

The Autism “Explosion,” and what it means for your child

James Coplan, MD
Neurodevelopmental Pediatrics of the Main Line, PC
Rosemont, PA
(610) 520-2130

<http://www.DrCoplan.com>



<http://www.rethinkautism.com/>

www.drcoplan.com

April 4, 2012

The ASD “Explosion”

- Are we in an epidemic?
- If so:
 - Is there a smoking gun?
 - Are there preventive or therapeutic measures?
- If not:
 - Where did all these kids come from?
 - Where are the “missing” adults?

www.drcoplan.com

DEFINITIONS

- Incidence
- Prevalence
- Epidemic
- “Explosion”

www.drcoplan.com

Incidence = Rate of occurrence of new cases



Epidemic = ↑↑ Incidence

www.drcoplan.com

Incidence = Rate

- The number of new cases of a disorder, over a specified period of time, in a defined population
 - New cases of Influenza / 100,000 persons / wk
 - New cases of ASD / 100,000 children / yr
 - Incidence of ASD =
 - Birth rate of newborns who will have ASD +
 - Rate of autistic regression among children
 - The incidence of ASD is unknown

www.drcoplan.com

Prevalence = % of population affected



“Explosion” = ↑↑ Prevalence

www.drcoplan.com

Prevalence = *Proportion*

- The percent of the population that is affected, at one point in time
 - The % of people with the Flu
 - The % of people with ASD
- We do not know the actual prevalence of ASD (requires random sampling and confirmatory testing). What we know is the prevalence of children being served with a *diagnosis* of ASD, based on secondary source records.

www.drcoplan.com

Prevalence of children with an ASD Diagnosis

- 1950s – 60s (Autism *only*) :
 - ~ 2 - 4 per 10,000 (1:2,500)
 - > 75% w. IQ below 70 (“MR”)
- Today (Autism, Asperger, PDD-NOS):
 - 1 in 100 (or more)
 - > 50% have IQ > 70
- ↑ prevalence of ASD Dx does not prove we are in an “epidemic” (↑ incidence)

www.drcoplan.com

You cannot get a speeding ticket for having a full tank of gas

INCIDENCE
(Epidemic)



PREVALENCE
 (“Explosion”)

www.drcoplan.com

CHANGING THE COURSE of AUTISM



A SCIENTIFIC
APPROACH FOR
PARENTS AND
PHYSICIANS

BRYAN JEPSON, M.D. with JANE JOHNSON

UNKNOWN

EVIDENCE-BASED MEDICINE SHOWS THAT:

- Autism is epidemic (1 in 150 children has been diagnosed).
- Autism is a medical disease, not a psychological disorder.
- Autism affects other body organ systems besides the brain.
- Autism is treatable; children are recovering.

TRUE

Age of Autism

Daily Web Newspaper of the Autism Epidemic

Sponsored by **LEE SILSBY** COMPOUNDING PHARMACY The leader in quality compounded medications for autism

REPORT AOA

Here to See What
Send you an A of A t.

Kevin Leitch's Leftbrain/Rightbrain Sees Conspiracies Left and
Right | Main | Autism File Magazine On Classic and Regressive
Autism »

MEET OUR
ADVERTISERS

www.drcoplan.com

Centers for Disease Control and Prevention

MMWR

Morbidity and Mortality Weekly Report
Surveillance Summaries / Vol. 61 / No. 3
March 30, 2012

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008

TABLE 2. Estimated prevalence* of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008

Site	Total no. with ASDs	Sex				Male-to-female prev ratio ^b
		Total ^a	Male	Female		
		Prev	95% CI	Prev	95% CI	
Total	337,093	3,820	11.3 (11.0–11.7)	18.4 (17.7–19.0)	4.0 (3.7–4.3)	4.6

www.drcoplan.com

11.3 cases / 1000 children = 1 in 88

March 30, 2012

PREVALENCE

AUTISM SOCIETY
Improving the Lives of All Affected by Autism

Dear James,

Today the Centers for Disease Control and Prevention released its latest report that estimates 1 in every 88 U.S. children has autism. While there is no agreement or proven reasons for this increase, the Autism Society believes we must address the issues important to those living with autism today.

The increasing incidence of autism should serve as an urgent call to address a critical issue facing society: individuals and families living with autism need support and services. These CDC statistics are a clear call that the need for services has never been greater. If society does not answer that call, particularly as the population grows, more and more individuals will not receive the help they desperately need.

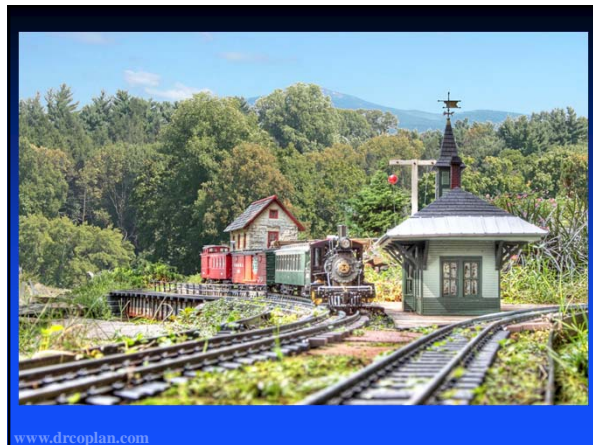
UNKNOWN

www.drcoplan.com

What difference does it make?

- If we are really in an epidemic:
 - Is there a smoking gun?
 - Immunizations
 - Mercury
 - Other?
 - Is there a cure or preventive measure?
- For now, we have to limit our discussion to **prevalence**. Incidence remains unknown

www.drcoplan.com



www.drcoplan.com

Known causes of ↑ prevalence of children with a Dx of ASD

- Broadening diagnostic criteria
- Broadening Federal service & reporting requirements
- Diagnostic substitution
- Broadening ascertainment methods

www.drcoplan.com

Relationship between *diagnostic criteria* and prevalence

What is the prevalence of “Tall Stature”

- If the cutoff for “Tall” = 7 feet?
- If the cutoff for “Tall” = 6 ft 10”
- If the cutoff for “Tall” = 6 ft 6”
- If the cutoff for “Tall” = 6 ft
- Etc.....

www.drcoplan.com

DSM III

Yr	Event	Comment
1980	DSM-III: First appearance of: <ul style="list-style-type: none"> • Infantile autism • Autism-residual state: Children who once met criteria for infantile autism but no longer do. 	6 mandatory, severe criteria for Dx of autism, including: <ul style="list-style-type: none"> • Pervasive lack of responsiveness to other people • Gross deficits in language development • Bizarre responses to various aspects of the environment

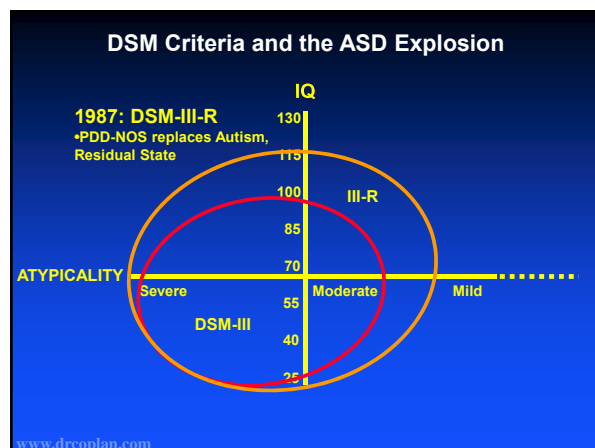
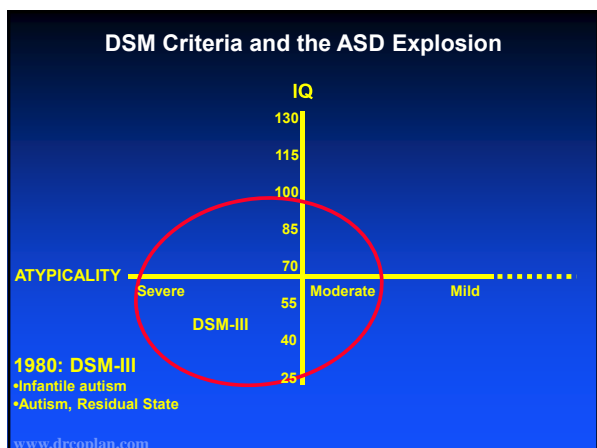
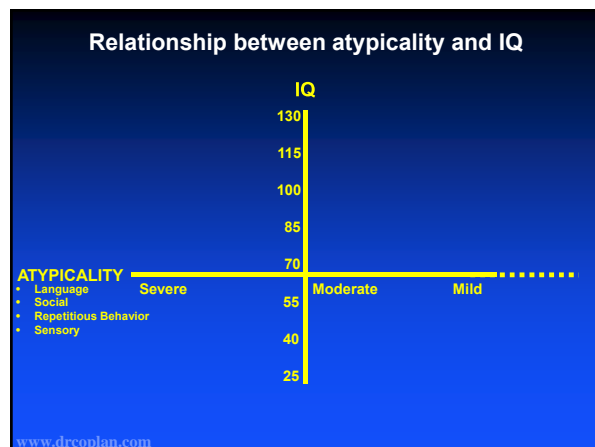
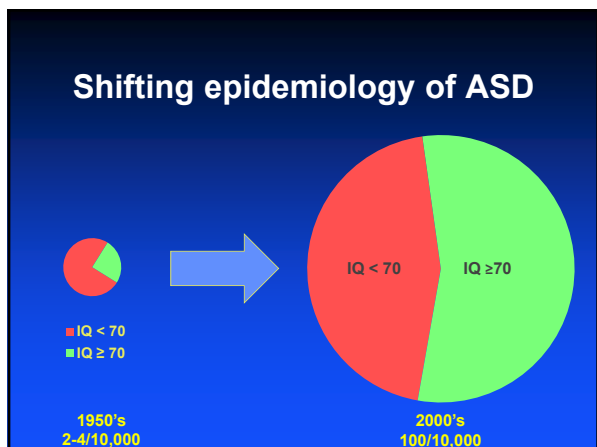
www.drcoplan.com

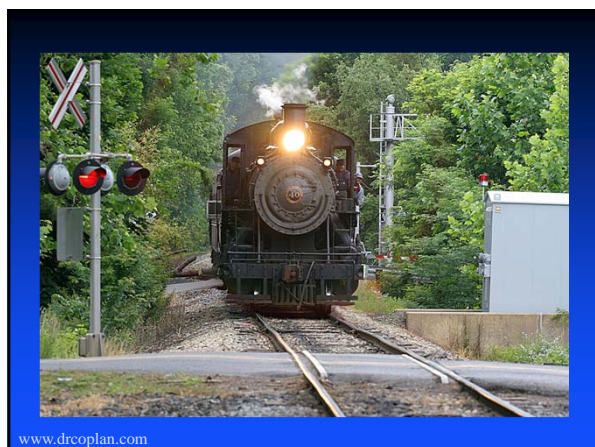
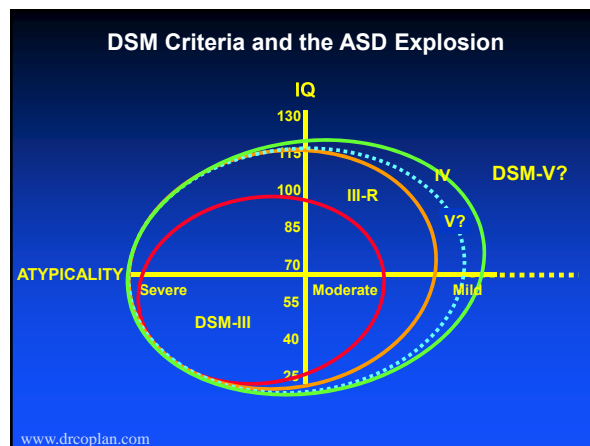
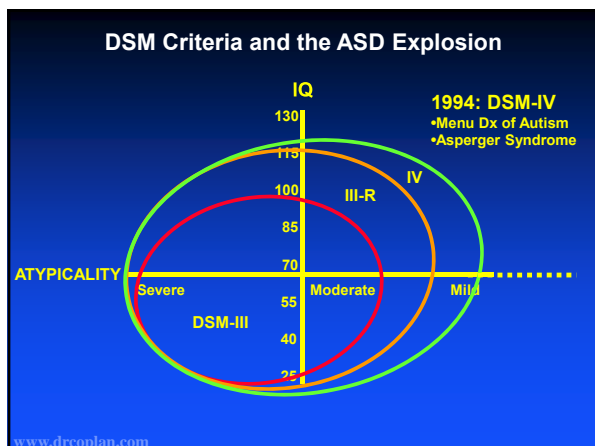
DSM III-R		
Year	Event	Comment
1987	DSM-III-R: •“Infantile autism” replaced by “Autistic Disorder” •“Autism-Residual State” replaced by PDD-NOS	PDD-NOS encompasses children who <i>never met full criteria for Autism</i> , as well as children who once met such criteria but improved over time.

www.drcoplan.com

DSM IV		
Year	Event	Comment
1994	DSM-IV: •Broader menu for diagnosis •Asperger's Disorder first appears	6 of 16 milder criteria, such as: •Lack of spontaneous seeking to share achievements with other people •Difficulty sustaining a conversation •Lack of varied social imitative play •Persistent preoccupation with parts of objects

www.drcoplan.com





- Known causes of ↑ prevalence of children with a Dx of ASD**
- Broadening diagnostic criteria
 - **Broadening Federal service & reporting requirements**
 - **Diagnostic substitution**
 - Broadening ascertainment methods
- www.drcoplan.com

Changes in Federal Law - 1

Year	Event	Comment
1975	Congress enacts Public Law 94-142: Education for All Handicapped Children (EAHC)	First Federal law requiring the States to provide free and appropriate public education (FAPE) to “all children >5 yrs old, regardless of disability”

But.....

www.drcoplan.com

- “Handicapping Conditions” (PL 94-142; 1975)**
- **Mentally Retarded**
 - **Learning Disabled**
 - **Speech impaired**
 - **Hearing / Vision Impaired**
 - **Seriously emotionally disturbed**
 - **Orthopedically impaired**
 - **Multi-handicapped**
 - **Other health impaired**
- Where is autism?*
- www.drcoplan.com

Changes in Federal Law - 2

Year	Event	Comment
1986	PL 99-457: Early Intervention Amendments to PL 94-142	<ul style="list-style-type: none"> •Extends FAPE to children age 3-5, mandated to take effect by 1991 (Section 619, Part B) •Creates Early Intervention for children 0-3 (Section 619, Part H).

www.drcoplan.com

Where is autism?

Changes in Federal Law - 3

Year	Event	Comment
1990	Congress Amends PL 94-142 again (PL101-476)	<ul style="list-style-type: none"> •Renamed <i>Individuals with Disabilities Education Act</i> (IDEA) •Includes Autism & Traumatic Brain Injury (TBI) as “eligible disabilities” under the scope of the law

www.drcoplan.com

Prior to 1990, according to Federal regulations, **Autism did not exist.**

Changes in Federal Law - 4

Year	Event	Comment
1991	US Department of Education, Office of Special Education Programs (OSEP) requires reporting of autism by the States, starting in 1992.	<ul style="list-style-type: none"> • Coincides with implementation of Part B (3 to 5 yr olds) & Part H (birth to 3) of PL 99-457

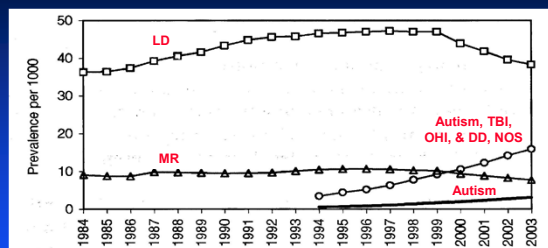
www.drcoplan.com

Impact of Federal Law & Regulations

- ↑ Services to children 0-5
- ↑ Reporting to US Dept of Education
- Re-classification of children already in the system (diagnostic substitution)
- Correct classification of children with autism entering the system

www.drcoplan.com

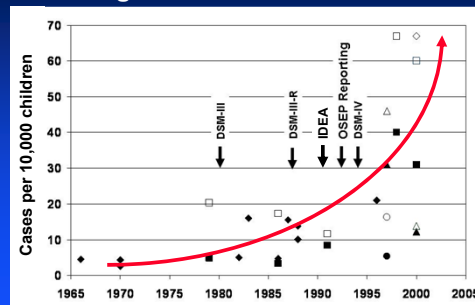
Diagnostic Substitution



Prevalence of selected reporting categories, US special education, age 6 to 11, 1984-2003. Shattuck, Pediatrics, 2006.

www.drcoplan.com

Prevalence of ASD, 1965 – 2005, relative to Changes in DSM & Federal Law



www.drcoplan.com

Following the money

- \$ earmarked for children with ASD
- Pressure to make an ASD diagnosis in order to access to services
- Limits the reliability of “second source” (school, medical records) information as a proxy for prevalence of ASD

www.drcoplan.com



Centers for Disease Control and Prevention
MMWR

Morbidity and Mortality Weekly Report
Surveillance Summaries / Vol. 61 / No. 3
March 30, 2012

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008

TABLE 2. Estimated prevalence* of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008

Site	Total no. Total no. with ASDs	Total†		Male		Female		Male to female prev ratio‡
		Prev	95% CI	Prev	95% CI	Prev	95% CI	
Total	337,093	11.3	(11.0–11.7)	18.4	(17.7–19.0)	4.0	(3.7–4.3)	4.6

11.3 cases / 1000 children = 1 in 88

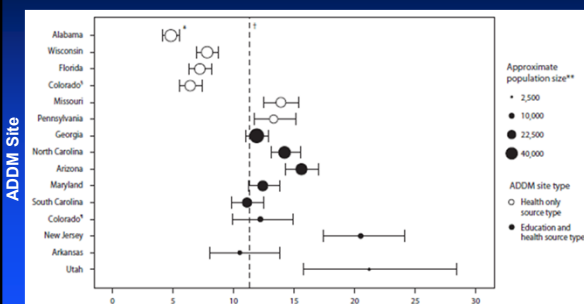
CDC Prevalence Estimates for ASD, 2008

- **Autism and Developmental Disabilities Monitoring Network (ADDM)**
 - 14 Sites (Universities, State Depts of Health; not demographically representative of the US as a whole)
- **Data sources:**
 - Healthcare organizations (general & specialty)
 - Schools (some sites)
- **N = 337,093 children, age 8**
- **3,820 met surveillance case criteria for ASD**
 - 79% had a pre-existing Dx of ASD in their records
 - 21% had no ASD Dx in their records

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, March 30, 2012 / 61(S503);1-19
http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?ts_cid=ss6103a1_w

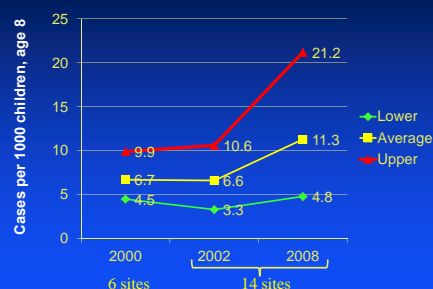
CDC Prevalence Estimates for ASD (2008)

MMWR 3/30/2012 http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?ts_cid=ss6103a1_w



Prevalence (cases / 1000 children, age 8)

CDC Prevalence Estimates for ASD, 2000, 2002, 2008



Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, March 30, 2012 / 61(S503);1-19
http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?ts_cid=ss6103a1_w

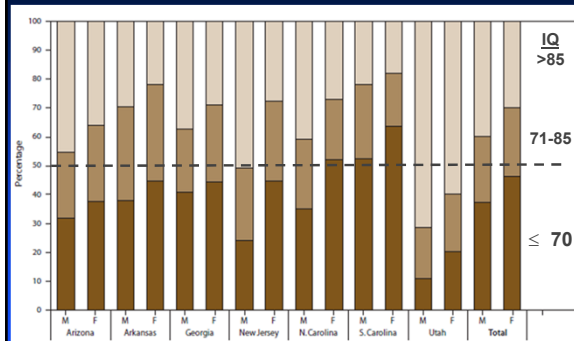
CDC Prevalence Estimates for ASD, 2008

Prevalence (cases per 1000 children), and Prevalence Ratios						
	White	Black	Hispanic	W:B	W:H	B:H
Mean	12.0	10.2	7.9	1.2 : 1	1.5 : 1	1.3 : 1
Range	5.0 – 40.0	4.0 – 25.9	1.4 – 20.0	1.0 – 1.9 : 1	0.6 – 3.5 : 1	0.4 – 5.8 : 1

TABLE 2. (Continued) Estimated prevalence of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. MMWR 3/30/2012
http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?_cid=ss6103a1_w

www.drcoplan.com

IQ breakdown for children meeting criteria for ASD (CDC, 2008)



MMWR 3/30/2012 http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?_cid=ss6103a1_w

CDC Data

- **Internal variability**
 - Overall prevalence
 - Ethnic ratios
 - IQ distribution (proportion with IQ > 70)
- **21% of CDC “cases” had no mention of ASD in their records. What does this mean?**
- **Need for random sampling with testing, rather than relying on secondary source information**

Confounding Variables

Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study

Durkin MS, Maenner MJ, Meaney FJ, et al.
2010 PLoS ONE 5(7): e11551.

Prevalence of children with an ASD diagnosis increased with increasing household SES* in a dose-response manner ($p < 0.001$):

- Low SES: 0.70
- Middle SES: 1.0 (reference standard)
- High SES: 1.25

*SES: Socioeconomic status (income, education)

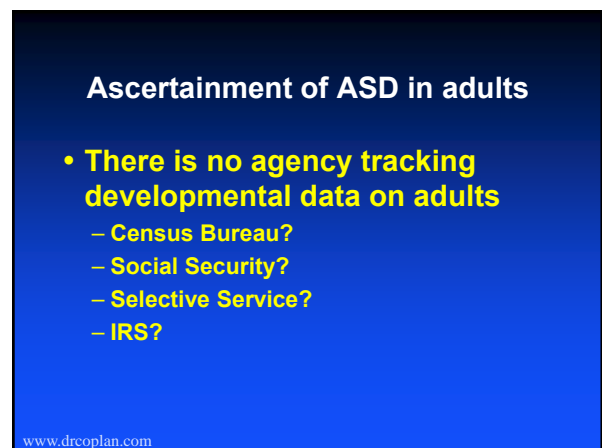
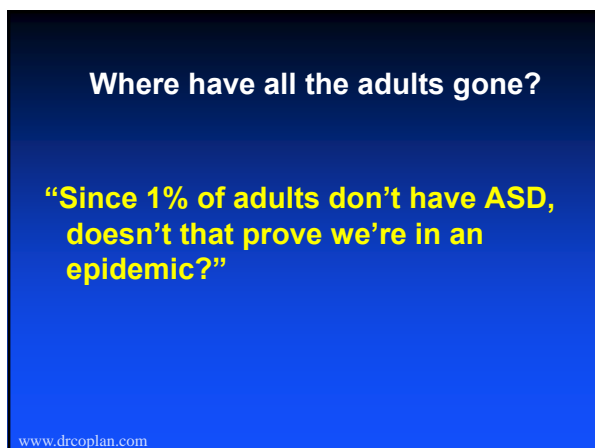
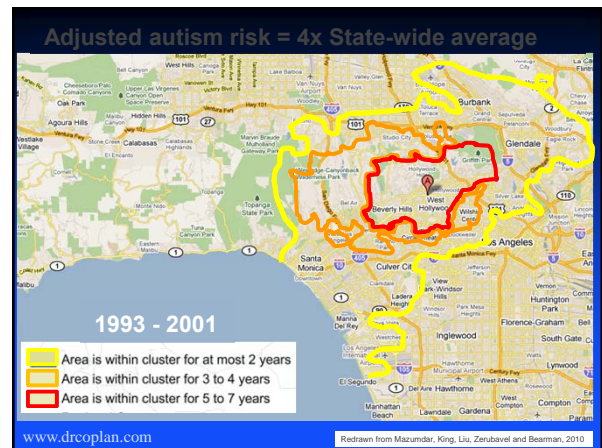
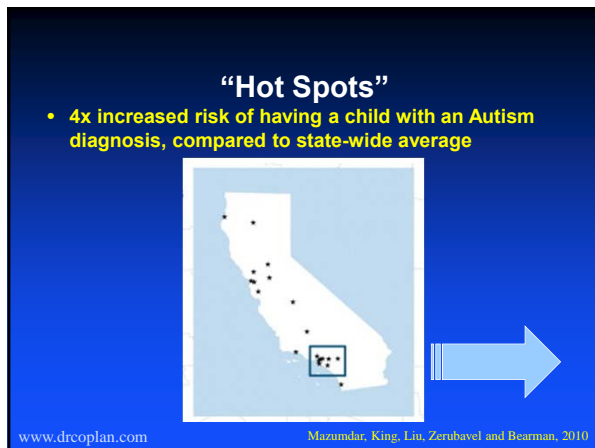
The spatial structure of autism in California, 1993–2001

Health & Place

Volume 16, Issue 3, May 2010, Pages 539–546

[Somenia Mazumdar](#), [Marissa King](#), [Ka-Yuet Liu](#), [Naomi Zaslavsky](#) and [Peter Dvoretzky](#)

Institute for Social and Economic Research and Policy Columbia University, New York, NY, USA



Post-High School Service Use Among Young Adults With an Autism Spectrum Disorder

Paul T. Shattuck, PhD; Mary Wagner, PhD; Sarah Narendorf, MSW; Paul Sterzing, MSSW; Melissa Hensley, MSW
Arch Pediatr Adolesc Med. 2011;165(2):141-146.

- **National Longitudinal Transition Study (NLTS)**
- **920 HS students with ASD → F/U to age 23**
- **Overall rates of service use after leaving HS:**
 - Medical services: 23.5%
 - Mental Health Services: 35.0%
 - Case management: 41.9%
 - Speech therapy: 9.1%
 - No services: 39.1%
- **Odds of not receiving any services:**
 - 3.31 times higher for African Americans compared with whites
 - 5.96 times higher for those with incomes < \$25,000 compared with those with incomes > \$75,000

www.drcoplan.com

“Missing” adults: NHS Survey

Autism Spectrum Disorders in adults living in households throughout England

Report from the Adult Psychiatric Morbidity Survey 2007

www.drcoplan.com <http://www.drcoplan.com/autism/missingadults.htm>

NHS Survey 2007



- National sample of survey of adults living in the community
- Excludes persons in residential care
- Therefore, under-counts adults with severe disability

www.drcoplan.com <http://www.drcoplan.com/autism/missingadults.htm>

NHS Survey 2007

Phase 1
• Autism Quotient (20-Item Screen)
• N=2,854

↓

Phase 2
• ADOS (Autism Diagnostic Observation Schedule)
• N=618

↓

Prevalence of ASD: 1 %

- Male: 1.8% (1 in 56)
- Female: 0.2% (1 in 500)

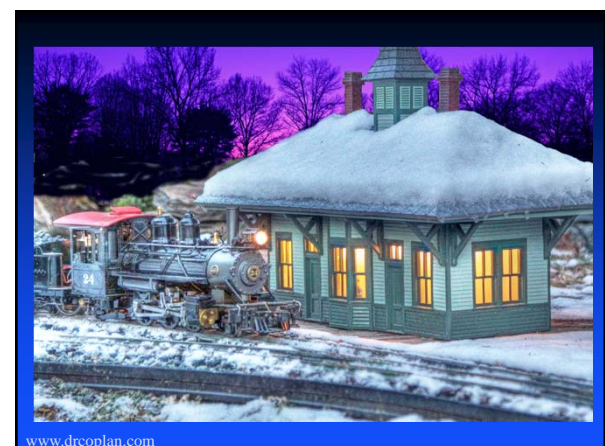
www.drcoplan.com <http://www.drcoplan.com/autism/missingadults.htm>

NHS Survey 2007: Prevalence of ASD per 100 adults

Age group		
16-44	45-74	75+
%	%	%
1.1	0.9	0.8

Prevalence x Age: Not statistically significant

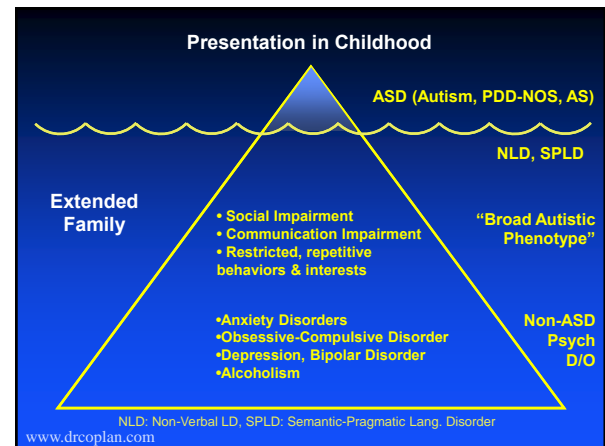
www.drcoplan.com <http://www.drcoplan.com/autism/missingadults.htm>



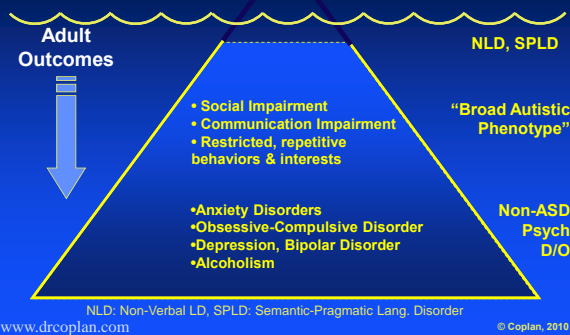
“Losing the diagnosis”

- **Just because someone outgrows childhood criteria for ASD does not mean that they are cured**

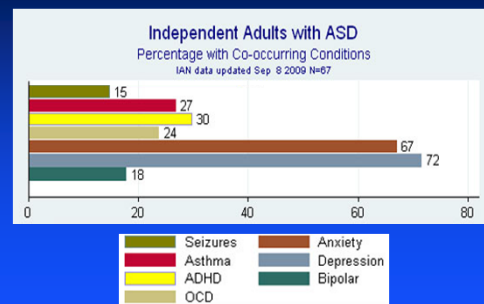
www.drcoplan.com



“Missing” adults

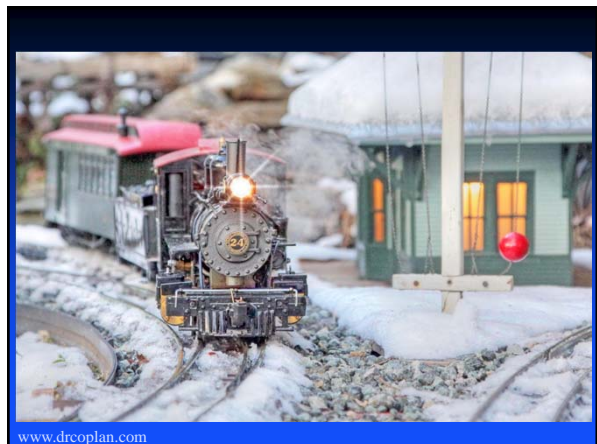


Interactive Autism Network On-Line Survey



“Missing” Adults

- Properly done epidemiologic investigation of adults suggests a 1% prevalence rate for **mild ASD plus normal IQ**.
- In addition, there are adults with:
 - Severe ASD / Low IQ in institutional care
 - Minimal residual atypicality, or who have gone off the spectrum altogether, but have significant emotional issues (anxiety, depression)
- The “missing” adults are out there!



Summing up....

The ASD “Explosion”

- Service load is definitely increasing, but unclear if true prevalence has changed
- ⬆ Prevalence of children getting ASD diagnosis
 - Broader definitions (DSM III, III-R, IV). Impact of DSM V?
 - US Dept of Education recognition of autism (1990)
 - Federal service & reporting requirements (1992)
 - Funding & services tied to Dx of ASD creates pressure to get the Dx
- Confounding variables
 - Racial and Geographic disparities in apparent prevalence
 - Higher SES ➔ higher chance of Dx
- No proof of an epidemic (⬆ Incidence)

www.drcoplan.com

You cannot get a speeding ticket for having a full tank of gas.



www.drcoplan.com

Implications

- Beware of any arguments that claim we are in an epidemic
 - Allegations as to cause
 - Promises of cure

www.drcoplan.com



Thank you!

www.drcoplan.com