Applied Behavior Analysis Benefit For NC State Health Plan

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Vice President
State Government Affairs Autism Speaks

North Carolina State Health Plan
For Teachers and State Employees
A Division of the Department of State Treasurer

November 21, 2013
What is Autism?

Complex neurobiological disorder

Communication

Social

Behavior

Medical condition, brought on through no fault of family
There are 5 Pervasive Developmental Disorders (PDDs).

Within the 5 PDDs, there are 3 Autism Spectrum Disorders (ASDs), shown in purple below.

- Childhood Disintegrative Disorder
- Rett’s Syndrome
- Autistic Disorder (classic autism) a/k/a “autism”
  - 1/3 of all ASDs
- Asperger’s Syndrome
  - Less than 1/6 of all ASDs
- Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)
  - Approx. ½ of all ASDs
Autism is Treatable

- Although there is no known cure for autism, it can be treated so that the symptoms are not disabling
  - A non-verbal child can gain the ability to communicate
  - A non-social child can gain interaction skills
- With treatment, children with autism are not cured but can overcome the disabling aspects of the condition.
Treatment

• Early diagnosis and treatment are critical to a positive outcome for individuals with an autism spectrum disorder (ASD)

• Treatment is prescribed by a licensed physician or licensed psychologist:
  - **Applied Behavior Analysis (ABA) Therapy**
  - Speech, Occupational and Physical Therapy
  - Psychological, Psychiatric, and Pharmaceutical Care
Applied Behavior Analysis (ABA)

- ABA is the most commonly prescribed evidence-based treatment for ASD
- Decades of research demonstrate the effectiveness of ABA therapy for autism
- Endorsed by leading national health agencies; pediatric, neurologic and psychological organizations
- Many insurers still deny coverage for ABA based on the assertion that ABA therapy is “experimental.” This assertion is simply not supported by science
United States Surgeon General (1999)

“Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”

Centers for Medicare and Medicaid (2011)

“...controlled trials have shown both the efficacy of programs based in the principles of ABA and that certain individual characteristics (age, IQ, and functional impairments) are associated with positive outcomes.”

National Institute of Mental Health (2011)

“One type of a widely accepted treatment is applied behavior analysis (ABA). The goals of ABA are to shape and reinforce new behaviors, such as learning to speak and play, and reduce undesirable ones.”
ABA is the Standard of Care

Centers for Disease Control and Prevention (2012)

“A notable treatment approach for people with an ASD is called applied behavior analysis (ABA). ABA has become widely accepted among health care professionals...”

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (2012)

“Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement... Therapists use highly structured and intensive skill-oriented training sessions to help children develop social and language skills, such as Applied Behavioral Analysis”
ABA is the Standard of Care

AMERICAN PSYCHOLOGICAL ASSOCIATION (2012)

“The field of applied behavior analysis has grown substantially in the past decade, enabling more children with autism and their families to obtain needed services. This growth appears to be related to an increase in the number of children diagnosed with an autism spectrum disorder and to the recognition of the effectiveness of behavior analytic services.”

The U.S. Office of Personnel Management (2012)

“The OPM Benefit Review Panel recently evaluated the status of Applied Behavior Analysis (ABA) for children with autism. Previously, ABA was considered to be an educational intervention and not covered under the FEHB Program. The Panel concluded that there is now sufficient evidence to categorize ABA as medical therapy. Accordingly, plans may propose benefit packages which include ABA.”
An example of a demonstrated, effective treatment for ASD is Applied Behavior Analysis, or ABA. ABA uses behavioral health principles to increase and maintain positive adaptive behavior and reduce negative behaviors or narrow the conditions under which they occur. ABA can teach new skills, and generalize them to new environments or situations. ABA focuses on the measurement and objective evaluation of observed behavior in the home, school, and community.”
Military insurance (TriCare) covers autism and specifically includes a benefit for Applied Behavior Analysis therapy.
Efficacy of ABA Therapy

Outcome of 1987 UCLA Lovaas Study

ABA Group:
- 47% Achieved Normal IQ
- 53% Did Not Achieve Normal IQ

Other Intervention (Control) Group:
- 2% Achieved Normal IQ
- 98% Did Not Achieve Normal IQ
Outcome of 1987 UCLA Study

Educational Placements for Group That Received ABA

- **47%** = Mainstreamed with No Support
- **42%** = Low-Intensity Special Education Placement (for language delay)
- **11%** = High-Intensity Special Education Placement (for autism or intellectual disability)
Cost Savings - *long term*

- **Without appropriate treatment**, the lifetime cost to the state has been estimated to be **$3.2 million per child** with ASD (Ganz, 2007)
  - special education
  - adult services
  - decreased productivity

- Estimated lifetime cost **savings** of providing appropriate treatment are **$1 million per child** (Jacobsen et al, 1998)
State Response

• Faced with these realities, states are moving to mandate insurance coverage for autism treatment.

• Indiana passed the first meaningful bill in 2001, the same year the Attorney General in Minnesota settled litigation with that state’s major insurer (BCBS) to require coverage for autism, including coverage of Applied Behavior Analysis therapy.
States with Autism Insurance Reform

2001 - Indiana
2007 - South Carolina
2007 - Texas
2008 - Arizona
2008 - Florida
2008 - Louisiana
2008 - Pennsylvania
2008 - Illinois

2009 - Colorado
2009 - Nevada
2009 - Connecticut
2009 - Wisconsin
2009 - Montana
2009 - New Jersey
2009 - New Mexico

2010 - Maine
2010 - Kentucky
2010 - Kansas
2010 - Iowa
2010 - Vermont
2010 - Missouri
2010 - New Hampshire
2010 - Massachusetts

2011 - Arkansas
2011 - West Virginia
2011 - Virginia
2011 - Rhode Island
2011 - California
2011 - New York

2012 - Michigan
2012 - Alaska
2012 – Delaware
2013 – Minnesota
2013 - Oregon
## State Autism Insurance Reform

<table>
<thead>
<tr>
<th>State</th>
<th>Year Enacted</th>
<th>State Population</th>
<th>Annual Dollar Cap</th>
<th>Age Cap</th>
<th>State E’ees?</th>
<th>Small Group?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indiana</td>
<td>2001</td>
<td>6,484,000</td>
<td>None</td>
<td>None</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>South Carolina</td>
<td>2007</td>
<td>4,625,000</td>
<td>$50K</td>
<td>16</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>Texas</td>
<td>2007</td>
<td>25,146,000</td>
<td>None thru 10; $36K after</td>
<td>None</td>
<td>Some</td>
<td>Yes</td>
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<tr>
<td>Arizona</td>
<td>2008</td>
<td>6,392,000</td>
<td>$50K: 0-8, $25K: 9-16</td>
<td>16/17</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>Louisiana</td>
<td>2008</td>
<td>4,533,000</td>
<td>$36K</td>
<td>&lt;21</td>
<td>Yes</td>
<td>Yes*</td>
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<tr>
<td>Florida</td>
<td>2008</td>
<td>18,801,000</td>
<td>$36K ($200K lifetime)</td>
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<td>Yes</td>
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<td>12,702,000</td>
<td>$36K</td>
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<td>$36K ($200K lifetime)</td>
<td>19/22</td>
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<td>Yes</td>
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<td>2009</td>
<td>989,000</td>
<td>$50K: 0-8, $20K: 9-16</td>
<td>18</td>
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<td>Yes</td>
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<td>Nevada</td>
<td>2009</td>
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<td>$36K</td>
<td>18/22</td>
<td>Yes</td>
<td>Yes</td>
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<td>Colorado</td>
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<td>5,029,000</td>
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<td>Connecticut*</td>
<td>2009</td>
<td>3,574,000</td>
<td>$50K: 0-8, $35K: 9-12; $25K: 13-14</td>
<td>&lt;15</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>Wisconsin</td>
<td>2009</td>
<td>5,687,000</td>
<td>$50K for 4 yrs, $25K after</td>
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<td>Yes</td>
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<td>New Jersey*</td>
<td>2009</td>
<td>8,792,000</td>
<td>$36K</td>
<td>21</td>
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<td>Yes</td>
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<tr>
<td>State</td>
<td>Year Enacted</td>
<td>State Population¹</td>
<td>Annual Dollar Cap</td>
<td>Age Cap</td>
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<td>Small Group?</td>
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<tr>
<td>Maine</td>
<td>2010</td>
<td>1,328,000</td>
<td>$36K</td>
<td>&lt;6</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Kentucky</td>
<td>2010</td>
<td>4,339,000</td>
<td>$50K: 0-7, $1000/mo: 7-21</td>
<td>1-21</td>
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<td>Yes</td>
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<td>Kansas</td>
<td>2010</td>
<td>2,853,000</td>
<td>$36K: 0-7, $27K: 8-19</td>
<td>&lt;19</td>
<td>Yes only</td>
<td>No</td>
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<td>Iowa</td>
<td>2010</td>
<td>3,046,000</td>
<td>$36K</td>
<td>&lt;21</td>
<td>Yes only</td>
<td>No</td>
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<tr>
<td>Vermont</td>
<td>2010</td>
<td>626,000</td>
<td>None</td>
<td>21</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Missouri</td>
<td>2010</td>
<td>5,989,000</td>
<td>$40K</td>
<td>19</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>New Hampshire</td>
<td>2010</td>
<td>1,316,000</td>
<td>$36K: 0-12, $27K: 13-21</td>
<td>21</td>
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<td>Yes</td>
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<tr>
<td>Massachusetts</td>
<td>2010</td>
<td>6,548,000</td>
<td>None</td>
<td>None</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Arkansas</td>
<td>2011</td>
<td>2,916,000</td>
<td>$50K</td>
<td>&lt;18</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>West Virginia</td>
<td>2011</td>
<td>1,853,000</td>
<td>$30K for 3 yrs; $24K up to 18</td>
<td>3-18</td>
<td>Yes</td>
<td>Yes*</td>
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<td>Virginia</td>
<td>2011</td>
<td>8,001,000</td>
<td>$35K</td>
<td>2-6</td>
<td>Yes</td>
<td>No</td>
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<td>Rhode Island</td>
<td>2011</td>
<td>1,053,000</td>
<td>$32K</td>
<td>15</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>New York</td>
<td>2011</td>
<td>19,378,000</td>
<td>None</td>
<td>None</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>California</td>
<td>2011</td>
<td>37,254,000</td>
<td>None</td>
<td>None</td>
<td>No</td>
<td>Yes</td>
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</tbody>
</table>
### State Autism Insurance Reform

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<tr>
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<th>Age Cap</th>
<th>State E’ees?</th>
<th>Small Group?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michigan</td>
<td>2012</td>
<td>98,836,640</td>
<td>$50K if &lt;7, $40K if 7-12, $30K if 13-18</td>
<td>18</td>
<td>Maybe</td>
<td>Yes</td>
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<tr>
<td>Alaska</td>
<td>2012</td>
<td>722,718</td>
<td>None</td>
<td>21</td>
<td>Yes</td>
<td>&gt;20</td>
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<tr>
<td>Delaware</td>
<td>2012</td>
<td>907,135</td>
<td>$36,000</td>
<td>21</td>
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<td>Yes</td>
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<tr>
<td>Minnesota</td>
<td>2013</td>
<td>5,303,925</td>
<td>None</td>
<td>18</td>
<td>Yes</td>
<td>No*</td>
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<tr>
<td>Oregon</td>
<td>2013</td>
<td>3,899,000</td>
<td>None (but ABA 25 hours per week)</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>D.C.</td>
<td>2013</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Plus Ohio due to executive action
What is the cost of autism insurance reform?
Actual Autism Related Claims Data
Missouri

- Implemented Jan 2011
- Terms
  - $40,000/yr (cap only applies to ABA)*
  - until age 18*

- Total claims paid = $6,550,602
- Total covered lives = 1,375,476
- Unique claimants = 2,508
- PMPM cost = .38 ¢

* Caps can be exceeded if deemed medically necessary

Cost of ABA

- Average monthly cost of ABA per individual with ASD = $101
- $0.17 PMPM
- 0.07% of total claims

“The costs associated with the autism and ABA coverage mandate has thus far been minimal, even as the mandate has led to dramatically expanded coverage and the delivery of medically beneficial services.”
Effect on Premiums

- Claims incurred for treatment of ASD with ABA represent 0.07% of total claims
- “While claims costs are expected to grow somewhat in the future, it seems very unlikely that costs for autism treatment will have an appreciable impact on insurance premiums.”
### Average Second Year Cost of Autism Insurance Reform

<table>
<thead>
<tr>
<th>State</th>
<th>Year of Coverage</th>
<th>Number of Covered Lives</th>
<th>Total Claims Paid</th>
<th>PMPM Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Carolina</td>
<td>2</td>
<td>397,757</td>
<td>$2,042,394</td>
<td>$0.43</td>
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<tr>
<td>Illinois</td>
<td>2</td>
<td>170,790</td>
<td>$197,290</td>
<td>$0.10</td>
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<tr>
<td>Louisiana</td>
<td>2</td>
<td>149,477</td>
<td>$722,828</td>
<td>$0.40</td>
</tr>
<tr>
<td>Florida</td>
<td>2</td>
<td>386,203</td>
<td>$1,748,849</td>
<td>$0.38</td>
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<tr>
<td>Arizona</td>
<td>2</td>
<td>130,000</td>
<td>$388,662</td>
<td>$0.25</td>
</tr>
<tr>
<td>Missouri</td>
<td>2</td>
<td>1,429,153</td>
<td>$6,555,602</td>
<td>$0.38</td>
</tr>
<tr>
<td>Kansas</td>
<td>2</td>
<td>99,465</td>
<td>$309,216</td>
<td>$0.26</td>
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</table>

**Average second year cost** $0.31

**References:** Data collected by Autism Speaks from State agencies responsible for administering State Employee Health Benefits Programs (2011); Missouri Department of Insurance, Financial Institutions and Professional Registration (2012); and the Kansas Department of Health and Environment (2012)
St. Charles Medical Center

- ABA - unlimited coverage through age 9
- ST, OT, PT - unlimited coverage

“The total cost of this benefit to our health plan? **Four cents** per member per month. Less than fifty cents per member per year to cover 7,000 people. **The benefit to our overall population health is immeasurable.**”

- Jay Henry, CEO, St. Charles Medical Center (Bend, OR)
Why Employers Should Implement an Autism Benefit

- Improves employee productivity
- Removes barriers to recruiting the best possible talent
- Improves company public image in the community
- Fiscally responsible
- Life-changing for the affected child and their family
Without an autism benefit

- Because ABA therapy must be administered intensively (sometimes 40 hours per week), it is quite expensive.

- Parents are forced to pay out-of-pocket to provide their children ABA therapy, which typically lasts 3-4 years.

- Often financially devastating to families - *most affected children go without or receive only a fraction of prescribed treatment*

- These children end up in costly special education programs and often become wards of the state.
### Mercer National Survey of Employer-Sponsored Health Plans 2011

#### Autism Coverage

<table>
<thead>
<tr>
<th></th>
<th>ST, OT, PT</th>
<th>Intensive Behavioral Therapies</th>
<th>Autism is not Covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large Employers</td>
<td>62%</td>
<td>31%</td>
<td>22%</td>
</tr>
<tr>
<td><strong>BY REGION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>West</td>
<td>59%</td>
<td>24%</td>
<td>25%</td>
</tr>
<tr>
<td>Midwest</td>
<td>64%</td>
<td>30%</td>
<td>16%</td>
</tr>
<tr>
<td>Northeast</td>
<td>62%</td>
<td>32%</td>
<td>26%</td>
</tr>
<tr>
<td>South</td>
<td><strong>62%</strong></td>
<td><strong>34%</strong></td>
<td><strong>23%</strong></td>
</tr>
<tr>
<td><strong>BY INDUSTRY</strong></td>
<td></td>
<td></td>
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<tr>
<td>Manufacturing</td>
<td>54%</td>
<td>26%</td>
<td>27%</td>
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<tr>
<td>Wholesale/Retail</td>
<td>77%</td>
<td>22%</td>
<td>6%</td>
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<tr>
<td>Services</td>
<td>70%</td>
<td>33%</td>
<td>19%</td>
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<tr>
<td>Transport/Communication/Utility</td>
<td>63%</td>
<td>27%</td>
<td>28%</td>
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<tr>
<td>Health Care</td>
<td>61%</td>
<td>40%</td>
<td>29%</td>
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<tr>
<td>Financial Services</td>
<td>55%</td>
<td>26%</td>
<td>24%</td>
</tr>
<tr>
<td>Government</td>
<td><strong>65%</strong></td>
<td><strong>34%</strong></td>
<td><strong>17%</strong></td>
</tr>
</tbody>
</table>
Examples of Self-Funded Plans that Provide Coverage for Autism Treatment

- Microsoft
- Home Depot
- Arnold & Porter
- Cerner
- Cisco
- Eli Lilly
- Ohio State University
- Time Warner
- Blackbaud
- Lahey Clinic
- Partners Healthcare
- Deloitte
- White Castle
- Wells Fargo
- salesforce.com

- Yahoo
- University of Minnesota
- Progressive Group
- Intel
- DTE Energy
- Iron Mountain
- State Street Financial
- Children’s Mercy
- Capitol One
- Lexington Medical Center
- Sisters of Mercy Health Systems
- Symantec
- Princeton University
- Genentech
- and many more . . .
Litigation over ABA Coverage


“Based upon a thorough examination of the record, this court concludes that the weight of the evidence demonstrates that ABA therapy is firmly supported by decades of research and application and is a well-established treatment modality of autism and other PDDs. It is not an experimental or investigational procedure.”
Litigation over ABA Coverage

California Department of Insurance

“Insurance Commissioner Dave Jones announced today that he has reached favorable settlement agreements with two major health insurers, Health Net and Cigna, to guarantee coverage of behavioral therapy for autism, and to provide it to all insureds whenever medically necessary.”
“A federal judge in Philadelphia entered an order today granting class action status to a case filed by families against Cigna Insurance for allegedly denying claims for Applied Behavior Therapy (ABA), a technique that involves using modern behavioral learning theory to modify overt behaviors to treat autism. The ruling means the case will now be brought on behalf of all persons who filed a claim with CIGNA for ABA therapy for a child having autism spectrum disorder . . .

The Court … explained that class action status … was appropriate given CIGNA's national policy of denying ABA therapy on the ground that it is ‘experimental.’”
Cost Savings - short term

Children who achieve a higher level of functioning:

• have lower overall health care costs
• do better in school
• need less assistance from their families

Improved employee productivity due to:

• improved mental health
• decreased absenteeism
• decreased work limitations
• “There are powerful economic and social arguments for providing this benefit. We know that if families have coverage for their children they will be better employees.”

- Ron Ashworth, Board Chair, Sisters of Mercy Health Systems
Employee Retention

“It meant so much to them that Microsoft cared about their employees, cared about their children, cared about their welfare, that Microsoft, as a company, was willing to do this. It made them feel really proud of their company. That’s not the kind of company you leave.” - Eric Brechner, Microsoft employee

(In an interview summarizing results of an employee survey relating to Microsoft’s health benefits plan)
What Should an Autism Benefit Look Like?

1. Coverage should include
   - Applied Behavior Analysis (ABA) Therapy
   - Speech Therapy, Occupational Therapy, and Physical Therapy
   - Psychological, Psychiatric, and Pharmaceutical Care
   - Diagnosis and Assessments
   - No visit limits (other than restrictions prescribed by treating physician)
What Should an Autism Benefit Look Like?

2. No denials on the basis that treatment is
   - Habilitative in nature
   - Educational in nature
   - Experimental in nature

3. Applied Behavior Analysis coverage, treatment must be provided or supervised by
   - a behavior analyst who is certified by the Behavior Analyst Certification Board®, or
   - a licensed psychologist so long as the services performed are commensurate with the psychologist’s formal university training and supervised experience
• 2013 Fortune 100 Best Companies to Work For #42
• 2007 National Business Group on Health
  o Behavioral Health Award Winner for their autism benefit
    ➢ 2007 - Added autism benefit that included coverage for Applied Behavior Analysis ($30,000/year; $90,000/lifetime)
    ➢ 2010 - Removed financial caps on coverage
    ➢ Plan designates a key contact within each plan that would specifically focus on autism claims from Cisco employees.
“[N]o disability claims more parental time and energy than autism.”

- *New York Times*, 12/20/04
May 27, 2010 at 5:08pm
Subject: thanks

I just wanted to say thank you for accomplishing what many people would not have attempted. I live in Charleston, SC. My husbands insurance is self funded so we are having to give up custody of our autistic 2 year old to my parents because their insurance is better. ABA is really helping and there is nothing I wouldn't do for him. You are inspirational to me and a hero. God bless you.
Contact Information

Autism Speaks
State Government Affairs

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Associate Director
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About Autism Speaks

**Autism Speaks** is the world’s leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

**Autism Votes** is an Autism Speaks initiative; a comprehensive grassroots advocacy program, coordinating activist efforts in support of federal and state legislative initiatives.

For more information, please visit [autismvotes.org](http://autismvotes.org) and [www.autismspeaks.org](http://www.autismspeaks.org).
August 25, 2011

To Whom It May Concern:

APS Healthcare Inc. is the behavioral health third party administrator for the South Carolina Employee State Health Plan. APS has been asked by advocacy group “Autism Speaks” to summarize coverage and cost information for the State Health Plan Autism Spectrum Disorder benefit implemented on January 1, 2009. The South Carolina Employee Insurance Program has given APS permission to share the following details of the benefit:

<table>
<thead>
<tr>
<th>Terms of coverage:</th>
<th>Covered Members</th>
<th>Enrolled in ASD Program</th>
<th>Cost of Benefit</th>
<th>Cost per Enrolled Member</th>
</tr>
</thead>
<tbody>
<tr>
<td>• $50,000 annual maximum on ABA</td>
<td>371,384</td>
<td>60*</td>
<td>$856,369</td>
<td>$14,273</td>
</tr>
<tr>
<td>• To age 16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td>371,384</td>
<td>60*</td>
<td>$856,369</td>
<td>$14,273</td>
</tr>
<tr>
<td>2010</td>
<td>397,757</td>
<td>80</td>
<td>$2,042,394</td>
<td>$25,530</td>
</tr>
<tr>
<td>Jan. through June 2011</td>
<td>406,660</td>
<td>85</td>
<td>$1,015,078</td>
<td>$11,942</td>
</tr>
</tbody>
</table>

* Thirty of these children were enrolled in July 2009 as transfers from Medicaid as primary payor, and therefore the cost does not represent a normal full year of expense.

If there are questions on this data, please contact me.

Linda Smith
State of SC Account Executive
APS Healthcare
803-732-9037
lsmith@apshealthcare.com
October 18, 2011

Michael L. Wasmer, DVM Dipl ACVIM
Associate Director, State Government Affairs
Autism Speaks
1990 K Street, NW
Washington, DC 20006
Michael.wasmer@autismspeaks.org

Re: FOIA 11-1373

Dear Mr. Wasmer:

Thank you for writing to the Illinois Department of Healthcare and Family Services with your request for information pursuant to the Illinois Freedom of Information Act, 5 ILCS 140/1 et seq.

We received your request on October 12, 2011 for the following information:

“There are now 28 states that have enacted autism insurance reform laws. These laws have been in effect for at least 1 year in 16 states where we are trying to determine the cost impact to the State Employee Health Plans (SEHP).

Illinois implemented an autism insurance reform bill (SB 934) on December 12, 2008.

I was hoping that you could direct me to someone who may be able to help me collect some data on this issue. I have attached a template that clarifies the data that we are looking for. Illinois should have claims data for fiscal years 2009 and 2010.”

The information you seek is attached.

Sincerely,

//S//

Kyong Lee
Freedom of Information Officer

KL:sb
Attachment
### Illinois FOIA 11-1373 Response Data (10/17/2011)

<table>
<thead>
<tr>
<th>ICD-9</th>
<th>Description</th>
<th>Claimants</th>
<th>Charges</th>
<th>Paid</th>
<th>Claimants</th>
<th>Charges</th>
<th>Paid</th>
</tr>
</thead>
<tbody>
<tr>
<td>299.0</td>
<td>Autistic Disorder</td>
<td>1,621</td>
<td>$291,693.80</td>
<td>$145,814.41</td>
<td>2,025</td>
<td>$243,233.20</td>
<td>$117,618.90</td>
</tr>
<tr>
<td>299.8</td>
<td>Asperger's Disorder</td>
<td>752</td>
<td>$87,784.57</td>
<td>$37,803.68</td>
<td>1,162</td>
<td>$133,376.10</td>
<td>$64,139.28</td>
</tr>
<tr>
<td>299.9</td>
<td>Pervasive Developmental Disorder - NOS</td>
<td>47</td>
<td>$8,138.00</td>
<td>$4,065.82</td>
<td>127</td>
<td>$40,983.80</td>
<td>$15,531.59</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>2,420</strong></td>
<td><strong>$387,616.37</strong></td>
<td><strong>$187,683.91</strong></td>
<td><strong>3,314</strong></td>
<td><strong>$417,593.10</strong></td>
<td><strong>$197,289.77</strong></td>
</tr>
</tbody>
</table>

**Total number of lives covered by the State Employees Self-Insured Health Plans**

<table>
<thead>
<tr>
<th>State members &amp; dependents as of July 1st</th>
<th>171,979</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>170,790</td>
</tr>
</tbody>
</table>
Insurance Coverage for Autism Treatment & Applied Behavior Analysis

Statistics Section
Feb. 1, 2013
Executive Summary

This is the second annual report to the General Assembly related to insurance coverage for Autism Treatment and Applied Behavioral Analysis. The findings of the first annual report reflected the fact that 2011 was a transitional year during which much of the infrastructure necessary to deliver the mandated benefits was developed. As expected, data show that the benefits of the mandate were more fully realized in 2012, while the costs as a percent of overall health care costs remained negligible.

1. **Coverage.** During 2012, all insureds in the small and large group markets were covered for autism and the associated ABA mandate. A much lower proportion, less than one-third, received similar coverage in the individual market, including individually-underwritten association coverage. A few large providers of individual insurance coverage extended autism coverage to all of their insureds. However, Missouri statute only requires autism benefits as an optional coverage in the individual market, and most insurers do not provide it as a standard benefit. For those insurers that do not provide the coverage as a standard benefit, only a negligible number of insureds purchased the optional autism rider.

2. **Number impacted.** Over 2,508 individuals received treatment covered by insurance for an ASD at some point during 2012. This amounts to 1 in every 548 insureds, ranging from 1 / 2,765 in the individual market to 1 / 438 in the large group market. These figures are consistent with estimates in the scientific literature of treatment rates.\(^1\)

3. **Licensure.** The first licenses for applied behavior analysis were issued in Missouri in December, 2010. Between 2011 and 2012 the number of individuals that held Missouri licenses as a behavior analyst grew by 44 percent. As of January 17, 2012, 161 individuals were licensed, and an additional 24 persons obtained assistant behavior analyst licenses.

4. **Claim payments.** Between 2011 and 2012, claim costs incurred for autism services increased from $4.3 million to $6.6 million, of which $3 million was directed to ABA services. These amounts represent 0.16 percent and 0.07 percent of total claims incurred, consistent with initial projections produced by the DIFP.\(^2\) For each member month of autism coverage, total autism-related claims amounted to $0.38, while the cost of ABA treatment amounted $0.17.

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\(^1\) While the CDC estimates that the prevalence of autism is 1/88, autism presents with a high degree of variability. Not all such individuals will benefit from, or seek, treatment specifically targeted at the ASD.

\(^2\) The DIFP estimated that the mandate would produce additional treatment costs of between 0.2 percent and 0.8 percent. The analytical assumptions associated with the lower-end of the estimate range appear to be validated by the claims data presented in this report.
5. **Average Monthly Cost of Treatment.** For each individual diagnosed with an ASD that received treatment at some point during 2012, the average monthly cost of treatment across all market segments was $222, of which $101 consisted of ABA therapies. The average, of course, includes individuals with minimal treatment as well as individuals whose treatments very likely cost significantly more.

6. **Impact on premiums.** Given that treatment for autism represent less than 0.2% of overall claims costs, it is very unlikely that such costs will have an appreciable impact on insurance premiums. However, because the DIFP has no authority over health insurance rates and does not receive rate filings, a more exact assessment of the impact of the mandate on rates cannot be provided.

7. **Market Segments.** This study focuses upon the licensed insurance market (i.e. those entities over which the DIFP has regulatory jurisdiction). Many employers provide health insurance by “self-insuring,” that is, by paying claims from their own funds. Such plans are governed under the federal Employee Retirement Income Security Act (ERISA), and states have little jurisdiction over private employers that choose to self-fund. The Missouri statute does extend the autism mandate to the Missouri Consolidated Health Care Plan (MCHCP), which covers most state employees, as well as all self-funded local governments and self-insured school districts.

The advocacy group Autism Speaks maintains a list of self-funded private employers that have chosen to voluntarily provide coverage autism and ABA therapy to their employees. Among this group are many of the most recognizable “high-tech” companies, including Microsoft, Intel, Adobe, Cisco, IBM, Apple, Yahoo and E-Bay. From the healthcare field are the Mayo Clinic and Abbott Laboratories. Additional companies come from a variety of sectors, from Home Depot to Wells Fargo. Because the DIFP lacks jurisdiction over private self-funded employers, the number of Missourians receiving autism benefits under private self-funded plans is unknown.

Autism Speaks created a “Tool Kit” for employees of self-funded plans to approach their employers about adding benefits to their company health plan. The Self-Funded Employer Tool Kit can be found at: [http://www.autismspeaks.org/sites/default/files/docs/gr/erisa_tool_kit_9.12_0.pdf](http://www.autismspeaks.org/sites/default/files/docs/gr/erisa_tool_kit_9.12_0.pdf)
Compared to 2011, claim costs incurred for autism-related treatments increased by 52%, from $4.3 million to $6.6 million. Most of the increase resulted from more intensive utilization of ABA therapies. Claim payments for ABA increased by 183% during the same period.

Another method of expressing the costs of the mandate is the ratio of autism-related treatment costs to the total member months during which autism coverage was in effect. The resulting figure should afford a general indication of how monthly premiums might be expected to increase due to extending coverage for autism treatment. Across all market segments, the average autism-related claim costs for each month of autism coverage was $0.38, and $0.17 for the costs of ABA treatments.
March 5, 2012

The Honorable Clark Shultz, Chairperson
House Committee on Insurance
Statehouse, Room 166-W
Topeka, Kansas 66612

Dear Representative Shultz:

SUBJECT: Fiscal Note for HB 2764 by House Committee on Federal and State Affairs

In accordance with KSA 75-3715a, the following fiscal note concerning HB 2764 is respectfully submitted to your committee.

HB 2764 would require that any individual or group health insurance policy, plan, contract, fraternal benefit society or health maintenance organization that provides coverage for accident and health services on or after July 1, 2012 to provide coverage for the treatment and diagnosis of autism spectrum disorders (ASD) for individuals less than 19 years of age. Insurers could limit the coverage to a maximum of $36,000 per year for individuals less than seven years old and $27,000 per year for individuals between seven and 19 years old. Reimbursement for services would be allowed only to providers who are licensed, trained and qualified to provide such services or by an autism specialist or intensive individual services provider, as defined by the Department of Social and Rehabilitation Services (SRS) autism waiver.

HB 2764 would allow insurers to deny any claim for services based upon medical necessity or a determination that the covered individual has reached maximum medical improvement for his or her autism disorder. The bill would prohibit an insurer from terminating coverage or refusing to deliver, issue or renew coverage to an individual solely because the individual has been diagnosed with or has received treatment for an autism spectrum disorder.

<table>
<thead>
<tr>
<th>Estimated State Fiscal Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>FY 2012 SGF</td>
</tr>
<tr>
<td>Revenue</td>
</tr>
<tr>
<td>Expenditure</td>
</tr>
<tr>
<td>FTE Pos.</td>
</tr>
</tbody>
</table>
The State Employee Health Plan (SEHP) is already piloting this coverage for ASD. Coverage began on January 1, 2011. HB 2764 would make this a permanent benefit instead of a pilot benefit for the SEHP. The Centers for Disease Control and Prevention (CDC) estimates the prevalence on average of one in 110 children being diagnosed with ASD. Under the pilot program during plan year 2011, 126 members received services for ASD. There were 23,087 children under age 19 in the SEHP, which would indicate an ASD prevalence factor of 0.55 percent. The plan expects that utilization of this benefit would increase over time as patients and providers become more familiar with the coverage. This would be consistent with any new mandated benefit and is not specific to ASD. The plan estimates increased utilization based on the prevalence rate of the CDC. Using the actual dollars spent in plan year 2011, the plan estimates additional expenditures of $259,184 in FY 2013.

Outside of the state budget, the fiscal effect of HB 2764 would be for health insurers and the insured. This mandated coverage would cause an increase in expenditures for plans that currently do not offer the coverage. Insurers could increase premiums to fund the additional expenditures. This increased cost of insurance would affect employers that provide health insurance for employees and individuals who pay for a part or all of their insurance. Conversely, individuals who currently receive services for ASD that are not paid for by their health care plan would realize personal savings from the additional coverage.

Sincerely,

Steven J. Anderson, CPA, MBA
Director of the Budget

cc: Aaron Dunkel, KDHE
    Jackie Aubert, SRS
    Zac Anshutz, Insurance
KANSAS STATE EMPLOYEES
HEALTH CARE COMMISSION

REPORT ON INSURANCE COVERAGE
FOR AUTISM SPECTRUM DISORDER
PILOT

REQUIRED BY 2010
SENATE SUBSTITUTE FOR HOUSE BILL NO. 2160
EXECUTIVE SUMMARY

Senate Substitute for House Bill number 2160 required the State Employee Health Plan (SEHP) to provide coverage for services for the diagnosis and treatment of Autism Spectrum Disorder (ASD) for members under the age of nineteen (19) beginning January 1, 2011. Modification of the SEHP was necessary to include the coverage. The coverage was added beginning January 1, 2011, to all three health plans offered to members of the SEHP. The bill requires the SEHP to provide this report to the legislature outlining the impact on the SEHP related to the coverage of Autism Spectrum Disorder (ASD).

During Plan Year 2011, the SEHP had 126 members who received services for ASD. This amounts to a prevalence rate of 1 in every 800 members. This prevalence rate is significantly lower than the prevalence rates sited by the Centers for Disease Control and Prevention (CDC) for ASD in the U.S. population.

For claims incurred and processed for services received during Plan Year 2011 with a diagnosis of ASD, the total allowed amount was $214,656 for all services. This figure includes $92,394 for Applied Behavioral Analysis (ABA) services. The average monthly treatment cost for each eligible member receiving ASD treatment was $141 for all services, of which $61 was for ABA services.

Due to the plan requirement that a treatment plan be developed and approved by the health plan, the number of services during the first quarter of 2011 may be lower. In addition, as members and providers become more aware of the services eligible for coverage provided under the autism coverage mandate, it is expected that more claims will be experienced by the plan in future years.