other than ABA may be available only if autism is not listed as a child’s primary diagnosis. In a study of diagnostic exclusions in private behavioral health care plans, researchers examined a total of forty-six commercial, employment-based behavioral health plans covering a total of 496,911 lives. The researchers found that

⁹ *Id.* at 1164.

¹⁰ U.S. Department of Health and Human Services, “Mental Health: A Report of the Surgeon General” 163-64 (1999).

autism was a diagnostic exclusion in *all* of the plans.¹¹ Even where a diagnosis of autism is not an absolute bar to treatment, the nature of the care may result in a denial of service. Children with autism often require habilitative care – that is, they require care that imparts a new ability, rather than care that restores one that has been lost. This arbitrary distinction can result in a denial of service.

HB 1291 and SB 2654 would prohibit insurers from restricting coverage to an individual solely because that individual was diagnosed with an autism spectrum disorder. At the same time, these bills would allow insurers to continue evidence-based policy decisions. The bills thus strike a balance between safeguarding the health-care needs of a vulnerable population and reimbursing effective medical care.

Extent to Which the Lack of Coverage Results in Persons Avoiding Necessary Health Care Treatment

Autism is an expensive disorder. In a 2006 study, children with autism had a higher annual number of total clinic, pediatric, and psychiatric outpatient visits compared with children without autism.¹² This same study found that the mean annual total cost per member in one large health care plan was more than three times higher for children with autism (\$2757 versus \$892). A 2007 study found that individuals with an autism spectrum disorder had average medical expenditures that exceeded those without an autism spectrum disorder by \$4,110-\$6,200 per individual.¹³ In yet another study, researchers found that average annual health care expenditures for individuals with an autism spectrum disorder increased 20.4% from 2000 to 2004, even after adjustment for inflation.¹⁴

The studies described in the preceding paragraph did not take into account costs associated with ABA, an intensive therapy. In an important 2001 report, the Commission on Behavioral and Social Sciences and Education, a division of the National Academy of Sciences, recommended that “services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives.”¹⁵ Some of the program models the Commission studied provided as many as 45 hours of week of behavioral therapy to children with autism.

The out-of-pocket cost of ABA will vary with the funding source for the intervention, the amount of financial assistance afforded, the service provider, and the number of hours of service delivered. According to survey data from the Interactive Autism Project (IAN), an

¹¹ Pamela B. Peele, Judith R. Lave, Kelly J. Kelleher, “Exclusions and Limitations in Children’s Behavioral Health Care Coverage,” 53 *Psychiatr. Serv.* 591 (2002).

¹² Lisa A. Croen, Daniel V. Najjar, G. Thomas Ray, Linda Lotspeich, and Pilar Bernal, “A Comparison of Health Care Utilization and Costs of Children With and Without Autism Spectrum Disorders in a Large Group-Model Health Plan,” 118 *Pediatrics* 1203 (2006).

¹³ Tom T. Shimabukuro, Scott D. Grosse, and Catherine Rice, “Medical Expenditures for Children with an Autism Spectrum Disorder in a Privately Insured Population,” 38 *J. Autism and Dev. Disord.* 546 (2008).

¹⁴ Douglas L. Leslie and Andres Martin, “Health Care Expenditures Associated with Autism Spectrum Disorders,” 161 *Arch. Pediatr. Adolesc. Med.* 350 (2007).

¹⁵ Commission on Behavioral and Social Sciences and Education, Educating Children with Autism 6 (2001).

online autism research project, seventy-seven percent of families nationwide, and seventy-eight percent of the families in Florida, pay the full cost of ABA out of pocket.¹⁶ Of the families surveyed, five percent nationwide and ten percent in Florida pay over \$2,500 per month for ABA. Needless to say, a \$30,000 or more yearly expenditure would put an enormous economic strain on most families.

Many families simply cannot afford the care that they desperately desire for their children. Without adequate health insurance, these families are at substantial disadvantage when it comes to paying for services, and may postpone or do without necessary care to save money.¹⁷ In the case of a child with autism, doing without care or diluting care could mean the loss of critical opportunities to ameliorate the devastating effects of the condition.

Extent to Which the Lack of Coverage Results in Unreasonable Financial Hardship

Families of children with autism face enormous pressure. “Diagnosis of autism places a large financial burden on families who often must pay for expensive treatments out-of-pocket. Documented efficacy of early intervention heightens the intense pressure to use whatever means possible – including placing the family’s financial future at risk – to secure needed therapy NOW.”¹⁸ According to IAN data for Florida, nineteen percent of the Florida families that use applied behavior analysis with their children spend over \$1,000 per month for the intervention.¹⁹ Twenty-seven percent of families reported quitting a job or significantly reducing hours at work to either take a child to treatment or to do treatment at home.²⁰

Survey data alone does not provide the full measure of suffering families must endure to look after their children. One family reported the following:

I am responding to your request for therapies and services that our son, [child’s name], who has Asperger’s Syndrome, ADHA, ODD, & OCD, doesn’t receive because our insurance doesn’t cover it, or that we can’t afford the out-of-pocket expense. Well, here goes:

Applied Behavior Analysis: his school psychologist says that [child’s name] needs this, but my husband [sic] makes a little to [sic] much to qualify for med-waivers, but not enough to afford this costly therapy.

Intensive social therapy: again, can’t afford it.

¹⁶ E-mail from Alison R. Marvin, Research Data Manager, Interactive Autism Network (IAN), to Stuart Spielman, Senior Policy Advisor and Counsel, Autism Speaks (March 10, 2008, 18:04 EST) (on file with Stuart Spielman).

¹⁷ Kristina W. Hanson, Patricia Neuman, David Dutwin, and Judith D. Kasper, “Uncovering the Health Challenges Facing People with Disabilities: The Role of Health Insurance,” *Health Affairs* W3-561, Nov. 19, 2003, <http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.552v1.pdf>

¹⁸ Deanna L. Sharpe & Dana Lee Baker, “Financial Issues Associated with Having a Child with Autism,” *28 J. Fam. Econ. Iss.* 247, 262 (2007).

¹⁹ E-mail from Alison R. Marvin, *supra* note 14.

²⁰ *Id.*

Respite: Aside from [child's] difficulties, I am also disabled. . . . [Child] can be very difficult to handle sometimes, and I could use a little break, once in a while.²¹

Another family gave the following information:

My son [child's name] is autistic and is still non-verbal at age 9. We tried our insurance company but they denied help with speech therapy. We tried the local school district for more speech help but they do not have enough staff to give the AVB that [the child] needs to start talking.

It would cost us at least \$30,000 to send [the child] to school . . . for an ABA program but we don't have that kinds of funds and the transportation to transport him daily We have 3 other sons that go to school in the [location] area.

I can find AVB specialist to come to our house for service. If we do find one, I would think it would cost at least \$10,000 a year for the service [the child] needs. [The child] goes to [name of school] autistic program and they do not have anyone that is a specialist in AVB that [the child] needs on a daily bases [sic]. I make enough money that [the child] would not get the SSI help or Medicaid help either.

I hope this helps out. You can use our name and [the child's] as a desperate 9-year special autistic boy who needs help in Applied Verbal behavior [sic] so he can live and survive a normal life.²²

A third family described its struggles as follows:

[Child] has been sorely in need of OT and PT since birth, but she has not been able to receive either service until this past September when she enrolled at [facility] and became eligible for 1 hour per week of OT. She was even denied these services when she was in Early Intervention (due to prematurity). We are currently privately paying for an hour per week of speech therapy, but she still needs the other services and we simply can't afford it. Our insurance policy has \$2500 in coverage available for speech, OT, and PT combined, but they refuse to pay because [child's] needs are not a result of a "LOSS" of skills due to "ILLNESS or INJURY". So because she's had deficits since she was born at 26 weeks, she technically doesn't qualify because she wasn't in an accident and/or didn't have a disease that took previously acquired skills away. This is a

²¹ E-mail provided to Sharon Boyd, Florida Statewide Advocacy Chair for Autism Speaks, and forwarded on March 12, 2008, to Stuart Spielman, Senior Policy Advisor and Counsel, Autism Speaks (on file with Stuart Spielman).

²² E-mail provided to Sharon Boyd, Florida Statewide Advocacy Chair for Autism Speaks, and forwarded on March 12, 2008, to Stuart Spielman, Senior Policy Advisor and Counsel, Autism Speaks (on file with Stuart Spielman).

RIDICULOUS situation!! It's akin to saying an insurance company doesn't have to pay for a NICU stay because her early birth is a pre-existing condition!

As for impact, [child] is still not speaking conversationally (at age 5). She can express some desires, but for the most part she is echolalic. She won't make choices, she won't answer yes or no, she won't tell us what she wants to eat, etc. It's very frustrating that we can't make more progress with a little girl who is SO bright that she's already reading and operating a computer on her own. She needs more speech therapy and ABA therapy to work on this. [Child] has low muscle tone, and this impacts her in many ways. She's physically awkward, cannot properly grip and operate a pencil, and thus is often unable to draw or write her letters. Yet this is a child who can name all her letters, numbers, colors, shapes, months, days, etc. Educationally, this is an issue because of her lower fine motor skills and inability to write. [Child] also refuses to potty train, an area that we REALLY would love to work intensively on with the help of an OT and/or a behavioralist. [Child] would be capable of mainstreaming into a regular education class if she could speak better, use the potty, and write better. With proper therapy, all three of these goals are possible, yet we cannot get this help for her. This frustrates us as a family as we are already spending more than we earn to try and provide her with weekly speech therapy, a weekly swim lesson, and a weekly gym class to help with her muscle tone.

Other states have been successful in getting insurance companies to provide coverage for autism-related disorders, and I'm hoping and praying that Florida will follow suit. Our kids deserve to be treated better.²³

The children of Florida do indeed deserve better.

The Level of Public Demand for the Treatment or Service

HB 1291 and SB 2654 require insurers, health maintenance organizations, and other entities providing health insurance coverage in Florida to provide coverage for screening, diagnosing, and treating autism spectrum disorders. Demand for these services has grown in recent years in Florida and across the country, as reported prevalence rates of autism have increased. Population-based studies conducted worldwide before 1985 indicated that the prevalence of autism was .4-.5 per 1000 children under the age of eighteen.²⁴ Findings from the first multisite study to monitor the prevalence of autism spectrum disorders nationwide showed a prevalence rate of 6.7 per 1000 children aged eight years.²⁵ Researchers at the Centers for Disease Control

²³ E-mail provided to Sharon Boyd, Florida Statewide Advocacy Chair for Autism Speaks, and forwarded on March 12, 2008, to Stuart Spielman, Senior Policy Advisor and Counsel, Autism Speaks (on file with Stuart Spielman).

²⁴ Department of Health and Human Services Centers for Disease Control and Prevention, *supra* note 4 at 2.

²⁵ Department of Health and Human Services Centers for Disease Control and Prevention, *supra* note 4 at 1.

interpreted this data as indicating that autism spectrum disorders are more common than previously believed.²⁶

As more children have been identified, the demand for services has grown. News media report new schools, new training programs, and critical shortages. In a 2005 story, CNBC reported that the Columbia University Teachers College Program in applied behavior analysis had to turn away forty qualified students.²⁷ CNBC noted that trained therapists were earning \$125 per hour. With skyrocketing costs for private therapy, there is little wonder that many Floridians look to the state for services. In a telling headline --“Across Florida, 16,446 People are Waiting” -- the Orlando Sentinel recently reported on the demand for public services in Florida²⁸. The Sentinel story is so pertinent to the issues addressed by House Bill 1291 and Senate Bill 2654 that we reprint it in its entirety:

They are children and adults with developmental disabilities -- autism, Down syndrome, spina bifida -- people who cannot take care of themselves, who need help to meet their most basic needs.

For a decade, the state has tried and largely failed to pay for services such as physical therapy and respite care that help them live at home instead of in expensive institutions. About 25,000 people do get help, but others continue to line up on a massive waiting list, where they may languish for five years or more.

This session, in spite of a looming state deficit, Gov. Charlie Chris has requested a \$13 million boost in funding for disabilities programs that now receive \$1.2 billion.

But even if lawmakers approve the spending -- and there is no assurance they will -- it will merely keep pace with rising expenses. The money isn't expected to make a significant dent in the waiting list.

For the foreseeable future, thousands of families will continue their daily struggle to care for their disabled loved ones at home without needed help.

In Florida, the Developmental Disabilities Home and Community-Based Services Waiver serves people with disabilities in the community. The waiver provides behavior analysis and assistant services, physical, occupational, and speech therapies, and other services. As of October 1, 2007, 21,728 individuals were on a waiting list for services.²⁹ Over eighty-five percent of the individuals on the waiting list have been waiting for

²⁶ *Id.* at 1.

²⁷ Sue Herera, “Demand Soars for Autism-Related Schools, Services,” <http://www.msnbc.msn.com/id/7013436/> (Feb. 25, 2005).

²⁸ . OrlandoSentinel.com, “Across Florida, 16,446 People are Waiting,” <http://www.orlandosentinel.com/services/newspaper/printedition/monday/localandstate/orl-lidintro08mar10.0.2013139.story> (March 10, 2008).

²⁹ Jennifer Johnson, Florida Legislative Office of Program Policy Analysis & Government Accountability, “APD Waiting List Should Be Improved for Agency’s Planning and Budgeting Purposes,” http://www.oppaga.state.fl.us/reports/pdf/1-9-08_APD_Waiting_List.pdf (Jan. 9, 2008).

services for over five years.³⁰ Fourteen and six-tenths percent of the individuals on the waiting list,³¹ or about 3,172 individuals, had autism as their primary diagnosis. This is perhaps the most salient statistical reflection of the demand for the services that HB 1291 and SB 2654 would require. It is a compelling reason to act.

Level of Public Demand for Insurance Coverage of the Treatment or Service

As we have already noted, private insurance coverage of the treatment or services provided by HB 1291 and SB 2654 is limited (in the case of services like occupational, physical, or speech therapies) or almost non-existent (in the case of ABA). Where the private sector has failed, the public sector has been forced to step in, to the detriment of all Floridians. Families in Florida who have private health insurance are forced to rely on public health insurance to meet the needs of children with autism. Private insurers are getting a free pass, while an overburdened public health system shoulders the responsibility of providing insurance to families who are getting little return on their purchase of health insurance.

Like the public health system, schools in Florida also suffer because of the lack of private insurance services. Under Florida law, each district school board must provide an appropriate program of special instruction for exceptional students.³² That mandate is complicated by the absence of private health insurance to treat the core symptoms of autism. For many parents, school services are a substitute for private insurance services. The goal of the educational system, of course, is not to provide medical services. Schools provide speech therapy and other related services to enable a child with a disability to receive a free appropriate public education.³³ Autism Speaks believes that the ability of schools to educate children is compromised when children with autism do not receive appropriate care through private insurance.

To alleviate the demand on the public health and school systems and in response to the demands of their citizenry, states around the country have enacted or are considering legislation to require insurers to provide autism services. Indiana has long required health insurers to provide autism services.³⁴ In the past year, South Carolina³⁵ and Texas³⁶ enacted laws similar to HB 1291 and SB 2654. Bills are pending in Arizona,³⁷ Hawaii,³⁸ Illinois,³⁹ Michigan,⁴⁰ Missouri,⁴¹ Oklahoma,⁴² Pennsylvania,⁴³ and other states. These bills are yet another indication of public demand for insurance coverage of the services provided in the pending Florida legislation.

³⁰ *Id.*

³¹ *Id.*

³² Fla. Stat. § 1003.57(1) (2007).

³³ 20 U.S.C.S. § 1401(26)(A) (2008).

³⁴ *See Ind, Code § 27-8-14.2* (2007).

³⁵ 2007 S.C. Act No. 65.

³⁶ Tex. Ins. Code § 1355.015 (2008).

³⁷ Az. SB 1263.

³⁸ Ha. HB 2727.

³⁹ Il. SB 1900.

⁴⁰ Mi. HB 5527 and HB 5529; SB 784 and SB 785.

⁴¹ Mo. HB 2351 and SB 1229.

⁴² Ok. SB 2118.

⁴³ Pa. HB 1150.

The Level of Interest of Collective Bargaining Agents in Negotiating for the Inclusion of This Coverage in Group Contracts

Autism Speaks has been unable to gauge the level of interest of collective bargaining agents in negotiating for the inclusion of the coverage provided in HB 1291 and SB 2654 in group coverage. We will supplement this submission as additional information becomes available.

Extent to Which the Coverage Will Increase or Decrease the Cost of the Treatment or Service

This submission has already noted the high cost of autism treatment services. We have observed that the demand for these services exceeds the available supply. Part of the reason for this imbalance may be explained by distortions in the delivery of services. For the most part, families have difficulty accessing treatment through private insurance coverage. This leaves them at a competitive disadvantage in negotiating the price of services. A study of exclusions and limitations in behavioral health coverage concluded that policy restrictions drove prices upwards:

Health insurance generally increases the affordability of children's behavioral health care, but the presence of benefit limits or diagnostic exclusions can mean that some children effectively become uninsured if they require more intensive services than those covered under the plan or if they need treatment for disorders that are excluded under the plan. Although current utilization management strategies employed by managed behavioral health organizations, through which few patients ever reach their benefit limits, render benefit parity almost irrelevant, some children do exceed their benefit limits. The cost of obtaining uncovered services can be very high, because *the price of services that are not billable to an insurance plan can be significantly higher than payments for those same services under negotiated agreements between insurers and providers.*

(citations omitted and emphasis added).⁴⁴ Autism Speaks expects that the added bargaining power of private insurers will reduce the cost of autism services. We further anticipate that the purchasing power of private insurers will draw additional providers into the market, increasing the supply of services and reducing their costs.

Extent to Which the Coverage Will Increase the Appropriate Uses of the Treatment or Service

The treatments and services HB 1291 and SB 2654 require are the core treatments for autism. Coverage of these treatments by private insurance may not only drive these costs down but may also increase their appropriate use. An insurance company can help consumers make appropriate medical decisions (providing, of course, that the company adheres to the terms of its contract with a subscriber). BlueCross BlueShield of Florida, for example, provides members with a range of benefits to better use their health care. These benefits include the following:

⁴⁴ Peele et al., *supra* note 9 at 593-94.

- Care Coordination, a program designed to help provide answers to members' questions as they navigate through the health care system;
- Member Outreach, a proactive program design to promote, among other things, informed health care choices; and
- Case Management, a voluntary, no-cost service to members with chronic health problems.⁴⁵

With inadequate insurance coverage, families of children with autism spectrum disorders are forced to go it alone in making difficult health care choices. HB 1291 and SB 2654 could well provide families with additional assistance in looking after the needs of their children.

Extent to Which the Mandated Treatment or Service Will Be a Substitute for a More Expensive Treatment or Service

The services HB 1291 and SB 2654 require are services that children with autism currently receive. These services are likely to become less costly but otherwise will not change.

Extent to Which the Coverage Will Increase or Decrease the Administrative Expenses of Insurance Companies and the Premium and Administrative Expenses of Policyholders⁴⁶

The likely maximum premium impact of HB 1291 and SB 2654 on individuals covered by private health insurance will be significantly less than 1%, amounting to no more than \$0.87 to \$1.56 per member per month (pmpm) for single policy rates and \$2.33 to \$4.20 pmpm for family rates. Individuals covered by the state group insurance program will likely experience a similarly small effect on their premiums. We reach these conclusions as follows:

Number of Eligible Beneficiaries of HB 1291 and SB 2654

According to estimates provided by the U.S. Census Bureau, there are approximately 4,260,000 Floridians between the ages of two⁴⁷ and twenty⁴⁸ who satisfy the age criteria for the benefits proposed in HB 1291 and SB 2654.⁴⁹ A recent source indicates that

⁴⁵ BlueCross BlueShield of Florida, Manual for Physicians and Providers 6-5 – 6-6 (July 2007) http://www.bcbsfl.com/DocumentLibrary/Providers/ManualForPhysProv_Sect6.pdf

⁴⁶ James N. Boudier, MPA, of The Vista Foundation, provided the narrative and methodology for this section of the submission. Autism Speaks gratefully acknowledges his contribution.

⁴⁷ We have excluded children under age two because few receive treatment so early in life.

⁴⁸ Benefits are available under HB 1291 and SB 2654 to eligible individuals diagnosed by eight years of age who are younger than eighteen years of age or who attend high school. For the purpose of projecting costs, we assume that all eligible persons will be diagnosed by eight years of age – an extremely conservative and unlikely scenario. We further assume that most children will remain eligible through age twenty.

⁴⁹ U.S. Bureau of the Census, “American Community Survey Demographic and Housing Estimates for Florida: 2006” http://factfinder.census.gov/servlet/ADPTable?_bm=y&-geo_id=04000US12&-qr_name=ACS_2006_EST_G00_DP5&-ds_name=ACS_2006_EST_G00_&-_lang=en&-_sse=on

approximately 15.1% of Floridians under the age of 18 are uninsured.⁵⁰ The number of insured Floridians, therefore, between the ages of two and twenty is approximately 3,616,000.

Based on information published by the Medical Expenditure Panel Survey (MEPS), 68.1% of private-sector enrollees in Florida businesses with over fifty employees are enrolled in self-insured plans.⁵¹ In addition, the proposed bills note that the term “Health Insurance Plan” does not include “any health insurance plan offered in the individual market, any health insurance plan that is individually underwritten, or any health insurance plan provided to a small employer.” Florida law defines small employers as those having fewer of fifty employees. According to the Florida Office of Insurance Regulation 2006 Annual Report, employers in Florida with more than fifty employees that also offer fully regulated major medical plans comprise approximately 64.40% of the fully regulated market. The potential pool of beneficiaries between the ages of two and twenty, therefore, after accounting for ERISA and small business exemptions and the uninsured, is approximately 742,856.

Number of Potential Eligible Beneficiaries with Autism in Florida

The prevalence of autism is estimated by the CDC to be approximately 1 in 150.⁵² Given this additional data, we estimate the total number of potential beneficiaries with an Autistic Spectrum Disorder to be 4,952.

Number of Likely Eligible Beneficiaries with Autism in Florida

Several recent examinations of health care utilization and expenditures associated with treating autism call into question the appropriateness of using epidemiological prevalence data to forecast the magnitude of health care utilization that would result from passage of autism insurance legislation in Florida. In 2007, Douglas L. Leslie and Andres Martin compiled data from the Thomson/Medstat MarketScan database, “which compiles claims information from private health insurance plans of large employers ... across the United States ... [with] covered individuals includ[ing] employees, their dependents, and early retirees.”⁵³ Leslie et al. note that the *treated prevalence* of autism in the claims database was 19.2 per 10,000 (*i.e.*, 1 in 520.83).⁵⁴ Independently, Gregory S. Liptak et al. obtained data from three national surveys and identified a treated prevalence of autism of 21 in 10,000 (*i.e.*, 1 in 476.19).⁵⁵ Similarly, in a previous article, David S. Mandell et al. reported a treated prevalence rate of youth diagnosed with autism in Allegheny County, PA of 0.2% (*i.e.*, 1 in 500) (Mandell et al., p. 477).⁵⁶ Finally, the American Academy of Pediatrics published an article indicating that

⁵⁰ Robin A. Cohen and Michael E. Martinez, Division of Health Interview Statistics, National Center for Health Statistics, “Health Insurance Coverage: Early Release of Estimates from the National Health Interview Survey, 2006,” <http://www.cdc.gov/nchs/data/nhis/earlyrelease/insur200706.pdf>.

⁵¹ See Medical Expenditure Panel Survey Report at <http://www.meps.ahrq.gov/mepsweb/data_stats/summ_tables/insr/state/series_2/2005/tiib2b1.pdf>

⁵² Centers for Disease Control and Prevention, *supra* note 2.

⁵³ Leslie et al., *supra* note 30 at 351.

⁵⁴ Leslie et al., *supra* note 30 at 351

⁵⁵ Liptak, Gregory S., Tami Stuart, and Peggy Auinger, “Health Care Utilization and Expenditures for Children with Autism: Data from U.S. National Samples.” 36 *J. Autism and Dev. Disord.* 871, 872 (2006).

⁵⁶ Mandell, David S., Jun Cao, Richard Ittenbach, and Jennifer Pinto-Martin, “Medicaid Expenditures for Children with Autistic Spectrum Disorders: 1994 to 1999.” 36 *J. Autism and Dev. Disord.*, 475 (2006).

the more severe form of autism requiring intensive behavioral interventions occurs at a frequency that is in line with the treated prevalence cited in the articles above.⁵⁷

The consistency of these data suggest that the treated prevalence of autism is a better measure to apply to premium impact analyses because, unlike epidemiological prevalence data, which simply report the number of persons satisfying the diagnostic criteria for autism spectrum disorder, treated prevalence accounts for those persons with autism actually requiring, and therefore consuming, health care services related to their disorder. Based on these findings, it is reasonable for forecast the likely beneficiaries of the Florida legislation based on a treated prevalence of 1 in 500. This places the pool of likely beneficiaries at approximately 1,486 in number.

Assumptions

While much of the data included in this analysis was derived from primary sources, some assumptions were necessary due to our inability to independently confirm certain data elements from primary sources. These assumptions are set forth below.

- The \$9.35 billion in total premiums collected in 2005 from private insurance ratepayers working for business firms with more than fifty employees, as reported by the Florida Office of Insurance Regulation in 2006, has remained constant.⁵⁸
- That 31.9 percent of health insurance plans in Florida that are not subject to ERISA or small business exemption is an accurate figure, as reported by the MEPS for 2005.
- That 100% of likely, increased costs attributable to services provided under HB 1291 and SB 2654 will be passed on to private insurance ratepayers participating in eligible plans.
- That additional, first year administrative expenses associated with implementation of the mandated benefits coverage will be consistent with those anticipated by insurers in other states and are assumed to be approximately 10%. This adder is to be considered a first-year expense only. After implementation of newly covered ABA services, administrative expenses associated with such services should be in line with other services' administrative expenses.
- That the Medical Loss Ratio of 83.78% reported by the Florida Office of Insurance Regulation in 2006 has remained constant.

In completing the rate impact analysis for the bills, we have attempted to err in favor of higher costs whenever primary source data were not obtainable.

Rate Impact Analysis

In the interest of providing a range of rate impact resulting from the coverage of services, we have provided calculations based on a number of variables. Attached as

⁵⁷ See Fombonne, Eric, Rita Zakarian, Andrew Bennett, Linyan Meng, and Diane McLean-Heywood , "Pervasive Developmental Disorders in Montreal, Quebec, Canada: Prevalence and Links With Immunizations." 118 *Pediatrics* 139 (2006).

⁵⁸ Florida Office of Insurance Regulation "2006 Annual Report" 96, <http://www.flor.com/AnnualReport/2006annualreport.pdf>.

Exhibit “A” is a spreadsheet detailing the likely range of impact the services covered will have on private insurance ratepayers in Florida. Please see Exhibit “B” for a comparable analysis of the state group insurance program.

The most likely scenarios are derived in part from peer-reviewed research evaluating real-life data concerning the treated prevalence of autism and average expenditures per treated person with autism. Persons living with autism present with varied symptoms requiring differing levels of attention based on the severity of symptoms. The more severe symptoms requiring behavioral health and other medical interventions are not necessarily present in every person diagnosed with an Autistic Spectrum Disorder. This is evidenced by the treated prevalence rates reported in Mandell et al (2006), Leslie et al. (2007), and Liptak et al. (2007), which consistently report a treated prevalence rate of approximately 1 in 500 (or 0.20%). It is reasonable to expect, therefore, that actual utilization rates of benefits covered will track more closely along treated prevalence rates noted in the abovementioned reviews of actual health care utilization data than prevalence rates reported from epidemiological studies such as the recent prevalence report of the Centers for Disease Control.

Three possible expenditure scenarios are included in our rate impact analysis. The first, \$12,500, is derived from calculating approximately 200% of the mean per capita expenditure for children with autism, as reported by Leslie et al. (2007). The second is derived from Chasson et al. (2007), which estimated the average cost of early intensive behavioral interventions for children with autism to be approximately \$22,500 annually.⁵⁹ The last expenditure scenario, considered to establish the highest parameters of potential rate impact, assumes full expenditures up to the \$36,000 cap included in HB 1291 and SB 2654. We are, however, unaware of any justification for this high mean expenditure rate in the extant literature.

Table 1 below illustrates the range of likely rate impact for expenditures associated with the treatment of autism if 100% of additional costs are passed on to ratepayers. The percentage rate impact, based on treated prevalence and the lowest statistic available for uninsured children in Florida, falls in the 0.26% to 0.75% range. Given extant literature on average utilization and expenditure rates, the likely range of cost impact falls in the 0.26% to 0.47% range.

TABLE 1.

Source	Average Per Capita Expenditure	% Rate Impact Based on Treated Prevalence* plus 10% Admin Costs
Leslie et al. (2007) x 200%	12,500	0.26%
Chasson et al. (2007)	22,500	0.47%
Full Capped Expenditure	36,000	0.75%

⁵⁹ Gregory S. Chasson, Gerald E. Harris, and Wendy J. Neely, “Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism.” 16 *J. Child and Fam. Stud.* 401 (2007)

* Assumes 15.1% uninsured rate for Floridians under age 21

Based on statistical data published by the Kaiser Family Foundation reporting average annual single and family policy rates in 2007, single policy rates will experience an increase no greater than \$0.87 to \$1.56 per member per month (pmpm) for single policy rates and \$2.33 to \$4.20 monthly for family rates as a result of implementing coverage provided by HB 1291 and SB 2654.⁶⁰

A brief discussion of our findings pertaining to the “Full Capped Expenditure” scenario based on the CDCs’ epidemiological prevalence (as opposed to *treated prevalence*) is also warranted. The least probable scenario involves expenditures reaching their capped, \$36,000 limit for every eligible person under age twenty-one with an autism diagnosis, based on the prevalence rate reported by the CDC. In order for the impact of this “Full Capped Expenditure” scenario to be realized, every eligible child with autism living in Florida must maximize his or her usage of the capped benefits provided by the proposed legislation. Assuming the uninsured percentage rate for children in Florida is consistent with the CDC’s findings (*i.e.*, 15.1%) and a 10% administrative cost rate, the rate impact would be, at most, 2.50%.

Summary and Conclusions

Given consistent reporting on treated prevalence, it is unreasonable to assume utilization rates will match the 1 in 150 epidemiological prevalence rate reported by the CDC. Not all children and youth with autism require significant medical treatment to ameliorate symptoms of their disorder. Researchers have also found that average expenditures for persons with autism are significantly lower than the mandated \$36,000 cap included in the legislation.

We believe that there is more than sufficient evidence to conclude that meeting the health care needs of people with autism living in Florida will result in a very small impact on private insurance premiums. Based on an average expenditure of \$22,500 annually (62.5% of the capped limit), which significantly exceeds average expenditures reported in the literature, *one can reasonably forecast a maximum rate impact of 0.47%*. This estimate is also consistent with forecasts offered by neutral parties in other states (*e.g.*, Wisconsin⁶¹) and opponents to similar bills as well (*e.g.*, South Carolina⁶²).

Last, while cost controls are a critical component of any affordable health care benefit program, the long-term effect of the diagnostic exclusion of autism will, in the long term, become a substantial burden on Florida’s taxpayers. Although immediate, short term savings might be realized, deferring treatment will ultimately cost taxpayers far more in the future. In the case of HB 1291 and SB 2654, the increased cost of affording children and youth with autism access to effective treatment is small (most

⁶⁰ See Kaiser Family Foundation and Health Research and Educational Trust, “Employer Health Benefits – 2007 Annual Survey,” which reports that the average annual total premium cost for single coverage in the Southeastern United States is \$3,991 and \$10,728 for family coverage.

⁶¹ See fiscal estimate for AB 417 in Wisconsin, <http://www.legis.state.wi.us/2007/data/fe/AB-417fe.pdf>

⁶² See 2007 veto message for S. 91 in South Carolina, <http://governor.sc.gov/NR/rdonlyres/C37D3E25-D2C6-4A5F-BD66-7D2D5906C74D/0/S91.pdf>. The veto was unanimously overridden by the state legislature.

probably between \$0.87 and \$1.56 per member per month), but the return on investment, both in human and financial terms, is very significant.

The Impact of This Coverage on the Total Cost of Health Care

By our calculation, the likely maximum premium impact of HB 1291 and SB 2654 will be significantly less than 1 percent. That cost will be far outweighed by the benefits to Floridians from the legislation. Treating autism effectively will *reduce* the long-term cost of health care.

In 2007 Michael Ganz of the Harvard School of Public Health examined how the large financial burdens of autism affect not only families with an autistic child but society in general.⁶³ Ganz broke down the costs of autism into direct costs and indirect costs. He counted as direct costs physician services, outpatient care, clinic services, dental care, prescription medications, complementary and alternative therapies, behavioral therapies, hospital and emergency services, allied health, equipment and supplies, home health, and medically related travel, as well as child care, adult care, respite and family care, home and care modifications, special education, and supported employment. He counted as indirect costs productivity losses for people with autism (estimated by combining standard average work-life expectancies for all men and women with average income and benefits and estimates of age- and sex-specific labor force participation rates).

Ganz estimated that the total annual societal per capita cost of caring for and treating a person with autism was \$3.2 million. For an entire birth cohort of people with autism, the cost would total about \$35 billion. Ganz direly warned that these costs would burden every American:

These results, especially on the substantial costs resulting from lost productivity of both individuals with autism and their parents and from rather large adult care costs, have important implications for those aging members of the baby boom generation approaching retirement. As those individuals retire, many of their adult children with autism will be transitioning into adult care settings. Those costs, combined with very limited to nonexistent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general.⁶⁴

The financial burden that Ganz describes can be lessened by effective autism services. Researchers estimated that the state of Texas would save \$208,500 per child across eighteen years of education with early intensive behavioral intervention.⁶⁵ An earlier study in Pennsylvania placed the cost savings from early intervention at \$187,000 to \$203,000 per child for ages three to twenty-two years and at \$656,000 to \$1,082,000 per

⁶³ Michael L. Ganz, "The Lifetime Distribution of the Incremental Societal Costs of Autism" 161 *Arch. Pediatr. Adolesc. Med.*, 343 (2007).

⁶⁴ *Id.* at 348.

⁶⁵ Chasson et al., *supra* note 57.

child for ages three to fifty-five years.⁶⁶ With proper treatment, children with autism can do better in school and can live healthier and more independent lives.

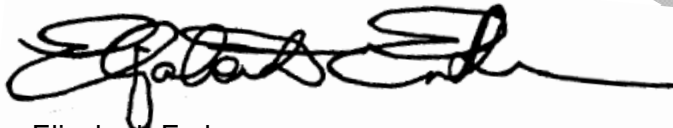
Autism Speaks believes that the pertinent question in the discussion of insurance reform is not whether we can afford to provide appropriate interventions to children with autism but, rather, whether we can afford not to. Autism is a financial drain on the health care system. Children with autism make more emergency and non-emergency hospital visits and incur greater outpatient, inpatient, and medication costs.⁶⁷ An investment towards reducing these costs would benefit everyone.

Of course, the cost of health care and other services is but one measure of the cost of autism. Another measure is the emotional cost of the condition, a measure that cannot readily be quantified. Whatever calculus is used, there can be no doubt that savings lie in reducing autism's toll. Ensuring that Florida children with autism receive appropriate health care is a wise investment.

Conclusion

Requiring the coverage provided by HB 1291 and SB 2654 is in the public interest. Autism Speaks urges the Legislature to make the benefits of these bills the law of the State of Florida.

Sincerely,



Elizabeth Emken
Vice President – Government Relations
Autism Speaks

⁶⁶ John W. Jacobson, James A. Mulick, and Gina Green, “Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case,” 13 *Behav. Intervent.* 201 (1998).

⁶⁷ Croen et al., *supra* note 10; James G. Gurney, Melissa L. McPheeters, Matthew M. Davis, “Parental Report of Health Conditions and Health Care Use Among Children With and Without Autism,” 160 *Arch. Pediatr. Adolesc. Med.* 825 (2006).

Appendix 4
APD Waiver Service Cost by Primary Disability and By Service FY 06-07 [Autism Only]

Disability Group	Service	Client	Cost
Autism	ADULT DAY TRAINING	194	\$ 1,383,666.04
	ADULT DAY TRAINING-SL WAIVER	39	\$ 178,028.99
	ADULT DENTAL SERVICES	164	\$ 132,003.05
	BEHAVIORAL SERVICES - BACHELORS DEGREE	259	\$ 773,398.71
	BEHAVIORAL SERVICES ASSISTANT SERVICES	100	\$ 965,508.84
	BEHAVIORAL SERVICES-ASSISTANT SERVICES	20	\$ 37,205.36
	BEHAVIORAL SERVICES-BACHELORS DEGREE	244	\$ 508,275.22
	BEHAVIORAL SERVICES-DOCTORATE DEGREE	450	\$ 1,168,174.98
	BEHAVIORAL SERVICES-MASTERS DEGREE	143	\$ 363,121.22
	BEHAVIORAL SEVICES - MASTERS DEGREE	187	\$ 684,866.91
	BEHAVIORAL THERAPY ASSESSMENT	338	\$ 114,519.94
	CHORE SERVICE	1	\$ 169.44
	COMPANION	106	\$ 457,149.41
	CONSUMABLE MEDICAL SUPPLIES	645	\$ 954,856.88
	DIETITIAN SERVICES	24	\$ 9,132.10
	DURABLE MEDICAL EQUIPMENT, MISCELLANEOUS	9	\$ 4,871.10
	ENVIRONMENTAL MODIFICATIONS	5	\$ 24,260.08
	ENVIRONMENTAL MODIFICATIONS ASSESSMENT	14	\$ 10,066.48
	HOMEMAKER SERVICE	22	\$ 51,899.00
	IN-HOME SUPORT SERVICES-SL WAIVER	450	\$ 2,583,697.36
	IN-HOME SUPPORT	23	\$ 186,805.48
	IN-HOME SUPPORT SERVICES	40	\$ 1,181,719.41
	IN-HOME SUPPORT SERVICES-SL WAIVER	1	\$ 113.40
	MEDICATION REVIEW	197	\$ 15,125.78
	MONTHLY BENEFIT AMOUNT-CDC-DD	193	\$ 5,783,245.33
	NON RESIDENTIAL SUPPORTS (QUARTER HOUR)	272	\$ 1,617,663.31
	NON-EMERGENCY TRANSPORTATION; PER DIEM	38	\$ 54,817.48
	OCCUPATIONAL THERAPY	12	\$ 36,851.90
	OT ASSESSMENT	3	\$ 464.50
	OTHER SPECIFIED CASE MANAGEMENT SERVICE	192	\$ 345,586.18
	P.T. ASSESSMENT	1	\$ 140.00
	PERSONAL CARE ASSISTANCE	374	\$ 5,116,044.11
	PHYSICAL THERAPY	7	\$ 21,389.12
	RESIDENTIAL HAB THERAPY (DAY)(STANDARD)	303	\$ 17,899,974.69
	RESIDENTIAL HABILITATION (QUARTER HOUR)	20	\$ 124,817.87
	RESIDENTIAL NURSING SERVICES	1	\$ 2,377.96
	RESPIRE CARE	344	\$ 843,677.27
	RESPIRE CARE (DAY)	146	\$ 212,877.56
	RESPIRE CARE (QUARTER HOUR)	382	\$ 1,326,516.57
	SELF-CARE/HOME MANAGEMENT TRAINING (EG,	47	\$ 376,997.86
	SPECIALIZED MEDICAL EQUIPMENT AND SUPPLI	1	\$ 39,968.76
	SPECIALIZED MENTAL HEALTH SERVICES ASSES	10	\$ 2,831.86
	SPECIALIZED MENTAL HEALTH SERVICES THERA	23	\$ 43,480.40
	SPEECH THERAPY	36	\$ 116,431.38
	SPEECH THERAPY EVALUATION	15	\$ 2,272.93
	SUPPORT COORDINATION (CAPITATION)	988	\$ 1,699,744.11
	SUPPORT COORDINATION(CAPITATION)FORDSWAI	1,076	\$ 1,876,317.38
	SUPPORTED EMPLOYMENT, PER 15-MINUTES	42	\$ 174,146.39
	SUPPORTED EMPLOYMENT-SL WAIVER	13	\$ 37,600.02
	SUPPORTED LIVING COACHING-SL WAIVER	2	\$ 6,362.25
	THERAPEAUTIC MASSAGE	29	\$ 70,978.57
	THERAPEAUTIC MASSAGE ASSESSMENT	17	\$ 2,192.38
	TRANSPORTATION (MILE)	1	\$ 1,775.10
TRANSPORTATION (ONE-WAY TRIP)	152	\$ 535,478.84	
TRANSPORTATION SERVICES-SL WAIVER	31	\$ 82,777.32	
Total	8,446	\$ 50,244,434.58	

Appendix 5
APD Waiver Service Cost by Primary Disability and By Service FY 07-08 [Autism Only]

Disability Group Autism	Service	Client	Cost
	ADULT DAY TRAINING	211	\$ 1,537,386.36
	ADULT DAY TRAINING-SL WAIVER	46	\$ 207,170.51
	ADULT DENTAL SERVICES	169	\$ 145,815.85
	BEHAVIORAL SERVICES - BACHELORS DEGREE	238	\$ 767,998.52
	BEHAVIORAL SERVICES ASSISTANT SERVICES	126	\$ 1,544,863.00
	BEHAVIORAL SERVICES-ASSISTANT SERVICES	29	\$ 92,128.86
	BEHAVIORAL SERVICES-BACHELORS DEGREE	187	\$ 551,555.24
	BEHAVIORAL SERVICES-DOCTORATE DEGREE	500	\$ 1,525,689.20
	BEHAVIORAL SERVICES-MASTERS DEGREE	139	\$ 326,122.73
	BEHAVIORAL SEVICES - MASTERS DEGREE	204	\$ 721,182.45
	BEHAVIORAL THERAPY ASSESSMENT	199	\$ 65,028.85
	CASE MANAGEMENT, PER MONTH	1,197	\$ 383,409.40
	COMPANION	195	\$ 1,127,059.86
	CONSUMABLE MEDICAL SUPPLIES	638	\$ 1,006,621.40
	DAY HAB, WAIVER; PERDIEM (BF)	9	\$ 33,794.01
	DAY HABILITATION, WAIVER; PER 15 MIN	1	\$ 4,440.00
	DIETITIAN SERVICES	17	\$ 9,145.53
	DURABLE MEDICAL EQUIPMENT, MISCELLANEOUS	14	\$ 8,828.70
	ENVIRONMENTAL MODIFICATIONS	6	\$ 28,641.21
	ENVIRONMENTAL MODIFICATIONS ASSESSMENT	7	\$ 5,339.92
	HOMEMAKER SERVICE	18	\$ 25,136.46
	IN-HOME SUPORT SERVICES-SL WAIVER	492	\$ 3,114,250.12
	IN-HOME SUPPORT	23	\$ 234,118.37
	IN-HOME SUPPORT SERVICES	49	\$ 1,486,522.56
	MEDICATION REVIEW	219	\$ 16,806.39
	MONTHLY BENEFIT AMOUNT-CDC-DD	188	\$ 6,112,128.02
	NON RESIDENTIAL SUPPORTS (QUARTER HOUR)	238	\$ 861,123.00
	NON-EMERGENCY TRANSPORTATION; PER DIEM	33	\$ 54,687.63
	OCCUPATIONAL THERAPY	13	\$ 38,076.72
	OT ASSESSMENT	6	\$ 900.79
	OTHER SPECIFIED CASE MANAGEMENT SERVICE	187	\$ 207,703.08
	P.T. ASSESSMENT	3	\$ 493.48
	PERSONAL CARE ASSISTANCE	384	\$ 5,991,708.68
	PHYSICAL THERAPY	7	\$ 30,743.96
	RES CARE,NOS, WAIVER; PER MONTH (BF)	93	\$ 2,132,017.42
	RES CARE,NOS, WAIVER; PER MONTH (STAND)	150	\$ 2,802,390.23
	RES HAB, WAIVER PER DIEM (IB)	80	\$ 4,862,079.42
	RESIDENTIAL HAB THERAPY (DAY)(STANDARD)	324	\$ 10,319,225.93
	RESIDENTIAL HABILITATION (QUARTER HOUR)	19	\$ 179,518.70
	RESIDENTIAL NURSING SERVICES	1	\$ 946.56
	RESPIRE CARE	372	\$ 1,152,593.09
	RESPIRE CARE (DAY)	163	\$ 243,115.33
	RESPIRE CARE (QUARTER HOUR)	406	\$ 1,685,940.44
	SELF-CARE/HOME MANAGEMENT TRAINING (EG,	56	\$ 343,388.85

SPECIALIZED MEDICAL EQUIPMENT AND SUPPLI	1	\$	27,995.20
SPECIALIZED MENTAL HEALTH SERVICES ASSES	10	\$	2,899.01
SPECIALIZED MENTAL HEALTH SERVICES THERA	24	\$	80,983.27
SPEECH THERAPY	32	\$	142,269.94
SPEECH THERAPY EVALUATION	14	\$	2,166.65
SUPPORT COORDINATION (CAPITATION)	991	\$	994,458.80
SUPPORT COORDINATION(CAPITATION)FORDSWAI	1,117	\$	1,464,817.69
SUPPORTED EMPLOYMENT, PER 15-MINUTES	50	\$	237,474.55
SUPPORTED EMPLOYMENT-SL WAIVER	12	\$	37,843.33
SUPPORTED LIVING COACHING-SL WAIVER	2	\$	14,514.72
THERAPEAUTIC MASSAGE	21	\$	41,828.81
THERAPEAUTIC MASSAGE ASSESSMENT	3	\$	389.00
TRANSPORTATION (MILE)	1	\$	843.48
TRANSPORTATION (ONE-WAY TRIP)	166	\$	670,821.33
TRANSPORTATION SERVICES-SL WAIVER	33	\$	90,302.33
Total	10,133	\$	55,797,444.94

**Appendix 6
Information on Funding Sources and Amounts of Early Steps**

Fiscal Year	# Children Enrolled	Funds/Child	% incr(dcr) enrollment	EI Program Budget Authority Appropriation	% incr(dcr) in budget	Historical % increase in budget from 94-95	Historical % increase in enrollment from 94-95
1994-95	20973	\$1,712		\$35,906,591			
1995-96	26158	\$1,257	25%	\$32,889,586	-8%	-9%	20%
1996-97	28424	\$1,150	9%	\$32,676,430	-1%	-10%	26%
1997-98	28290	\$1,249	0%	\$35,345,369	8%	-2%	26%
1998-99	28205	\$1,253	0%	\$35,345,369	0%	-2%	26%
1999-00	29053	\$1,251	3%	\$36,345,369	3%	1%	28%
2000-01	32382	\$1,122	11%	\$36,345,369	0%	1%	35%
2001-02	36272	\$1,052	12%	\$38,145,369	5%	6%	42%
2002-03	39333	\$958	8%	\$37,695,369	-1%	5%	47%
2003-04	40554	\$930	3%	\$37,695,369	0%	5%	48%
2004-05	38420	\$981	-5%	\$37,695,369	0%	5%	45%
2005-06	37853	\$1,051	-1%	\$39,787,541	6%	10%	45%
2006-07	37691	\$1,221	0%	\$46,024,475	16%	22%	44%
2007-08	39912	\$1,183	6%	\$47,212,235	3%	24%	47%
2008-09 Estimated	42041	\$1,162	5%	\$48,869,898	4%	27%	50%
Average		\$1,169	5.34%		2.27%		

Enrollment is Estimated for 2008-09
 After Authority Increase \$42,910,356.00

