What is Autism?

- Autism is a medical condition, brought on through no fault of the family.
- Autism affects a person’s communication abilities and social skills, and often causes repetitive patterns of behavior and a narrow range of interests.
- Its symptoms range from mild to severe.

“Autism”

- The term “autism” is often used imprecisely:
  - some people use it interchangeably with “autism spectrum disorder” (ASD)
  - others use it to mean one of the autism spectrum disorders.
- In fact, there are 3 distinct diagnoses within the family of autism spectrum disorders.
- Across the spectrum, people vary greatly in terms of type and severity of deficits.
There are 5 Pervasive Developmental Disorders (PDDs).

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

**Diagnosing Autism**

- The American Academy of Pediatrics recommends screening every child for autism at their 18 and 24 month checkups.

- Autism is diagnosed by a medical doctor; usually by a developmental pediatrician, pediatric neurologist or team of developmental specialists.

**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.
Optimizing medical care and therapy can have a positive impact on the habilitative progress and quality of life for the child. Medically necessary treatments ameliorate or manage symptoms, improve functioning, and/or prevent deterioration. Thus, in addition to routine preventive care and treatment of acute illnesses, children with ASDs also require management of sleep problems, obsessive behaviors, hygiene and self-care skills, eating a healthy diet, and limiting self-injurious behaviors.

Effective medical care and treatment may also allow a child with ASD to benefit more optimally from therapeutic interventions. Therapeutic interventions, including behavioral strategies and habilitative therapies, are the cornerstones of care for ASIDs. These interventions address communication, social skills, daily-living skills, play and leisure skills, academic achievement, and behavior.

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
- Many insurers still deny coverage for ABA based on the assertion that ABA therapy is "experimental." This assertion is simply not supported by science
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.

ASD is a medical/neurodevelopmental condition with behavioral symptoms that are directly addressed by applied behavior analysis methods. ABA has proved effective in addressing the core symptoms of autism as well as developing skills and improving and enhancing functioning in numerous areas that affect the health and well-being of people with ASD.

The effectiveness of ABA-based interventions in ASDs has been well documented through a long history of research in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial gains in cognition, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.
ABA endorsements

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.”

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.”

United States Department of Defense

Military insurance (TriCare) covers autism and specifically includes a benefit for Applied Behavior Analysis therapy.

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.

State Response

32 states mandate coverage for ABA for autism

August 2012
### Terms of State Autism Mandates

<table>
<thead>
<tr>
<th>State</th>
<th>Year Enacted</th>
<th>Annual Dollar Cap</th>
<th>Age Cap</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>2012</td>
<td>None</td>
<td>21</td>
</tr>
<tr>
<td>Arizona</td>
<td>2008</td>
<td>$50K: 0-5, $75K: 5-18</td>
<td>21</td>
</tr>
<tr>
<td>Arkansas</td>
<td>2011</td>
<td>$50K: 0-5</td>
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</tr>
<tr>
<td>California</td>
<td>2011*</td>
<td>None</td>
<td>21</td>
</tr>
<tr>
<td>Colorado</td>
<td>2008</td>
<td>$50K: 0-5, $75K: 0-15</td>
<td>21</td>
</tr>
<tr>
<td>Connecticut</td>
<td>2009</td>
<td>$50K: 0-5, $75K: 5-12</td>
<td>21</td>
</tr>
<tr>
<td>Delaware</td>
<td>2012</td>
<td>$50K</td>
<td>21</td>
</tr>
<tr>
<td>Florida</td>
<td>2008</td>
<td>$50K (50% of amount)</td>
<td>21</td>
</tr>
<tr>
<td>Georgia</td>
<td>2001</td>
<td>None</td>
<td>21</td>
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<tr>
<td>Idaho</td>
<td>2008</td>
<td>$50K</td>
<td>21</td>
</tr>
<tr>
<td>Illinois</td>
<td>2001</td>
<td>None</td>
<td>21</td>
</tr>
<tr>
<td>Indiana</td>
<td>2010</td>
<td>$50K</td>
<td>21</td>
</tr>
<tr>
<td>Iowa</td>
<td>2010</td>
<td>$50K</td>
<td>21</td>
</tr>
<tr>
<td>Kansas</td>
<td>2010</td>
<td>$50K: 0-5, $75K: 0-15</td>
<td>21</td>
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<tr>
<td>Kentucky</td>
<td>2010</td>
<td>$50K: 0-5, $100K (after)</td>
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<tr>
<td>Louisiana</td>
<td>2008</td>
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<td>21</td>
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<tr>
<td>Maine</td>
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<td>21</td>
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<tr>
<td>Maryland</td>
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<td>21</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>2010</td>
<td>None</td>
<td>21</td>
</tr>
</tbody>
</table>

**August 2012**

### In States with Autism Insurance Reform...

- Children who have never before been able to receive treatment are making remarkable progress.
- Providers have joined adequate networks of participating providers and negotiated satisfactory reimbursement rates.
- The impact on premiums has been negligible.

### What is the cost of autism insurance reform?
Average First 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</th>
<th>PMPM Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Carolina</td>
<td>1</td>
<td>371,384</td>
<td>$856,369</td>
<td>$0.19</td>
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<td>Illinois</td>
<td>1</td>
<td>171,979</td>
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<td>Florida</td>
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<td>382,083</td>
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<td>Kentucky</td>
<td>1</td>
<td>240,000</td>
<td>$278,922</td>
<td>$0.10</td>
</tr>
</tbody>
</table>

Average first year cost: $0.15

Source: Data collected from State agencies responsible for administering State Employee Health Benefits Programs

Cost of ABA

- Average monthly cost of ABA per individual with ASD = $35
- 6 cents PMPM
- 0.02% of total claims

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

Average Second Year Cost of Autism Insurance Reform

<table>
<thead>
<tr>
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<th>Number of Covered Lives</th>
<th>Total Claims</th>
<th>PMPM Cost</th>
</tr>
</thead>
<tbody>
<tr>
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<td>2</td>
<td>130,000</td>
<td>$388,662</td>
<td>$0.25</td>
</tr>
</tbody>
</table>

Average second year cost: $0.31

Source: Data collected from State agencies responsible for administering State Employee Health Benefits Programs
Affect on Premiums

- Claims incurred for treatment of ASD represent 0.1% 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.”

Examples of Self-Funded Plans that Provide Coverage for Autism Treatment

- Microsoft*
- Home Depot
- Arnold & Porter
- Symantec
- Cisco*
- Eli Lilly
- Ohio State University
- Time Warner
- Blackbaud
- Lahey Clinic
- Partners Healthcare
- Deloitte*
- White Castle
- Wells Fargo
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Intel*
- DTE Energy
- Cerner
- State Street Financial
- Children’s Mercy
- Capitol One*
- Yahoo
- Sisters of Mercy Health Systems
- Princeton University
- and many more . . .

What Should an Autism Benefit Look Like?

- Coverage should include
  - Applied Behavior Analysis (ABA) Therapy
  - Speech Therapy, Occupational Therapy, and Physical Therapy
  - Psychological, Psychiatric, and Pharmaceutical Care
  - Diagnosis and Assessments
What Should an Autism Benefit Look Like?

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

• For Applied Behavior Analysis coverage, treatment must be provided or supervised by
  - a behavior analyst who is certified by the Behavior Analyst Certification Board®,
  - a licensed psychologist so long as the services performed are commensurate with the psychologist’s formal university training and supervised experience

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About Autism Speaks

Autism Speaks is the world’s largest 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 www.autismvotes.org and www.autismspeaks.org