The Arguments for Quality Autism Insurance

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Background: The Frightening Reality

About 1.5% of US children are now diagnosed with autism, according to data from 11 regions in the United States.

- 1 in 42 boys\(^1\)
- 1 in 189 girls\(^1\)
- If one child in a family has an ASD, odds are others will

\(^1\)CDC, “Community Report on Autism”, 2014
Autism in General

• Social and Communication Impairment
  – Can be accompanied by other developmental disorders (e.g., cognitive delay, social-pragmatic problems)
  – Generally accompanied by sensory processing difficulties
    • Some sensory systems over-regulated, some under

• Spectrum disorders (based on DSM-IV)
  – Asperger Syndrome (Asperger’s) is mildest form
    • “Aspies” frequently live full, ‘normal’ lives
  – Autistic Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
    • Substantially more profound challenges in communication, sensory integration, lifeskills
Autism Treatment

• Early, intense treatment IS SUCCESSFUL

• Accepted therapies
  – ABA (Applied Behavioral Analysis)
    • Most effective and best established (meets “Evidence-based” standard)
    • 2 clinics in W. Lafayette area (Little Star and Cornerstone)
      – Purdue insurance **EXCLUDES** these
  – Speech & language, physical, feeding, & occupational therapies
    • Foods, toileting, sign language, picture communication, electronic communication devices, proprioception (body’s orientation in space)
    • Purdue insurance **WHOLLY INADEQUATE** (1 hr/week)

• K-12 system largely ineffective
  – Overwhelmed, cannot provide adequate support
Snapshot of an Autistic Child

• David Beaudoin (current age – 13 years)
  – ‘Typical’ child until ~22 months
  – Stopped speaking; withdrew from most human interaction
    • No eye contact
    • No playing with toys
  – Developed stereotypical, self-stimulatory behaviors
    • Jumping
    • Flapping hands
    • Running in circles
    • No playing games
    • DID NOT SPEAK UNTIL AGE 8
    • Obsessions with same repetitive activities
    • Covering ears
  – Diet changed dramatically, limited to
    • Bacon (40 - 50 lbs/month)
    • Mike Sells Rippled Potato Chips
    • McDonald’s French Fries
    • Coke
    • Pepsi
    • Water
  – Cannot toilet reliably
Competitive Disadvantage

• Purdue wants to grow engineering faculty by 107

Competition VOLUNTARILY offering full autism coverage

• Boston University
• Cornell
• Eastern Michigan
• Michigan
• Minnesota
• MIT
• Ohio State
• Penn
• Princeton
• Stanford
• Tufts

**ENORMOUS competitive disadvantage for faculty recruitment and retention**

Purdue faculty candidates have asked about autism insurance during interviews
Purdue faculty are seeking employment elsewhere because of our poor insurance coverage

*Green states have autism insurance mandates, red states have endorsed reform bills, yellow states pursuing reform and blue states not pursuing reform.*
Purdue wants to be an international leader in autism research and clinical practice
  – Currently there is an ‘Autism cluster hire’ plan to add up to 7 international autism experts
  – Most of the treatments they are developing are explicitly not covered by Purdue insurance

Not providing adequate support for Purdue families with autism is diametrically opposed to our plan to be an international leader in autism treatment
Human Cost: Purdue Families

• ASD kids frequently require expensive, specialized diets
• Due to limitations of Purdue autism insurance, most Purdue families pay out of pocket for therapy
  – Crushing for multi-child families
  – Financial, emotional, psycho-social burden; often secondary impact on siblings
• The psychological and emotional cost to Purdue families is exceptionally high
  – Depression and other stress-related psychological and emotional disorders
  – Divorce
  – Loss of productivity
  – Professional / academic career at jeopardy
• State of Indiana has an ‘Autism Mandate’
  – Requires autism therapies prescribed by physicians to be covered
    • Passed with bipartisan support and signed by Gov. O’Bannon in 2001
    • Exception for organizations that self-insure
    • Purdue self-insures and thus does not follow the mandate
    • IU follows the mandate

• Purdue EO/EA/AA policy:
  – Purdue University
    • Recognizes and values the inherent worth and dignity of every person
    • Will not tolerate discrimination against any individual on the basis of disability
    • Resolution of the Board of Trustees and to ensure the University’s compliance with Americans with Disabilities Act of 1990, as amended

• Americans with Disabilities Act, Title II
  – “protects qualified individuals with disabilities from discrimination on the basis of disability in services, programs, and activities…”

• Voluntarily ignoring the mandate flies in the face of our values
## Financial Cost: Follow Autism Mandate

### Rates of Autism Incidence Among Purdue Families (from Purdue HR, ARC of Indiana)

<table>
<thead>
<tr>
<th>Covered Lives 0-19 yrs</th>
<th>Prevalence</th>
<th>Diagnosed ASD</th>
<th>Mild (1/6)</th>
<th>Moderate (1/2)</th>
<th>Severe (1/3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>3350</td>
<td>1 in 54</td>
<td>61</td>
<td>10</td>
<td>31</td>
</tr>
<tr>
<td>Female**</td>
<td>3238</td>
<td>1 in 252</td>
<td>13</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>6788</td>
<td></td>
<td>74</td>
<td>12</td>
<td>36</td>
</tr>
</tbody>
</table>

### ARC of Indiana Est. Annual Cost Increase (in Claims) to Follow IN Autism Mandate

<table>
<thead>
<tr>
<th>Diagnosed ASD</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$42,280</td>
<td>$1,172,826</td>
<td>$1,561,560</td>
</tr>
</tbody>
</table>

### Mercer (Purdue Consultant) Est. Annual Cost Increase (in Claims) to Cover ABA Therapy

<table>
<thead>
<tr>
<th>Diagnosed ASD</th>
<th>~$1,800,000</th>
</tr>
</thead>
</table>

### Changes in Costs if IN Autism Mandate Followed

<table>
<thead>
<tr>
<th>Savings (total, over lifetime) to taxpayers</th>
<th>$124,000,000 (if moderate and severe cases considered)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$52,000,000 (if only severe cases considered)</td>
</tr>
<tr>
<td>Typical premium increase (per member, per month)</td>
<td>$0.13 - $0.30</td>
</tr>
</tbody>
</table>

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1. This does not describe an increase in premiums, rather this describes an increase in claimed costs.
2. Provided by Autism Speaks and ARC of Indiana
3. ABA Therapy is the oldest, best-established form of autism treatment – it is not currently covered.
Legal Liability

• Recent rulings against insurers
  • Not covering ASD therapies is in violation of the ADA and State and Federal Mental Health Parity Acts
    • Recent cases in WA, OR, CA
    • WA case will involve compensation to families back to 2006
  – ERISA insurers who do not cover ASD therapies but who cover other neurological/mental health disorders are acting in an arbitrary and capricious manner
• Purdue may be (likely to be) subject to lawsuits
• Not following the Indiana Autism Mandate puts Purdue at great disadvantage compared to competitor schools
• Not following the Indiana Autism Mandate saves Purdue a comparatively small amount of money and passes crushing expense to IN taxpayers
• Not following the Indiana Autism Mandate exposes Purdue to lawsuits for discrimination, violation of ADA and Mental Health Parity acts
• Not following the Indiana Autism Mandate flies in the face of our stated values
• Not following the Indiana Autism Mandate is devastating to Purdue families