Study of the Social and Financial Impacts of Mandatory Health Insurance Coverage for the Diagnosis and Treatment of Autism Spectrum Disorders

A Report to the
Governor
and the
Legislature of
the State of
Hawai‘i

Report No. 09-09
July 2009

THE AUDITOR
STATE OF HAWAI‘I

Office of the Auditor

The missions of the Office of the Auditor are assigned by the Hawai‘i State Constitution (Article VII, Section 10). The primary mission is to conduct post audits of the transactions, accounts, programs, and performance of public agencies. A supplemental mission is to conduct such other investigations and prepare such additional reports as may be directed by the Legislature.

Under its assigned missions, the office conducts the following types of examinations:

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2. Management audits, which are also referred to as performance audits, examine the effectiveness of programs or the efficiency of agencies or both. These audits are also called program audits, when they focus on whether programs are attaining the objectives and results expected of them, and operations audits, when they examine how well agencies are organized and managed and how efficiently they acquire and utilize resources.

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OVERVIEW

Study of the Social and Financial Impacts of Mandatory Health Insurance Coverage for the Diagnosis and Treatment of Autism Spectrum Disorders

Report No. 09-09, July 2009

Summary

In Senate Concurrent Resolution No. 196, Senate Draft 1, the 2008 Legislature requested the Auditor to conduct an impact assessment of mandating health insurance coverage for the diagnosis and treatment of autism spectrum disorders (ASD), as provided in Senate Bill 2532, Senate Draft 1 (SB 2532, SD 1). We assessed the social and financial effects of mandating health insurance for ASD for individuals under age 21 by applying the criteria set forth in Sections 23-51 and 23-52, Hawaiʻi Revised Statutes (HRS).

The federal *Individuals with Disabilities Education Act* (IDEA), defines autism as a "developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance." The IDEA assures a free and appropriate public education for children with diagnosed learning deficits attributable to developmental disorders, including autism. In Hawaiʻi, the Departments of Health (DOH) and Education (DOE) share responsibility for administering the IDEA through the DOH Early Intervention Services, DOE Special Education Program, and the DOE Private School Participation Project. Currently, there are 1,308 children with autism in public school, one of 20 enrolled in a private school, and an estimated 132 children from birth to age three in the DOH Early Intervention Services program, receiving treatments and utilizing health care services through federal- and state-funded programs under the IDEA.

The Hawaiʻi population of children between the ages of zero to 21 diagnosed with ASD is estimated to be 1,460. A majority of this population is receiving treatment and utilizing health care services available under the DOH and DOE programs. The level of public demand for treatment coincides with the population utilizing services available through the DOH and DOE and not the public at large. According to the four health care insurers who responded to our survey, the level of public demand for individual or group insurance coverage for ASD from its membership base is low. The level of interest of collective bargaining organizations in negotiating privately for coverage seems low based on a survey from the state Employer-Union Trust Fund.

Applied behavior analysis (ABA) is one of the more common treatments used not only for increasing useful behaviors but also for reducing behaviors that may be harmful or interfere with learning. While shown to improve social and educational outcomes in ASD children, it is not a covered family health benefit for insurance purposes in Hawaiʻi, but mandated under SB 2532, SD 1. Both the DOH and DOE report that ABA, in addition to other treatment and services, is available to

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children under their care. None of the four health care insurers surveyed offer coverage for ABA. Of the 11 states that have enacted legislation to require health insurance coverage for ASD, five mandate coverage for ABA.

SB 2532, SD 1, amends Chapters 431 and 432, HRS, to require insurance coverage for the diagnosis and treatment of ASD with a maximum benefit of $75,000 per year and unlimited visits to providers. The bill is problematic in defining the standard of care broadly so long as the care is prescribed, provided, or ordered by a licensed physician, psychologist, or registered nurse and determined to be "medically necessary." Under *medical necessity* as defined in Chapter 432E, HRS, health care insurers have the discretion to decide whether or not a treatment qualifies as a covered benefit within its health plans even though the treatment is deemed medically indicated. As a result, health care insurers may continue to deny coverage for educational interventions such as ABA, based on the statutory definition under Chapter 432E, HRS.

We found the social impacts appear minimal in Hawai‘i, since both educational interventions and health services, including ABA, are generally available through the DOE and DOH programs. In addition health care insurers provide partial coverage for the diagnosis of and treatment for symptoms related to ASD through statutory mandates and provisions in health care insurance contracts. However, an increase in demand for service providers and significant financial impacts to insurance carriers would result as families would have the option of increasing the frequency of educational interventions such as ABA and health services, if the bill is enacted. Moreover, costs could potentially and unintentionally pass to health care insurers and ultimately consumers for treatments and services. We estimated that mandated insurance coverage could initially cost health insurers over $100 million per year to reimburse policy holders. Without inflation, payments for mandated services could exceed $1 billion up to the age of 21.

Recommendations and Response

Enactment of Senate Bill No. 2532, Senate Draft 1, is not recommended. The DOE declined to comment on the provision of medical services and the Department of Commerce and Consumer Affairs opted not to respond. The DOH does not dispute our findings and conclusion, but opposes our recommendation based on its contention that the services available are not "comprehensive" and do not "meet all the needs of children with autism." We stand by our assessment based on criteria required under Section 23-52, HRS.

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A Report to the
Governor
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Submitted by

THE AUDITOR
STATE OF HAWAI‘I

Report No. 09-09
July 2009

Foreword

We assessed the social and financial impacts of mandating insurance coverage for the diagnosis and treatment of autism spectrum disorders in Hawai‘i, pursuant to Sections 23-51 and 23-52, Hawai‘i Revised Statutes (HRS). The 2008 Legislature requested this assessment through Senate Concurrent Resolution No. 196, Senate Draft 1.

We acknowledge and appreciate the cooperation of the Departments of Commerce and Consumer Affairs, Health, and Education and other organizations and individuals that we contacted during the course of this assessment.

Marion M. Higa
State Auditor

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Chapter 1

Introduction

This report responds to Senate Concurrent Resolution No. 196, Senate Draft 1, of the 2008 legislative session requesting the Auditor to assess the social and financial impacts of requiring health insurers to provide coverage for the diagnosis and treatment of autism spectrum disorders. We conducted the study pursuant to Sections 23-51 and 23-52, Hawai‘i Revised Statutes (HRS). Section 23-51, HRS, requires passage of a concurrent resolution requesting an impact assessment by the Auditor before any legislative measure mandating health insurance coverage for a specific health service, disease, or provider can be considered. The statute also requires that the concurrent resolution designate a specific bill that has been introduced in the Legislature and that includes, at a minimum, the following information:

- Specific health service, disease, or provider that would be covered;
- Extent of the coverage;
- Target groups that would be covered;
- Limits on utilization, if any; and
- Standards of care.

Background

Senate Bill No. 2532, Senate Draft 1

The resolution refers to Senate Bill No. 2532, Senate Draft 1 (SB 2532, SD 1), introduced in the regular session of the 2008 Legislature. The bill would amend Chapters 431 and 432, HRS, to require health insurers to cover the treatment of autism spectrum disorders for individuals under age 21 and to provide a maximum benefit of $75,000 per year with unlimited visits to autism service providers. This additional coverage does not limit benefits that would otherwise be available under a health insurance policy. Diagnosis is defined as “medically necessary assessments, evaluations, or tests conducted” to determine whether an individual has an autism spectrum disorder. Covered treatment includes care, determined to be medically necessary by a licensed physician, psychologist or registered nurse practitioner, as follows:

- Psychiatric care—direct or consultative services provided by a licensed psychiatrist;
- Psychological care—direct or consultative services provided by a licensed psychologist;
- Rehabilitative and habilitative care—professional, counseling, and guidance services and treatment programs, including applied behavior analysis necessary to develop, maintain and restore, to the maximum extent practicable, the functioning of an individual;
- Therapeutic care—provided by licensed speech pathologists, registered occupational therapists, or licensed physical therapists; and
- Pharmacy care—medications prescribed by a licensed physician or registered nurse practitioner and any health-related services to determine the need or effectiveness of the medications.

SB 2532, SD 1, defines *autism spectrum disorders* as "any of the pervasive developmental disorders . . . in the most recent edition of *Diagnostic and Statistical Manual of Mental Disorders* including autistic disorder, Asperger's disorder, pervasive developmental disorder not otherwise specified, Rett's disorder, and childhood disintegrative disorder."

Autism is a developmental disability

Autism is a developmental brain disorder. Although autism spectrum disorders (ASD) are neurodevelopmental conditions with strong genetic underpinnings, the why and how, or exact cause, and the genetic component involved, if any, are still unknown. Research indicates that intensive early intervention in optimal educational settings for at least two years during the preschool years result in improved outcomes in most young children with ASD. Thus, the earlier the diagnosis is made, the earlier interventions can begin. However, diagnosis cannot be done through medical testing. Typically, a diagnosis is made after an evaluation that might include clinical observations, parent interviews, developmental histories, psychological testing, and language assessments.

Autism spectrum disorders

According to a report by the National Institute of Mental Health (NIMH), most children with ASD seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact, and avoid eye contact.

Children with ASD are slower in learning to interpret what others are thinking and feeling. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering. To compound the problem, people with ASD have difficulty seeing things from another person's perspective. This inability leaves them unable to anticipate and understand other people's actions. The NIMH credits the Public Health Training Network webcast, *Autism Among Us*, in identifying a possible range of behaviors indicative of autism spectrum disorders, as shown in Exhibit 1.1. In addition to the social symptoms, communication difficulties and repetitive behaviors, other problems such as sensory experiences, mental retardation, seizures, fragile X syndrome, and tuberous sclerosis, may afflict ASD children.

Exhibit 1.1 Possible Indicators of Autism Spectrum Disorders

Language	Socialization	Behavior
Does not babble, point or make meaningful gestures by one year of age	Does not respond to name	Doesn't seem to know how to play with toys
Does not speak one word by 16 months	Poor eye contact	Excessively lines up toys or other objects
Does not combine two words by two years	Doesn't smile	Is attracted to one particular toy or object
Loses language or social skills	At times seems to be hearing impaired	Odd movement patterns

Source: Public Health Training Network Webcast, *Autism Among Us*

There is no single best treatment package for all ASD children. Along with early intervention, most individuals with ASD respond well to highly structured, specialized programs. Effective programs will teach early communication and social interaction skills. These interventions target specific deficits in learning, language, imitation, attention, motivation, compliance, and initiative of interaction. One of the more common treatments used is applied behavior analysis (ABA). ABA, which is specifically identified as a treatment in SB 2532, SD 1, under rehabilitative and habilitative care, includes developed techniques not only for increasing useful behaviors but also for reducing behaviors that may be harmful or that interfere with learning.

Many parents of children with ASD continually seek new treatments in an effort to do everything possible to help their children. Some of the interventions are based on the idea that autism may be caused by either food allergies or a vitamin or mineral deficiency. Medications are often prescribed to treat behavioral problems such as aggression, self-injurious behavior, and severe tantrums, but many such medications have not been officially approved by the Food and Drug Administration for the treatment of autism. The Kennedy Krieger Institute, which is dedicated to improving the lives of children and adolescents with pediatric developmental disabilities, has collected data indicating that families are using over 300 different autism treatments. In many cases, there is little or no scientific evidence to support their effectiveness.

Distinguishing features of each autism spectrum disorder

Autistic disorder is the most characteristic and best studied of the pervasive developmental disorders. The essential features are the presence of markedly abnormal or impaired development in social interaction, impaired communication that affects both verbal and nonverbal skills, and a markedly restricted repertoire of activity and interests.

Asperger's disorder, also termed Asperger's syndrome, like autistic disorder, is marked by severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests, and activities. The disturbance causes clinically significant impairment in social, occupational, or other areas of functioning.

Pervasive developmental disorder not otherwise specified has the essential features of autistic disorder, but the criteria for a specific pervasive developmental disorder are not met. For example, this category includes "atypical autism" because of the late age at onset or atypical symptoms.

Rett's disorder is the development of multiple specific deficits following a period of normal functioning after birth. Cases are rare and reported to occur only in females, with the age of onset between five to 30 months. It starts with the loss of previously acquired purposeful hand skills, followed by the development of hand movements that resemble hand-wringing. After the first few years, interest in the social environment diminishes, but social interaction may develop later. Problems develop in gait or trunk movements, and severe impairment occurs in expressive and receptive language development, with severe psychomotor retardation.

Childhood disintegrative disorder, like Rett's, is rare in occurrence and marked by the regression of normal development in age-appropriate verbal and nonverbal communication, social relationships, play and adaptive behavior. The onset of regression begins at age two but before ten years.

Autism Spectrum Disorders Benefits and Coverage Task Force

The Autism Spectrum Disorders Benefits and Coverage Task Force, established by the 2008 Legislature under Act 221, Session Laws of Hawai'i 2008, met between October and December 2008 to:

- Gather information about the problems faced by parents of children with autism;
- Discuss what can be done to ensure that benefits and services are provided through public and private resources for the special needs of children with autism, including providing services for applied behavioral analysis techniques;
- Research other states' health insurance plans that cover autism spectrum disorders; and
- Develop a plan of services that health insurers should be mandated to cover.

In December 2008, the task force issued its *Report to the Twenty-Fifth Legislature, State of Hawai'i, 2009, Pursuant to Act 221, H.B. 2727, H.D. 2, S.D. 1, C.D. 1, Hawai'i State Legislature, 2008 Relating to Health Insurance*. According to the report, there are an estimated 1,240 children and youth with ASD in Hawai'i. It notes, however, that the total number of ASD children and youth is actually higher, as an estimated 200 children in the multiple disabilities category have ASD.

The report included recommendations in the areas of health insurance coverage, medical home, community-based services, and family support. The task force recommends:

- Insurance coverage for all autism spectrum disorders;
- A lower maximum insurance benefit of $50,000, instead of $75,000 per year as proposed in SD 2532, SD1;
- Including respite care as a covered benefit; and
- Documenting services by a treatment plan.

Mandated coverage in other states

Eleven states (Arizona, Connecticut, Florida, Indiana, Kentucky, Louisiana, Maryland, Oregon, Pennsylvania, South Carolina, and Texas) have enacted legislation to require health insurance coverage for autism spectrum disorders. Compared with coverage provided in SB 2532, SD 1, insurance coverage for ASD varies from state to state as shown in Exhibits 1.2 and 1.3. There does not appear to be a consensus as to the amount of benefits or types of covered services or benefit amounts. Five states (Louisiana, Arizona, Pennsylvania, Texas, and Florida) specifically mandate insurance coverage for ABA. Louisiana's statutory definitions for autism spectrum disorders, ABA, habilitative and rehabilitative care, and covered treatments, are nearly identical to SB 2352, SD1. Coverage does not apply to employers with 50 or fewer employees, and benefits are limited to $36,000 per year. Arizona prohibits the exclusion of medically necessary behavioral therapy including ABA and limits benefits to $50,000 per year up to age nine, then reduces the annual amount to $25,000 when the child reaches the age of nine. Kentucky provides the lowest benefit amount—$500 per month or $6,000 per year.

Exhibit 1.2 Insurance Coverage – Hawai‘i and Other States

State/Treatment	Psychiatric Care	Psychological Care	Rehabilitative and Habilitative Care	Applied Behavior Analysis	Therapeutic Care (Speech, Occupational, and Physical	Pharmacy Care	Respite Care	Treatment for ASD
Hawai‘i (SB 2532, SD 1)	✓	✓	✓	✓	✓	✓		
Hawai‘i (Task Force)	✓	✓	✓	✓	✓	✓	✓	
Arizona (Enacted 2008)				✓				✓
Connecticut (Enacted 2008)					✓			
Florida (Enacted 2008)				✓	✓			
Indiana (Enacted 2001)								✓
Kentucky (Enacted 1998)					✓		✓	
Louisiana (Enacted 2008)	✓	✓	✓	✓	✓	✓		
Maryland (Enacted 2000)								✓
Oregon (Enacted 2007)					✓			✓
Pennsylvania (Enacted 2008	✓	✓	✓	✓	✓	✓		
South Carolina (Enacted 2007)								✓
Texas (Enacted 2007)				✓				✓

Source: Office of the Auditor

Exhibit 1.3 Insurance Coverage – Limitations

State/Treatment	Age	Maximum Annual Benefit	Lifetime Benefit	Prescribed by: Physician, Psychologist, or Registered Nurse Practitioner	Treatments are Medically Necessary	Treatment Providers Required to be Licensed	Treatment Plan Required	Individuals and Small Employers Excluded
Hawai‘i (SB 2532, SD 1)	< 21	$75,000		✓	✓	✓		
Hawai‘i (Task Force)	< 21	$50,000		✓	✓		✓	
Arizona (Enacted 2008)	16	$50,000, age 9 $25,000, age 16				✓		✓
Connecticut (Enacted 2008)		Not specified						
Florida (Enacted 2008)	< 18 or still in high school	$36,000	$200,000	✓	✓	✓	✓	✓
Indiana (Enacted 2001)		Not specified		✓			✓	
Kentucky (Enacted 1998)	2 – 21	$6,000						
Louisiana (Enacted 2008)	< 17	$36,000	$144,000	✓	(Diagnosis only)	✓		✓
Maryland (Enacted 2000)	< 19	Not specified						
Oregon (Enacted 2007)	< 18	Not specified			✓			
Pennsylvania (Enacted 2008	< 21	$36,000		✓	✓	✓	✓	✓
South Carolina (Enacted 2007)	< 16	$50,000		✓			✓	✓
Texas (Enacted 2007)	2 – 5	Not specified		✓		✓		

Source: Office of the Auditor

Objectives of the Study

1. Assess the social and financial effects of mandating health insurance coverage for the diagnosis and treatment of autism spectrum disorders in individuals under the age of 21.
2. Make recommendations as appropriate.

Scope and Methodology

Our study examined the social and financial impacts of mandating coverage of and treatment for autism spectrum disorders in Hawai‘i as proposed in SB 2532, SD 1. We reviewed relevant literature relating to other states’ mandatory health insurance requirements, national trends, and healthcare organizations’ research data. We reviewed recent research literature and reports on the social and financial aspects of insurance coverage for autism spectrum disorders, applicable federal and state statutes, proposed legislation and the task force report pursuant to Act 221, Session Laws of Hawai‘i 2008. We surveyed and obtained information from commercial insurers, mutual benefit societies, health maintenance organizations, employer groups, collective bargaining organizations, and autism advocacy groups. Four health insurers, one employer/union trust fund, and one autism advocate responded to our inquiry. We contacted or obtained information from national organizations, including the National Conference of State Legislatures, the Blue Cross and Blue Shield Association, the United States Surgeon General, and the American Academy of Pediatrics. To the extent that information was available, we reviewed and documented coverage for autism spectrum disorders adopted in other states.

To assess the potential social and financial effects of providing coverage for the diagnosis and treatment of autism spectrum disorders, we used the following criteria set forth in Section 23-52, HRS, as applicable:

Social impact

1. Extent to which treatment or services for autism spectrum disorders is generally utilized by a significant portion of Hawai‘i’s population.

2. Extent to which insurance coverage for autism spectrum disorders is generally available.

3. If coverage is not generally available, the extent to which the lack of coverage results in persons unable to obtain necessary health care treatment.

4. Extent to which the lack of coverage results in unreasonable financial hardship on persons needing treatment.

5. Level of public demand for treatment or services.

6. Level of public demand for individual or group insurance coverage for autism spectrum disorders.

7. Level of interest of collective bargaining organizations in negotiating privately for this coverage.

8. Impact of providing coverage for treatment or services on quality of care, practice patterns, or provider competition.

9. Impact of indirect costs upon the costs and benefits of coverage.

Financial impact

1. Extent to which proposed insurance coverage would increase or decrease the cost of the treatment or service.

2. Extent to which the proposed coverage might increase the use of treatment or service.

3. Extent to which the mandated treatment or service might serve as an alternative for more expensive treatment or service.

4. Extent to which insurance coverage of the health care service can be reasonably expected to increase or decrease insurance premiums and administrative expenses of policyholders.

5. Impact of this coverage on the total cost of health care.

We conducted this study between February 2009 and May 2009 in accordance with the Office of the Auditor's *Manual of Guides* and generally accepted government auditing standards. Those standards require that we plan and perform the study to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our assessment objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our objectives.

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Chapter 2

Assessment of Proposed Mandatory Health Insurance for Autism Spectrum Disorders

There is no single treatment package for children with autism spectrum disorders (ASD). In fact, we found that the vast majority of children diagnosed with autism in Hawaiʻi utilize a wide variety of treatments. Both educational interventions and health services are generally available through federal- and state-funded programs mandated under the federal *Individuals with Disabilities Education Act* and implemented by the state Departments of Health and Education.

In addition, we analyzed Senate Bill No. 2532, Senate Draft 1 (SB 2532, SD 1) of the 2008 legislative session and found that the bill is problematic in defining the standard of care. The bill would include educational interventions such as applied behavior analysis (ABA) that could potentially and unintentionally shift costs to health care insurers and ultimately consumers for treatments and services. Moreover, health insurers may continue to deny coverage for treatments when determining whether educational interventions such as ABA are a medical necessity as defined in the Patients' Bill of Rights and Responsibility Act.

Summary of Findings

1. Health insurance coverage for diagnosis and treatment of children with autism spectrum disorders is generally available through federal- and state-funded programs.

2. Senate Bill No. 2532, Senate Draft 1, is problematic in defining the standard of care.

Coverage Is Generally Available for Diagnosis and Treatment of Autism Spectrum Disorders

The federal government assists state and local efforts through the *Individuals with Disabilities Education Improvement Act* of 2004 (IDEA), which ensures free access to public education and improves educational results for children with disabilities. Infants and children diagnosed with autism fall within the definitions of "child with a disability" and "at-risk infant or toddler" under the act and are entitled to early intervention and related services and free special education. In Hawaiʻi, the Departments of Health (DOH) and Education (DOE) are responsible for administering the IDEA. The DOE also administers the Private School Participation Project that provides services to children with autism who are enrolled in private school. In addition to federal programs, the State enacted an additional health law that mandates insurance coverage for child health supervision services from birth to age five. For example, developmental assessments through regular wellness examinations are included as part of this mandate. Moreover, in cases where health insurance policies include spouses and children, the State's mandated health insurance coverage for child health supervision services exempts deductible provisions and copayment for immunizations for newborns through age five.

Federal law mandates and funds state programs

In 1975, Congress enacted the *Education for All Handicapped Children Act* to support states and local educational results for infants, toddlers, and children with disabilities and their families. Currently enacted as the *Individuals with Disabilities Education Improvement Act* of 2004, the act assures a free and appropriate public education for children with diagnosed learning deficits attributable to developmental disorders, including autism. Many needs of children with disabilities from age three to 21 are provided in IDEA Part B. Benefits for newborns through age three are provided in IDEA Part C.

The IDEA defines *autism* as:

> [A] developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

By law, the state DOE pays for all necessary services, such as speech therapist, occupational therapist, school psychologist, social worker, school nurse, or aide. For children with developmental disabilities enrolled in a special education program, the school is required to prepare and carry out a set of specific skills known as the child's Individualized Education Program, reviewed annually to assess the child's progress and make any changes to the services as necessary. For children with autism under age three, the DOH is the lead agency that provides early intervention services for toddlers and families.

The DOE reported a total of 20,441 children with disabilities under IDEA Part B in Hawai‘i's public school system. Of those children, 1,308 children (6.4 percent) are receiving special education and other services for autism. A private school on Oahu that specializes in educating children with learning disabilities, attention deficit disorder, and high-functioning autism currently has enrolled an estimated 20 students with ASD. These students are eligible to receive a different amount of services compared to public school students, as determined by DOE. In the 2006-2007 school year, Hawaii's prevalence rate of autism cases was one of 179, or 56 cases per 10,000 births as shown in Exhibit 2.1. Exhibit 2.1 also compares Hawaii's prevalence rate with those of other states.

The Hawai'i Department of Health administers early intervention services

The DOH's Early Intervention Section provides health services to support the development of infants and toddlers from birth to age three and increases the knowledge and ability of parents to support their child's development. The DOH estimates that 3,628 children are receiving early intervention services under IDEA, including 132 children (3.6 percent) with autism from birth to age three. In FY2007-08, 101 of the 132 children under age three were newly diagnosed. In 2008, DOH received approximately $2.1 million IDEA funds. This federal- and state-mandated program ensures that Hawai'i meets all the requirements and regulations of IDEA Part C, codified under Sections 321-351 through 321-357, Hawai'i Revised Statutes (HRS).

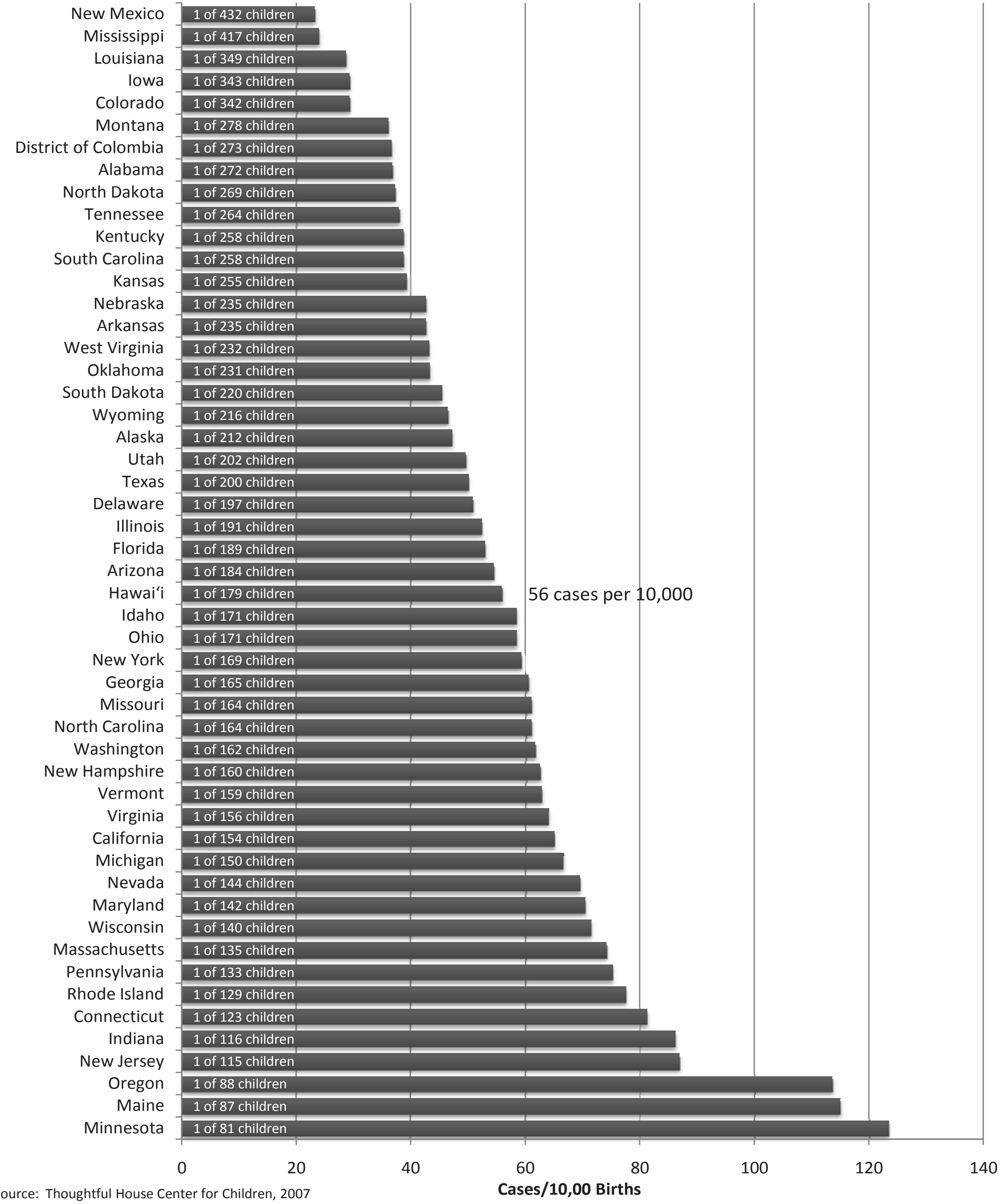
The DOH provides a wide range of early intervention services such as audiology; family support/education; specialized teaching, including applied behavior analysis; health, nursing, and nutrition services; and occupational, physical, and speech and language therapies, among others. In addition, a DOH care coordinator assists families with developing an Individualized Family Support Plan that identifies services and support to address the needs of the family and child and supporting transition at age three from DOH to the DOE's Special Education Preschool, Head Start, or other community preschools.

The Hawai'i Department of Education provides services through its special education program

Under IDEA Part B, which is administered by DOE, grants are available to states to assist them in providing special education and related services to children with disabilities between the ages of three through 21. Related services include transportation and a wide range of developmental, corrective, and other support services. For FY2007-08, the DOE received over $37 million from IDEA for special education. For FY 2009-10, it received an additional $368 million from the State's general fund.

Exhibit 2.1

Autism Prevalence, Public Schools State Rankings, 2006 - 2007 School Year



Source: Thoughtful House Center for Children, 2007

The DOE also uses federal funds to provide limited services to meet the needs of students with disabilities enrolled in private schools through its Private School Participation Project. Currently, one child enrolled in private school receives special education services under IDEA.

Health care insurers provide partial coverage for diagnosis and medical treatments

In addition to the educational and health services available through federally mandated programs, the diagnosis of and medical treatment for symptoms related to autism spectrum disorders are partially covered by health care insurers through statutory mandates and provisions in health care insurance contracts.

Two of the four health care insurers we surveyed offer partial health benefits for diagnosis such as well-baby check ups and medical treatments regardless of the diagnosis. For example, under Section 431:10A-115.5, HRS, family plans must include coverage for child health supervision services from the moment of birth through age five, including 12 pediatric visits. Covered services include history, physical examination, developmental assessment, anticipatory guidance, immunizations, and laboratory tests, in keeping with prevailing medical standards. Of the medical treatments listed and defined in SB 2532, SD 1, the two largest health care insurers provide coverage for four of the five treatments, such as psychiatric care, psychological care, therapeutic care, and pharmacy care. One of the larger health care insurers we surveyed requires that not only treatments be delivered by licensed clinicians but also be considered medically necessary as defined under Section 432E-1.4, HRS. Of the four health care insurers we surveyed, none offer coverage for ABA, which is identified as a specific health service under rehabilitative and habilitative care in SB 2532, SD 1. One explanation from one of the larger health care insurers is that ABA is already available through school or government programs; hence, it does not provide duplicative services.

Senate Bill No. 2532, Senate Draft 1, Is Problematic in Defining the Standard of Care

The standard of care under SB 2532, SD 1, is broadly defined to include educational interventions such as ABA so long as the care is prescribed, provided, or ordered by a licensed physician, psychologist, or registered nurse and determined to be “medically necessary.” Under the statutory definition of *medical necessity* in Chapter 432E, HRS, health care insurers play a significant role in determining whether treatment is covered within the health plans. While ABA research has been shown to improve social and educational outcomes, it is not a covered family health benefit for insurance purposes in Hawai‘i. Since SB 2532, SD 1, broadly defines the standard of care to be medically necessary, health care insurers may continue to deny coverage for educational interventions such as ABA, based on the statutory definition under Chapter 432E, HRS. Moreover, if SB 2532, SD 1, is enacted, costs could potentially and unintentionally pass to health care insurers and ultimately consumers for treatments and services.

Medical necessity for applied behavior analysis is discretionary

Medical necessity is defined in the Patients' Bill of Rights and Responsibility Act, codified in Chapter 432E, HRS. Health care insurers play a role in determining medical necessity. One of the criteria in determining medical necessity requires the treating physician or treating health care provider to recommend the health intervention. At the same time, the health plan's medical director or physician designee must also approve of the health intervention. Moreover, under Chapter 432E, health care insurers have the discretion to decide whether or not a treatment qualifies as a covered benefit within its health plans even though the treatment is deemed medically indicated. One of the larger health insurers responded to our survey by stating that it provides coverage for treatment that is delivered by licensed clinicians and is considered "medically necessary." However, coverage for ABA is excluded because it is either not provided by licensed clinicians or is not an evidenced-based treatment. The health care insurer also excludes coverage for ABA because it is a duplicative service already provided by the DOH and DOE in implementing the IDEA. The other health insurers we surveyed do not cover ABA for similar reasons.

Mandated coverage for autism spectrum disorders could lead to unintended shifts in costs to health care insurers and ultimately to consumers

If SB 2532, SD 1, were enacted, the costs for mandated coverage would pass from health care insurers to consumers. Using the December 2007 population counts provided by DOE and DOH, and multiplying that total by the maximum benefit amount of $75,000 per individual per year provided by SB 2532, SD 1, we estimate that health care insurers could be required to pay over $100 million per year for autism spectrum disorders. Again, based on the 2007 population with the ages of children with ASD factored in, the cost to health care insurers is estimated at over $1 billion. These estimates assume that there are no changes in the population and no changes in the annual maximum benefit amount.

SB 2532, SD 1, would provide parents of children with ASD the option to add educational interventions or health services that complement or alter the treatment plans (Individualized Family Support Plan and Individual Educational Plan) prepared as part of the DOH and DOE programs. For example, although the bill requires all treatments to be prescribed, provided, or ordered by a licensed physician, psychologist, or registered nurse practitioner, there is no provision for the coordination of care or services similar to what is provided by the DOH or DOE.

Social Impact

1. Extent to which treatment or services for autism spectrum disorders is generally utilized by a significant portion of Hawai‘i’s population

In Hawai‘i, the population of children between the ages of zero to 21 diagnosed with an autism spectrum disorder is estimated to be 1,460. The majority of this population of Hawai‘i children identified by the DOH and DOE, diagnosed with autism spectrum disorders is receiving treatment and utilizing health care services provided under the DOE Special Education Program and DOH Early Intervention Services. Neither the DOE nor the DOH maintain statistics on the entire population of children, diagnosed or undiagnosed, with ASD in Hawai‘i.

2. Extent to which insurance coverage for autism spectrum disorders is generally available

We surveyed six health insurance carriers. The four who responded confirmed that partial coverage for diagnosis and medical treatments identified under SB 2532, SD 1, to a large extent are generally available through family health plans. However, applied behavior analysis is not a covered health benefit. The four health insurance providers responded that diagnostic services, pharmacy, psychiatric, and psychological care are covered by health insurers. However, one of the health insurance providers responded that coverage includes only short-term therapies related to psychiatric and psychological care. For rehabilitative and habilitative care, one health insurance provider responded that therapy is available according to a member’s plan benefits if performed by a licensed clinician. Another health insurance provider responded that coverage is provided, however, long-term care is not covered. A third insurance provider (with approximately 27,000 members) responded it did not cover rehabilitative and habilitative therapies. The fourth health insurance provider (with approximately 33,000 members), did not respond to this question. Two of the largest insurance providers specifically do not provide coverage for ABA. One responded that ABA was a duplicative service that was provided by school or government programs. The other responded that ABA was still controversial.

For therapeutic care, one of the larger providers responded that any intervention could be classified as therapeutic care and felt that the category was very vague. Another large health insurance provider responded that therapeutic care is covered, while two smaller health insurance providers responded that therapeutic care was only covered for short-term therapies. One of the smaller health insurance providers added that short-term therapies are available for acute conditions, while coverage is not available if the conditions are related to developmental delay.

3. If coverage is not generally available, the extent to which the lack of coverage results in persons unable to obtain necessary health care treatment

As discussed previously, coverage of and treatment for autism spectrum disorders are generally available from federal and state programs and health or mental health insurance policies. We did not assess the adequacy of the health care coverage. Both the Departments of Health and Education report that applied behavior analysis, in addition to other treatment and services, is available to children under their care. Two of the larger insurance carriers report that they do not exclude the diagnosis of ASD from their covered benefits. However, the carrier with the largest membership reports that services that are not provided by licensed clinicians or are not evidenced-based treatments, such as ABA, are not covered benefits.

4. Extent to which the lack of coverage results in unreasonable financial hardship on persons needing treatment

This is unknown. The only information available about cost to families paying for ABA services is based on a national survey by Autism Speaks, an autism advocacy group. Information specific to Hawai‘i was not available.

5. Level of public demand for treatment or services

In Hawai‘i, the level of public demand coincides with the entire population utilizing the services as reported in item 1, and not the public at large. The entire population of children diagnosed with ASD is receving and utilizing treatment and services provided by the DOE and the DOH.

6. Level of public demand for individual or group insurance coverage for autism spectrum disorders

According to health insurers we surveyed, the level of public demand from its membership base is low. The health insurers representing approximately 987,420 members, reported that either they have not had requests to provide services beyond the medical care currently provided or that they receive few inquiries. In addition, one health insurer reports that very few members have submitted appeals for the denial of coverage related to the treatment of autism spectrum disorders.

7. Level of interest of collective bargaining organizations in negotiating privately for this coverage

The level of interest seems low based on a survey response from the state Employer-Union Trust Fund (EUTF) and the level of demand reported in item 6. The EUTF reported that it has not received requests from participants to cover autism spectrum disorders. Public collective bargaining units no longer negotiate separate health insurance programs. Private unions each negotiate separate and independent contracts which include health benefits with individual employers. Only the Hawai‘i State Teachers Association (HSTA) continues to negotiate a dollar amount with the State for health benefits. Responsibility for negotiating benefits with individual health care insurance carriers rests with the HSTA Voluntary Employees’ Beneficiary Association Trust. The HSTA did not respond to our survey.

8. Impact of providing coverage for treatment or services on quality of care, practice patterns, provider competition

The impact of providing coverage for treatment or services is unknown. Regarding practice patterns and provider competition, one of the smaller health care insurers responded that the impact of providing coverage would add more health services to complement treatment plans for educational interventions and health services already generally available. Another small health care insurer responded that there would be more providers drawn to provide services.

9. Impact of indirect costs upon the costs and benefits of coverage

One of the larger health insurers in the state reports that there would be indirect costs, including administrative expenses, updating claims processing systems, increased credentialing and licensure for potential providers, and educational outreach to providers. Another health insurer reports that indirect costs would include an increase in staffing and “very expensive” training for ABA. Currently, there is no ABA training program in Hawai‘i. More importantly, due to the increased cost, this health insurer expects subscribers would leave their plan and thus put the non-profit organization at risk financially. A third health insurer responded that with many new treatments available, a health plan would have to hire experts to evaluate the medical necessity of such treatments and spend resources to credential providers.

Financial Impact

1. **Extent to which proposed insurance coverage would increase or decrease healthcare costs**

   Two of the larger health insurers report that there would be significant increases in the cost of treatment for autism spectrum disorders in the areas of rehabilitative, habilitative, therapeutic, and pharmacy care, but minimal, if any, increases for diagnosis and psychiatric and psychological care. A smaller health insurer responded that there would be significant increases in diagnosis, rehabilitative, habilitative, and therapeutic care. The increase in pharmacy care would be moderate. Another smaller health insurer responded that rehabilitative, habilitative, and therapeutic care would significantly increase. As discussed earlier, the rehabilitative and habilitative care includes ABA identified in SB 2532, SD 1.

2. **Extent to which the proposed coverage might increase the use of treatment or services**

   Two of the larger health insurance providers responded that there would be significant increases in the use of treatments in the areas of rehabilitative, habilitative, and therapeutic care. One of the smaller health insurers responded that it “anticipate[s] that the use of all of the services would increase as some providers would see this as an opportunity for financial gain” and that “solid standards” would need to be developed by independent health care providers. Another smaller health insurer responded that there would be significant increases in rehabilitative, habilitative, and therapeutic care.

3. **Extent to which mandated treatment or services might serve as an alternative for more expensive treatment or services**

   The two larger health insurance carriers responded that mandated insurance coverage as provided in SB 2532, SD 1, would not serve as an alternative to more expensive care or services in any of the areas of diagnosis and psychiatric, psychological, rehabilitative, habilitative, therapeutic, and pharmacy care. A smaller health care insurer responded that arguably insurance companies may have more resources and buying power than individuals to question services being rendered. On the other hand, the same health insurer contends that the government has the greater power and ability to deliver services at the lowest cost and in the most effective manner. Contrary to the two larger health carriers, another smaller health insurer responded that the most expensive care regimen is mandated under the proposed legislation.

4. **Extent to which insurance coverage of the health care service would increase or decrease insurance premiums and administrative expenses for policyholder**s

   The extent to which insurance coverage for autism spectrum disorders might increase or decrease insurance premiums or administrative expenses varies depending on who is asked. One of the larger health insurers and a smaller health insurer responded that there would be significant increases because of rehabilitative, habilitative, and therapeutic care. Another large health insurer added that pharmacy care would also significantly increase. A small health insurer responded that diagnosis, rehabilitative, habilitative, and therapeutic care would increase significantly while pharmacy care would moderately increase. Costs would be passed on to the employer and consumer.

5. **Impact of insurance coverage for autism spectrum disorders on the total cost of health care**

   One of the large health insurers and a smaller health insurer responded that there would be significant increases in rehabilitative, habilitative, and therapeutic care. Another large health insurer responded that it believes that there would be significant increase in premiums. It was estimated that a similar mandate proposed in Virginia would raise rates by $1.90 per member per month. A smaller health insurer did not know what the impact would be but questioned if the child would be best served in the school or outside the school.

   Based upon population data prepared by the Departments of Health and Education, and using the $75,000 annual maximum benefit provided in SB 2532, SD 1, we estimated that mandated insurance coverage for autism spectrum disorders could initially cost health insurers over $100 million per year to reimburse policyholders. Without inflation, payments for mandated services for the current population of children with an autism spectrum disorder could exceed $1 billion up to the age of 21.

Conclusion

We conclude that the treatments identified in SB 2532, SD 1, including applied behavior analysis, are generally available through federally funded and state mandated educational and health programs despite the lack of standards of care. Hence, the social impacts appear minimal. However, by mandating health insurers to cover the broad range of treatments generally available, families would have the option of increasing the frequency of educational interventions and health services for children diagnosed with autism spectrum disorders, resulting in an increase in demand for service providers and significant financial impacts to insurance carriers. Those costs, estimated to be $1 billion, more than likely would be passed on to the employer and consumer.

Recommendation

Enactment of Senate Bill No. 2532, Senate Draft 1, is not recommended.

Responses of the Affected Agency

Comments on Agency Responses

We submitted a draft copy of this report to the Departments of Health, Education and Commerce and Consumer Affairs on July 27, 2009. A copy of the transmittal letter to the Department of Health (DOH) is included as Attachment 1. Similar letters were sent to the Department of Education (DOE) and Commerce and Consumer Affairs (DCCA). The DCCA opted not to respond. Comments received by the director of health and DOE superintendent are included as Attachments 2 and 3, respectively.

The DOE replied that it is committed to providing appropriate educationally related services to students eligible under the category of autism and support to parents in educating their children as required under the *Individuals with Disabilities Education Improvement Act of 2004* (IDEA). The department declined to comment on the provision of medical services since they are outside its purview.

The DOH provided extensive comments on the current status of autism research and evidence based treatment and urged that we "find more specific recommendations for private insurance treatments rather than to regard the current government systems to be comprehensive." The department reiterated its position, more consistent with its mission and support for the work of the Autism Spectrum Disorders Benefits and Coverage Task Force, that private insurance limited to a benefit of $50,000 annually is needed to "supplement" the educational interventions, therapies, and health services available through the DOE and DOH programs. Using the December 2007 population counts provided by DOE and DOH, and multiplying that total by the maximum benefit amount of $75,000 per individual per year provided by Senate Bill 2532, Senate Draft 1 (SB 2532, SD 1), we estimate that health care insurers could be required to pay over $100 million per year to reimburse policy holders. Without inflation, payments for mandated services could exceed $1 billion up to the age of 21, and more than likely would be passed on to the employer and consumer.

The department does not dispute our finding that health insurance coverage for diagnosis and treatment of children with autism is generally available through federal- and state-funded programs, but contends that these services are not "comprehensive" and do not "meet all the needs of all children with autism." However, the criteria we used to assess the potential social and financial effects of providing coverage set forth in Section 23-52, Hawai'i Revised Statutes, asks to what extent is treatment or services "generally utilized by a significant portion of Hawai'i's population;" and to what extent is insurance coverage "generally available." As we report, in addition to the educational and health services available through federally mandated programs, the diagnosis of and medical treatment for symptoms related to autism spectrum disorders (ASD) are partially covered by health care insurers through statutory mandates such as coverage for child health supervision services from birth through age five that include pediatric visits and developmental assessments. Partial coverage is also provided through provisions in health care insurance contracts. Among the four health insurance carriers who responded to our survey, all confirmed that partial coverage for diagnosis and medical treatments identified in SB 2532, SD 1, to a large extent are generally available through family health plans. These include diagnostic services, pharmacy, psychiatric and psychological care. Although two providers responded that some coverage for rehabilitative and habilitative care is available, none of the health insurers provide coverage for applied behavioral analysis (ABA).

The DOH did not dispute our finding that SB 2532, SD 1, is problematic in defining the standard of care, and agreed that "defining medical necessity for new treatments and determining the efficacy is problematic, but not an impossible barrier to overcome for insurance companies." Our analysis of the bill found that health insurers may continue to deny coverage for treatments when determining whether educational interventions such as ABA, are a medical necessity as defined in the Patients' Bill of Rights and Responsibility Act. The department stated that "[m]andating health insurance coverage does not preclude the responsibility of the insurer to determine medical necessity but is not a reason to deny coverage." Nevertheless, under the statutory definition of medical necessity, health care insurers have the discretion to decide whether or not a treatment qualifies as a covered benefit within its health plans even though the treatment is deemed medically indicated.

We reviewed and considered the concerns raised by the DOH, but found that statements made in the report, as noted by the department are not inaccurate. For example, it is more appropriate to identify ABA as an educational intervention rather than a therapy since we found that among the list of early intervention services provided by the DOH, ABA is included under specialized teaching. ABA is one of the more common treatments used not only for increasing useful behaviors but also for reducing behaviors that may be harmful or interfere with learning. While shown to improve social and educational outcomes in ASD children, it is not a covered family health benefit for insurance purposes in Hawai‘i, but mandated under SB 2532, SD 1. We therefore stand by our findings, conclusions and recommendation.

ATTACHMENT 1

STATE OF HAWAIʻI
OFFICE OF THE AUDITOR
465 S. King Street, Room 500
Honolulu, Hawaiʻi 96813-2917

MARION M. HIGA
State Auditor

(808) 587-0800
FAX: (808) 587-0830

July 10, 2009

COPY

The Honorable Chiyome Leinaala Fukino
Director
Department of Health
Kinau Hale
1250 Punchbowl Street
Honolulu, Hawaiʻi 96813

Dear Dr. Fukino:

Enclosed for your information are three copies, numbered 6 to 8, of our confidential draft report, *Study of the Social and Financial Impacts of Mandatory Health Insurance Coverage for Autism Spectrum Disorders*. We ask that you telephone us by Tuesday, July 14, 2009, on whether or not you intend to comment on our recommendations. If you wish your comments to be included in the report, please submit them no later than Friday, July 17, 2009.

The Department of Education, Department of Commerce and Consumer Affairs, Governor, and presiding officers of the two houses of the Legislature have also been provided copies of this confidential draft report.

Since this report is not in final form and changes may be made to it, access to the report should be restricted to those assisting you in preparing your response. Public release of the report will be made solely by our office and only after the report is published in its final form.

Sincerely,

Marion M Higa

Marion M. Higa
State Auditor

Enclosures

ATTACHMENT 2

LINDA LINGLE
GOVERNOR OF HAWAII

JAMES R. AIONA, JR.
LT. GOVERNOR

CHIYOME LEINAALA FUKINO, M.D.
DIRECTOR OF HEALTH

1959

STATE OF HAWAII
DEPARTMENT OF HEALTH
P.O. BOX 3378
HONOLULU, HAWAII 96801

in reply, please refer to:
File

July 16, 2009

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OFC. OF THE AUDITOR
STATE OF HAWAII

The Honorable Marion M. Higa
State Auditor
Office of the Auditor
465 S. King Street, Room 500
Honolulu, Hawaii 96813

Dear Ms. Higa:

Enclosed is the Department of Health's comments regarding the draft report, *Study of the Social and Financial Impacts of Mandatory Health Insurance Coverage for Autism Spectrum Disorder.*

We appreciate the opportunity to comment on the draft report.

Sincerely,

Chiyome Leinaala Fukino, M.D.
Director of Health

Enclosure

State Auditor Request for Comments from the Department of Health - Study of the Social and Financial Impacts of Mandatory Health Insurance Coverage for Autism Spectrum Disorders

I would like to thank you and your staff on the thorough study on the social and financial impacts of mandatory health insurance coverage for Autism Spectrum Disorders. However, some of the statements and conclusions in your study are not consistent with the Department of Health's mission or our position on the current status of autism research and evidence based treatment. It is the position of the Department that a limited benefit of $50,000 per year is needed since the mandates of educational and health services by the Department of Education (DOE) and Department of Health (DOH) are not comprehensive and do not supplant the medical necessity of treatment by physicians and other health care providers. While the amount of annual benefit may be debatable, the need to supplement existing public services with private insurance exists.

Following are the some areas of the report that give us concern:

1) Chapter One, Section on Autism Spectrum Disorders pages 2-4. We do support the conclusion on page four of the report that many families seek unproven new treatment interventions for food allergies, vitamin or mineral deficiencies. There are no single treatments for autism and it is an evolving area of research. However, the off label use of medications by physicians to treat aggressive behavior is common and the concern is not warranted. The Food and Drug Administration does not limit the clinical judgment of physicians and many of the current established methods of pharmacological treatments were first developed with such uses. I agree that defining medical necessity for new treatments and determining the efficacy is problematic, but not an impossible barrier to overcome for insurance companies. Mandating insurance coverage does not preclude the responsibility of the insurer to determine medical necessity but is not a reason to deny coverage. Autism coverage will improve outcomes for public assistance.

2) Chapter Two, pages 11-12. While educational and behavioral interventions are available through the Departments of Education and Health, these are not comprehensive services that meet all the needs of all children with autism. Under the Individuals with Disabilities Education Act of 2004 (IDEA), there are available many therapies and services to children. However, these services are not mandated beyond the scope of the educational need and environment. The identification of Applied Behavioral Analysis (ABA) as an educational intervention is inaccurate. It is a therapy and while it does facilitate education it cannot be dismissed from a health plan benefit package. On page twelve, third paragraph: the report states that the state DOE must pay for all necessary services and lists several. This is not an accurate statement. Many treatments for autism are beyond the federal mandate of IDEA and are not related to the educational needs of an individual.

3) While learning is an integral part of the behavioral treatment of autism the educational mandate does not meet all the needs of persons with autism. On page thirteen it is indicated that the DOH has primary treatment responsibility for children with autism prior to age three. This is not an accurate statement. The provision of both Developmental Disabilities Division (DDD) and Early Intervention (EI) services is limited by the eligibility requirements for state services and availability of state and federal funds. Funding is a critical issue for the foreseeable future. The mission of the Department of Health is not a comprehensive program of therapy nor is the Department mandated to treat all children within the spectrum. Private insurance coverage is one way of leveraging state dollars to better meet the needs of affected children. Medicaid Early and Periodic Screening Diagnosis and Treatment (EPSDT) also is responsible for assuring that services are provided to children with Autism Spectrum Disorders (ASD), I believe that it is not the sole responsibility of the DOH to meet the health and behavioral needs of children who have a diagnosis of "ASD." Private insurance is needed in addition to public programs.

4) Autism is a complex developmental disorder characterized by repetitive behavior and pervasive impairments in language and the ability to relate to others. It is a medical condition requiring treatment beyond educational mandates in federal and state laws. It is often grouped with related disorders, such as Asperger's syndrome and pervasive developmental disorder, all of which collectively are known as ASD. These related disorders are not all covered under the legislatively mandated services of the DOH. We agree with your conclusions on the flux of diagnostic and treatment criteria. The underlying causes of ASD are unclear and currently, there is no cure for these debilitating disorders with life-long impact. Many research projects are being actively pursued as the nation struggles to identify the etiology, best practices and treatments for a growing health issue. Prevalence of ASDs, a challenging behavioral disorder that affects 1 in 150 children has increased more than ten-fold over the past two decades, according to estimates from the Centers for Disease Control and Prevention (CDC). Prevalence rates from educational settings by state are not the best indicator of service needs or demands (page 14).

The DOH does have programs that are limited in scope for some children and adults within the autism spectrum. The Family Health Division provides intensive behavioral support services as part of EI Services (Part C-IDEA) for children zero to three years of age who have a diagnosis of ASD. After age three those services are provided to children through the DOE under the Individuals with Disabilities Education Act of 2004. The DDD does provide services and supports for some but not all persons within the autism spectrum due to the specific statutory eligibility in Hawaii Revised Statute 333F.

All children with ASD are mandated by federal educational law to receive services and supports to facilitate their education. These educational services however do not fully meet the growing demand for family training, respite care and therapy from families with children in the autism spectrum. The Department cannot per federal and state statutory requirement supplant services available or provided by the DOE, the Medicaid State Plan or private insurance.

The prevalence of the autism spectrum is projected by some researchers to increase to possibly 1 in 100 children in the future. Some of the growth over the past decades is attributable to increased awareness and identification of autism as well as a "diagnostic shift" from previously diagnosed mental health disorders. A specific autism diagnosis may be influenced by the potential future change in government or insurance benefits. The growth in service demands for autism in Hawaii has been significant to both the DOH and DOE in the past five years. While the prevalence rate may have underlying secondary gain influence, the true increase of persons impacted by autism over the past twenty years is without doubt.

Many states have passed parity legislation requiring private insurers to provide varying amounts of ABA therapy and other less proven interventions for children with challenging behaviors within the Autism Spectrum. The types of parity vary widely by state and in estimated cost to the insurance companies. Research in the efficacy for ABA therapy has demonstrated over many years the benefits for children especially if provided before age ten. Some states utilize a system of family training to reduce the amount of paid ABA therapy. Family therapy will be an added benefit of private insurance coverage and reduce the dependence on long term care for those families that become overwhelmed by behavioral crises.

The fiscal burden to the state Medicaid system and the state educational systems will continue to grow without the participation of insurers in coverage for these and other therapies. With the adoption of similar legislation in Hawaii, the state may reduce the taxpayer born cost of care, but the overall cost to every citizen with health insurance will increase. The difficulty for an insurance company is the actuarial determination of a cost without adequate basis to estimate demand or the amount of services to achieve optimal efficacy. The old adage, "If you build it, they will come" certainly can be expected to apply to this legislative initiative.

In March 2009, the Interagency Autism Coordinating Committee (IACC), a federal government advisory panel, released its first blueprint for autism research. The IACC Strategic Plan for Autism Spectrum Disorder Research will advise federal agencies and Congress on needs and opportunities for research investigating autism. The plan will define the established knowledge about autism and what will be needed to help affected families and communities in the future.

This study by the state auditor's office can follow this blueprint and be beneficial to determine appropriate levels of treatment versus the expectation of family training for unpaid reinforcement and thus true actuarial costs for insurers. For instance, the number of hours per week that children receive for ABA widely varies based upon the practitioner preference and the needs and training of the family. Many in the field believe that less than twenty hours are optimal while others advocate for more than 40 hours. This cost is very high and controversial. The evidence based research conclusions are lacking, so a conservative approach is warranted.

I encourage you to find more specific recommendations for private insurance treatments rather than to regard the current government systems to be comprehensive. The resulting IACC plan reflects a diversity of views and the breadth of research that will be required to address the needs of people with ASD and their families. The State should advocate for a limited approach to parity that is based upon an incremental approach to insurer rates. This has been followed in other states with a minimal increase in costs per insured person. The explosion of autism cannot be met by the current available systems of services in the DOH and DOE.

The Department of Health participated in an autism taskforce and supported the recommendations to move forward prudently and provide services through private insurance. This will reduce the costs to Medicaid programs and serve those many families that do not meet the Medicaid income asset eligibility. The financial burden for many families to provide ABA can be extreme and some families seek second mortgages on their homes. The risk for families to be influenced to provide far more than is clinically necessary exists. Having parity provides guidance to all stakeholders and should be considered as a benefit to any insurance plan. To not insure for autism is the equivalent of not covering other recognized diseases. The question is how much is enough? That must be answered incrementally until the research can support outcome conclusions.

The areas that still need much research in the field of autism are: diagnosis, the biology of autism, risk factors, treatments and interventions, services and supports and issues faced by adolescents, adults and seniors with autism and their families. Further areas of research include: new diagnostic tools; complete longitudinal and comprehensive studies of the biological, clinical and developmental profiles of children; identify genetic and environmental risk factors; conduct clinical trials of interventions; and assess the efficacy and cost-effectiveness of evidence-based services for people with ASD of all ages in community settings.

Thank you for the opportunity to comment on this study. If you or your staff would like to discuss our concerns with the Department please do not hesitate to contact me.

ATTACHMENT 3

LINDA LINGLE
GOVERNOR

PATRICIA HAMAMOTO
SUPERINTENDENT

1959

STATE OF HAWAIʻI
DEPARTMENT OF EDUCATION
P.O. BOX 2360
HONOLULU, HAWAIʻI 96804

OFFICE OF THE SUPERINTENDENT

July 17, 2009

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OFC. OF THE AUDITOR
STATE OF HAWAII

Ms. Marion M. Higa, State Auditor
State of Hawaii
Office of the Auditor
465 South King Street, Room 500
Honolulu, Hawaii 96813-2917

Dear Ms. Higa:

Thank you for your letter dated July 10, 2009 regarding the audit report, *Study of the Social and Financial Impacts of Mandatory Health Insurance Coverage for Autism Spectrum Disorders*. The Department of Education (Department) appreciates the opportunity to comment on the audit report.

Senate Bill No. 2532, Senate Draft 1 (SB 2532, SD 1) will require health care insurers to provide coverage for diagnosis and medical treatments for individuals with Autism Spectrum Disorders. As noted in the audit report, the Department provides educationally related services to its students eligible under the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), under the eligibility category of autism. As such, the Department feels that commenting on the provision of medical services is outside of its purview.

The Department is committed to providing appropriate educational services to students with autism, and supports to parents in the education of their children, as required by IDEA.

If you have any questions, please contact Ms. Marilyn Jakeway, Educational Specialist, Special Education Section, at (808) 733-9131.

Very truly yours,

Patricia Hamamoto

Patricia Hamamoto
Superintendent

PH:jn

c: Ms. Denise Yoshida, Internal Audit
Office of Curriculum, Instruction and Student Support

AN AFFIRMATIVE ACTION AND EQUAL OPPORTUNITY EMPLOYER