



Self-Funded Health Plans:

Establishing an Autism Benefit

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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.
- Autism is diagnosed by a medical doctor (usually a developmental pediatrician).
- Treatment is prescribed by a medical doctor.



“Autism”

- The term “autism” is often used imprecisely:
 - some people use it interchangeably with “autism spectrum disorder”
 - 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. (See chart on next slide.)
- Across the spectrum, people vary greatly in terms of type and severity of deficits.

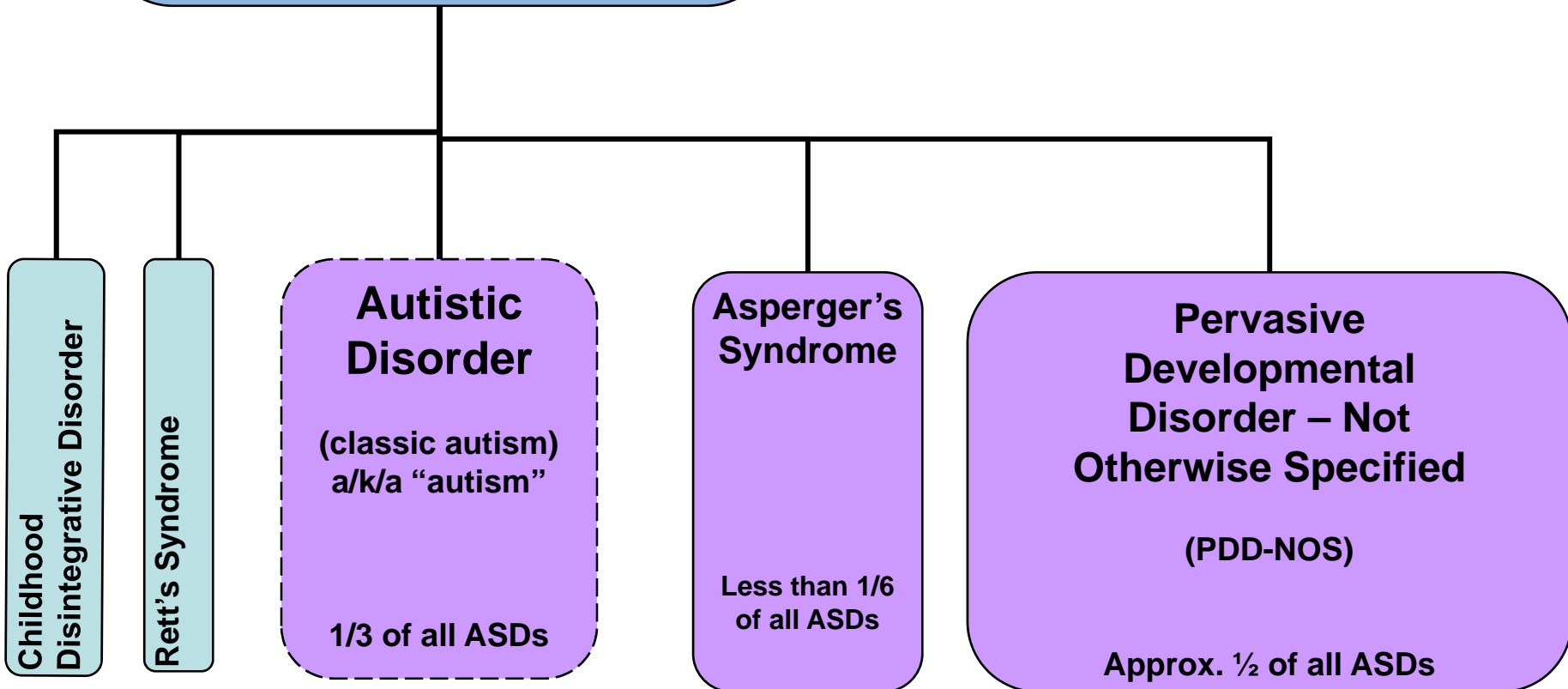


Pervasive Developmental Disorders

(the umbrella category in the DSM-IV)

There are 5 Pervasive Developmental Disorders (PDDs).

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



Curable? 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.



Autism Treatment:

- The most commonly-prescribed treatment protocol involves a therapy called “**Applied Behavior Analysis,**” or ABA therapy.
- ABA therapy has been used for many decades to treat autism, but many insurers deny coverage on the basis that ABA therapy is “experimental.”
- That conclusion is simply not supported by the science, and the **Surgeon General, the National Research Council, and the American Academy of Pediatrics** endorse the use of ABA therapy for kids with autism.



American Academy of Pediatrics, 2007:

“The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, 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.”



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.”



Treatment Outcomes:

- Studies show that, if ABA therapy is administered intensively and by properly-trained therapists, approximately half of the treated kids will “overcome” their autistic characteristics to such an extent that they can enter 1st grade **indistinguishable from their peers**. And the other half make significant gains, too, such that they need less support for the rest of their lives. (Lovaas, UCLA 1987)
- Because ABA therapy must be administered intensively – sometimes 40 hours per week – it is quite expensive. (See next slides)
- Wealthy parents pay out-of-pocket to provide their children ABA therapy, which typically lasts 3-4 years.
- Less fortunate children go without therapy, end up in costly special education programs, and eventually become wards of the state.



Applied Behavior Analysis: *Three Tiers of a Typical Program*

1. Consultant
 - Highly educated and trained
 - Board Certified
 - Evaluates, designs, trains
 - 3-6 hours per month

2. Mid-level supervisor (lead therapist)
 - Highly educated and trained
 - May be Board Certified
 - Updates programming; trains; oversees
 - 6 hours per week

3. Line therapists
 - Often recent graduates or college students, trained by above
 - Provide 25-40 hours per week of direct therapy, usually in 3-hour shifts



Applied Behavior Analysis: *Cost of a Sample Program*



1. Consultant

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

2. 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/year**

3. Line Therapists

- 40 hours per week
- \$10-\$20/hour
- 40 hours x \$20 = \$800/week
- \$800/week x 52 weeks = **\$41,600/year**

$$\mathbf{\$10,800 + \$18,720 + \$41,600 = \$71,120}$$



Taxpayer Burden

- A 2006 Harvard study found that if a child with autism is not properly treated, the societal cost for that one child over their lifetime is \$3.2 million. (Ganz 2006).
- A Pennsylvania study projected an actual cost savings to the state of over a million dollars per child. (Jacobson, Green 1998).



Increased Prevalence = Higher Burden

- In 1985, the prevalence rate of autism was 1 case per 2500. Today, it is 1 in 110. (CDC, 2009)
- Do the math: 1 in 110 kids diagnosed; only the wealthy few get treatment; and multiply each remaining child by over a million dollars. That's how much taxpayers will shell out if these kids don't get treatment.



Increased Prevalence = Higher Burden

- Scientists don't know the reason for the increase in prevalence, but we all understand the ramifications. There's a huge autism tsunami coming, and it is going to cost taxpayers an extraordinary amount in special education and adult care if the current generation of kids does not get treatment.
- Without private insurance coverage, the treatment is simply not going to happen.



States Taking Action

- Faced with this reality, 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.
- 21 states have passed autism mandates; 12 states & Congress are now considering them.



Comparison of State Autism Benefits

	SC	MN (BCBS Covera ge)	AZ	MT	IN	PA
Annual Cap	\$50K (only on ABA)	Unlimited	\$50K thru 8; \$25K 9-16	\$50K thru 9; \$20K 9-18	Unlimite d	\$36 K
Diagnosed by age	8	n/a	n/a	n/a	n/a	n/a
Benefits until age	16	No age cap	17	18	No age cap	21

Treatment must be prescribed by licensed physician or psychologist.



In The 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.
- The insurance industry's own association – the Council for Affordable Health Insurance – estimates that mandated autism benefits have increased premium costs by LESS than 1%. (See chart)



Excerpt from 2008 Report of the Council For Affordable Health Insurance: “*Health Insurance Mandates in the States*”

BENEFITS:	Est. Cost	#
Alcoholism	1-3%	45
Autism	<1%	11
Contraceptives	1-3%	31
In Vitro Fert.	3-5%	13
Prescriptions	5-10%	2

Available at www.CAHI.org.

The Council for Affordable Health Insurance is a research and advocacy association of insurance carriers active in the small group, individual, HSA, and senior markets. CAHI is an active advocate for market-oriented solutions to the problems in America's health care system.



United States Department of Defense



- Also, military insurance (TriCare) covers autism and specifically includes a benefit for Applied Behavior Analysis therapy.



Unfortunately . . .

- Even in the states that have passed autism insurance mandates, many children are still unable to receive treatment because they are insured through self-funded plans that are not regulated by the state.



What is a Self-Insured Employer?

- If you work for a large company or government, there is a chance your health plan is self-insured.
- These self funded plans are not really insurance. The employer pays employee benefits from the employer's own pocket and assumes the risks.
- Self-funded employers often hire third-party administrators (TPAs) to keep track of premiums, claims, and related paperwork.
- If the employee is in a self-insured plan, [ERISA](#) preempts most state insurance regulation, including benefit mandates.



ERISA: The Employee Retirement Income Security Act

- The Employee Retirement Income Security Act of 1974 (ERISA) is a federal law that sets minimum standards for most voluntarily established pension and health plans in private industry to provide protection for individuals in these plans.
- ERISA allows companies to set up self-funded plans that are governed by federal law and exempt from state insurance regulations.
- There have been a number of amendments to ERISA, including COBRA and HIPAA, expanding the protections available to health benefit plan participants and beneficiaries.
- The Autism Treatment Acceleration Act (ATAA) of 2009 seeks to amend ERISA law by requiring coverage of autism treatments.
- For more information about ERISA, visit the U.S. Department of Labor's website at www.dol.gov.



Companies With Self-Funded Plans that Cover Autism

Many self-funded companies have elected to implement autism benefits, even though ERISA law does not yet require them to do so.

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Symantec
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- Mayo Clinic
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Greenville Hospital System
- Time Warner
- City of Atlanta



Why Implement an Autism Benefit?

- Greater employee productivity.
- Employee retention is maximized - employees will not feel the need to leave in search of a job with state-regulated insurance.
- Children who achieve higher levels of functioning
 - have lower overall health care costs
 - do better in school
 - need less assistance from their families, from whom autism often exacts a terrible financial and psychological toll
- A child is given the opportunity for a functional, happy life and is saved from a lifetime of institutionalization.



“[N]o
disability
claims
more
parental
time and
energy
than
autism.”

New York Times,
12/20/04



What Should the 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
- No visit limits (other than restrictions prescribed by treating physician)



What Should the 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.



For more assistance in crafting an autism benefit for your company, please contact Autism Speaks

Autism Speaks, the world's largest autism advocacy organization, is dedicated to increasing awareness of autism spectrum disorders, to funding research into autism, and to advocating for the needs of affected families.

Please visit www.AutismVotes.org and www.AutismSpeaks.org for more information

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