Update on Autism Spectrum Disorders

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Autism and the Law
Cases, Statutes, and Materials
by Lorri Shealy Unumb & Daniel R. Unumb
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Autism Speaks
- Headquartered in New York

Autism Speaks
Government Relations
- Headquartered in D.C.
Autism Spectrum Disorder

- A medical condition, brought on through no apparent fault of family
- Diagnosed by doctor or psychologist; often a developmental pediatrician
- Four-five times more common in boys than girls

What is Autism?

- Communication
- Social
- Behavior

Complex neurobiological disorder
There are 5 Pervasive Developmental Disorders (PDDs).

Within the 5 PDDs, there are 3 **Autism Spectrum Disorders** (ASDs), shown in purple below.
An 30-year-old study looked at 21 pairs of twins, at least one of each pair being affected by autism. It compared identical twins, who share all of their genetic makeup, with fraternal twins, who share around half their genes. It found that when one identical twin had autism, so did the other 83 percent of the time. By contrast, this was true of only 10 percent of the fraternal twins. For decades, it was taken as fact that the causes of autism were almost completely genetic.

That changed this past year with the largest ever autism twin study. A Stanford University study found a significantly lower autism concordance between identical twins—just 70 percent. They also found a much higher than expected overlap between fraternal twins—around 35 percent, considerably higher than the 15 percent or lower concordance we know exists between siblings who are not twins. This strongly suggests that environmental influences play a significant role in autism -prenatal influences being among the most likely.
AUTISM: A PUBLIC HEALTH CRISIS
PREVALENCE ON THE RISE.
NUMBER OF AUTISM DIAGNOSES
PER PERSON SINCE 1975.

1 IN 5000 1 IN 2500 1 IN 500 1 IN 250 1 IN 166 1 IN 150 1 IN 110

1000% INCREASE IN PREVALENCE OVER THE LAST 40 YEARS

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Johns Hopkins University’s Kennedy Krieger Institute
Children’s National Medical Center
Georgetown University Hospital
• One-on-one therapy

• Up to 40 hours/week

• Uses behavioral stimuli & consequences to produce significant improvement in human behavior

• Breaks down into discrete components the skills that neurotypical children acquire naturally

• Trains child to acquire skills through repetition, prompting, and positive reinforcement
Applied Behavior Analysis: Sample Therapy Structure

- **Consultant**
  - Highly educated and trained in ABA
  - Board certified in ABA
  - Evaluates, designs, trains
  - 3-6 hours per month

- **Mid-level supervisor (lead therapist)**
  - Educated and trained
  - May be board certified
  - Updates programming; trains; oversees
  - 6 hours per week

- **Line therapists**
  - Trained & supervised by above
  - Provide 40 hours per week of direct therapy, usually in 3-hour shifts
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
Applied Behavior Analysis: Cost of a Sample Therapy Program

- Consultant
  - 3-6 hours per month
  - $100-$150/hour
  - 6 hours x $150 = $900/month
  - $900 x 12 months = $10,800

- Mid-level supervisor (lead therapist)
  - 6 hours per week
  - $30-$60/hour
  - 6 hours x $60 = $360/week
  - $360/week x 52 weeks = $18,720

- Line therapists
  - 40 hours per week
  - $20 - $30/hour
  - 40 hours x $20 = $800/week
  - $800/week x 52 weeks = $41,600

- $10,800 + $18,720 + $41,600 = $71,120

- How does a family pay for this?
- THANK GOODNESS FOR HEALTH INSURANCE!
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 is the Standard of Care

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.”
Cost of Autism to Society/State

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

- State estimated lifetime cost **savings** of providing appropriate treatment are **$1 million per child** (Jacobsen et al, 1998)
2002 Snapshot

7-20-10
2006 Snapshot
2007 Snapshot
Considering Autism Insurance Reform in 2013
South Carolina State Employee Plan

• Dates
  – Applicable to state health plan as of 1-1-09

• Population
  – State health plan has 350-390,000 members

• Terms
  – $50,000 cap on ABA
  – To age 16

• Projected Cost
  Original: $18.9 million
  Revised: $9 million

• Actual cost
  2010: $2,042,392
  PMPM - 44 cents
  PEPM – 75 cents
  (228,048 employees/subscribers;
   79 kids accessing coverage)

lorri.unumb@autismspeaks.org
Actual Claims Data
Missouri (2012)

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

- Total claims paid = $6,555,602
- Total covered lives** = 1,429,153
- Unique claimants = 2,508
- PMPM cost = 38 ¢

* Caps can be exceeded if deemed medically necessary
** Member months of policies with ASD coverage = 17,149,845

Source: Missouri Department of Insurance, Financial Institutions and Professional Registration, 2012
Effect 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.”
## 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>
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<td>397,757</td>
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<td>$6,555,602</td>
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<td>2</td>
<td>100,000</td>
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</tbody>
</table>

|               | Average second year cost | $0.31 |

* 11 months (Jan-Nov 2012)

**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)
Efficacy of ABA Therapy

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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)
Sources of Health Care Coverage

- Medicaid - 20%
- Medicare - 10%
- Uninsured - 11%
- State Health Plan - 10%
- ERISA - ASO - 25%
- Federal Tricare - 2%
- Federal Civilian - 2%
- Other Insured - Large Group - 15%
- Other Insured - Small Group - 4%
- Other Insured - Individual - 1%
Self-Funded “ERISA” Plans That Cover ABA

- Arnold & Porter
- Eli Lilly
- Ohio State University
- Global Foundries
- Blackbaud
- Lahey Clinic
- Indiana University
- Partners Healthcare
- Wells Fargo
- Capitol One
- White Castle
- Pacific Gas & Electric
- CH2M Hill
- Stanford University
- University of Minnesota
- Progressive Group
- Greenville Hospital System
- Symantec
- DTE Energy
- Cerner
- State Street Financial
- Children’s Mercy
- EMC
- Sisters of Mercy
- Princeton University
- Pinnacle Casinos
- Squire Sanders & Dempsey
- Newell Rubbermaid
- And many more . . .

Does your self-insured firm or company cover ABA therapy? Please let me know!
<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>
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<td>16</td>
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<td>State</td>
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<td>722,718</td>
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<td>21</td>
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Behavior Analyst Licensure Laws

ND has state “certification”
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 husband's 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.
“[N]o disability claims more parental time and energy than autism.”
New York Times, 12/20/04