

Health Insurance Options for Children with Autism Spectrum Disorders

Meg Comeau, MHA



Boston University School of Public Health

Who we are

- **Funded by** the Maternal and Child Health Bureau
- **A project of** the Health and Disability Working Group at the Boston University School of Public Health
- **The National Center dedicated to the MCHB outcome measure:** “...all children and youth with special health care needs have access to adequate health insurance coverage and financing”.

What do we do?

- Conduct policy research to identify and evaluate financing innovations
- Create resources (publications, webinars)
- Provide technical assistance on health care financing policy and practice
- Connect those interested in working together to address complex financing issues

What can't we do?

- No direct advocacy
- No benefits counseling
- No lobbying

Children with Autism and Autism Spectrum Disorders:

The Numbers

Out of all children with special health care needs, **5.4%** of them have autism or an ASD (approximately 544,181)

Almost half (**44.1%**) have four or more co-existing health conditions

Unless otherwise noted, statistics in this presentation are from the Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved 3/24/11 from www.cshcndata.org

Health Insurance and Children with Autism/ASD: The Numbers

Children with Autism/ASD: comparison of insurance coverage types

Type of insurance	Children with Autism/ASD	Other CSHCN
Private insurance only	48.7%	61.5%
Public insurance only	32.6%	28.0%
Both public and private	15.3%	7.0%
Uninsured	3.5%	3.5%

Currently insured children
with Autism/ASD whose insurance
is inadequate
(according to their families)

Children with Autism/ASD	Other CSHCN
48.6%	32.0%

Impact on families of children with Autism/ASD

Children with Autism/ASD whose families pay \$1,000 or more out-of-pocket in medical expenses per year for their child

Children with Autism/ASD	Other CSHCN
31.0%	19.5%

Children with Autism/ASD whose condition(s) cause financial problems for the family

Children with Autism/ASD	Other CSHCN
38.6%	16.7%

Children with Autism/ASD whose condition(s) caused family members to cut back on or stop working

Children with Autism/ASD	Other CSHCN
57.2%	21.7%

Impact on Children with Autism/ASD - Summary

Compared with other CSHCN, children with Autism/ASD:

- Have significantly higher rates of co-existing conditions than other CSHCN
- Have slightly lower rates of private insurance and slightly higher rates of public insurance
- Have just over twice the rate of dual (combined public/private) coverage than other CSHCN
- Are just about as likely to be uninsured

Impact on Families of Children with Autism/ASD - Summary

Compared to other families of CSHCN, families of children with Autism/ASD:

- Experience financial hardship at significantly higher rates
- Have significantly higher out-of-pocket medical expenses (\$1,000 or more per year)
- Are significantly more likely to have employment impacts

Coverage Options for Autism/ASD Services

- Private Insurance
 - State Mandated Benefits
- Medicaid
 - Buy-in Programs and Waivers
- Provisions related to private and public coverage in Federal Health Care Reform (ACA)

State Mandated Benefits

- Mandated benefits are state laws requiring private insurance companies to cover specific care/services
- Self-funded (sometimes called ERISA) plans are exempt from state mandated benefits – approximately 50-60% of private insurance is through self-funded plans
- The devil is in the details – variation from state to state in what is actually covered

States in which Autism insurance reform laws have been passed

- Arizona
 - Arkansas
 - Colorado
 - Connecticut
 - Florida
 - Iowa
 - Illinois
 - Indiana
 - Kansas
 - Kentucky
 - Louisiana
 - Maine
 - Massachusetts
 - Missouri
 - Montana
 - Nevada
 - New Hampshire
 - New Jersey
 - New Mexico
 - Pennsylvania
 - South Carolina
 - Texas
 - Vermont
 - Wisconsin
- n = 24

Source: Autism Speaks

States not currently pursuing Autism insurance reform legislation

- Oklahoma
 - Utah
 - Wyoming
- n = 3

Every other state either has an autism insurance reform bill under consideration or one is being worked on....



It's time for lawmakers to listen.



AUTISM SPEAKS
It's time to listen.



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TAKE ACTION

Autism Votes News:

 [Autism Speaks Endorses Delaware Autism Insurance Reform Bill](#)
(March 22, 2011)

 [Autism Speaks Endorses North Carolina Autism Insurance Reform Bill](#)
(March 18, 2011)

 [Autism Speaks Applauds Introduction of Legislation to End Insurance Discrimination Against New Yorkers with Autism](#)
(March 15, 2011)

2011 State Autism Insurance Reform Initiative Map:

The map below shows the current status of the state autism insurance reform initiatives.

Click the map to learn more about autism insurance reform legislation in your state!



STAY INFORMED

Enter your email address below to receive updates from Autism Votes

GO »

▶ TAKE ACTION IN YOUR STATE!

▶ TAKE ACTION ON FEDERAL LEGISLATION!

▶ JOIN AUTISM VOTES MOBILE: TEXT "AVOTES" TO 30644 TO GET ACTION ALERTS RIGHT ON YOUR MOBILE PHONE!

To learn more about state-specific mandated benefit laws for autism services*:

Frequently Asked Questions About the State Autism Insurance Reform Laws

at

<http://www.autismvotes.org/site/c.frKNI3PCImE/b.5216007/k.EE12/Resources.htm>

*Needs to be updated to include all 24 current reform laws

Medicaid 101

- Public benefit program that covers low income/disabled children
- Generally offers a more comprehensive benefit package with lower cost-sharing than CHIP or private insurance (EPSDT)
- Federal match stretches state dollars further than they'd go otherwise
- Can serve as a 'wrap' to fill in gaps in private coverage
- Serves as the "children's health insurance safety net"

Some ways to expand coverage for and close gaps in autism services through Medicaid

- Medicaid buy-in program created through a waiver
- Medicaid buy-in program created through the Family Opportunity Act
- Create HCBS waiver programs or increase the number of slots within existing waivers
- TEFRA state plan option/Katie Beckett waivers

Medicaid buy-in programs created through a waiver

Example: The Massachusetts CommonHealth program

Families can 'buy in to' Medicaid coverage for a child:

- With a 'severe disability' – SSI criteria
- Full Medicaid coverage if uninsured
- Supplemental coverage if privately insured

The Massachusetts CommonHealth program

- No limit on family income
- Premium schedule based on a sliding scale

The Family Opportunity Act's Medicaid Buy-in Option

Part of the 2005 Deficit Reduction Act
Not a waiver; state plan option

Families can 'buy-in' to Medicaid coverage
for a child:

- With a 'severe disability' – SSI criteria
- Full Medicaid coverage if uninsured
- Supplemental coverage if privately insured

FOA provisions

- Limit on family income: must be below 300% of FPL (AGI)
- Premiums may be charged and there is a limit on how high they can be
- States may provide premium assistance to help families purchase private coverage

Medicaid Waivers

- “Waives” certain federal rules: allows states to offer different benefits to specific populations, disregard income limits, more....
- Can include a more expansive list of services/supports than state plan offers (not just medical care)
- Approximately 30 states have waivers that serve children/people with autism (either specifically or as part of a larger ID/DD population)
- Cost neutrality = **waiting lists**
- The devil is in the details – variability across states with regard to what is covered exactly and who is eligible

Resource on state Medicaid waivers for children with autism/ID/DD

- Centers for Medicare and Medicaid Services (CMS) website – Medicaid Waivers and Demonstrations List:

<http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/itemdetail.asp?filterType=dual,%20keyword&filterValue=autism&filterByDID=0&sortByDID=2&sortOrder=ascending&itemID=CMS1229190&intNumPerPage=2000>

TEFRA state plan option/Katie Beckett Waiver

- **TEFRA state plan option:** requires institutional level of care (ILC) but parental income is deemed
- Covers 'medically necessary' care
- Cost neutrality does not apply – generally means no waiting list

- **Katie Beckett waiver** – also includes ILC; waiting list may be a concern
- Wrap services offered along with medical care

Waiver-TEFRA-FOA comparison

	Waiver (HCBS, KB etc.)	TEFRA	FOA
Level of care	Institutional	Institutional	SSI disability
Income level	None	None	300% FPL limit
Benefits	Medicaid + wrap services	Medicaid	Medicaid
Authority	Waiver	State Plan	State Plan
Premiums	Optional/none	Optional/none	Optional/none
Entitlement	No – wait list	Yes	Yes

Relevant provisions in ACA for children with Autism/ASD

- Prohibition on pre-existing condition exclusions
- Guaranteed issue and guaranteed renewal
- Prohibition against rescission of coverage
- Removal of lifetime and annual benefit caps
- Cost-sharing limits
- Essential benefits in Exchange plans and individual/small group market include:
 - Mental and behavioral health services
 - Habilitative and rehabilitative therapies
 - More?

ACA – the devil is in the details

- Many of the consumer protection provisions will provide relief for many of the gaps in the current system of financing care for children with autism/ASD and their families
- Not every provision applies to every plan – grandfathered and self-funded plans are exempt from some provisions
- Many provisions roll out over time (2010-2014)
- Essential benefits only apply to some plans; while the broad categories identified in ACA are very promising, the exact scope, depth and duration of the specific benefits (like ABA for example) are still being worked out

Catalyst Center health care reform resources

- The Affordable Care Act: a side-by-side comparison of major provisions and the implications for children and youth with special health care needs
- The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers

Both papers can be found at

<http://aca.catalystctr.org>, along with other health care reform and CSHCN resources

Questions?

For more information, contact

Meg Comeau, MHA

The Catalyst Center

Boston University School of Public Health

617-638-1936

mcomeau@bu.edu

www.catalystctr.org