



Developing a CWDA

Children with Disabilities Algorithm

Massachusetts Child Health Quality Coalition

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Pediatric Quality Measure Development

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Definition of “Person with Disabilities”

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.”

United Nations Convention 2010, Article 1

Prevalence of Children with Disabilities



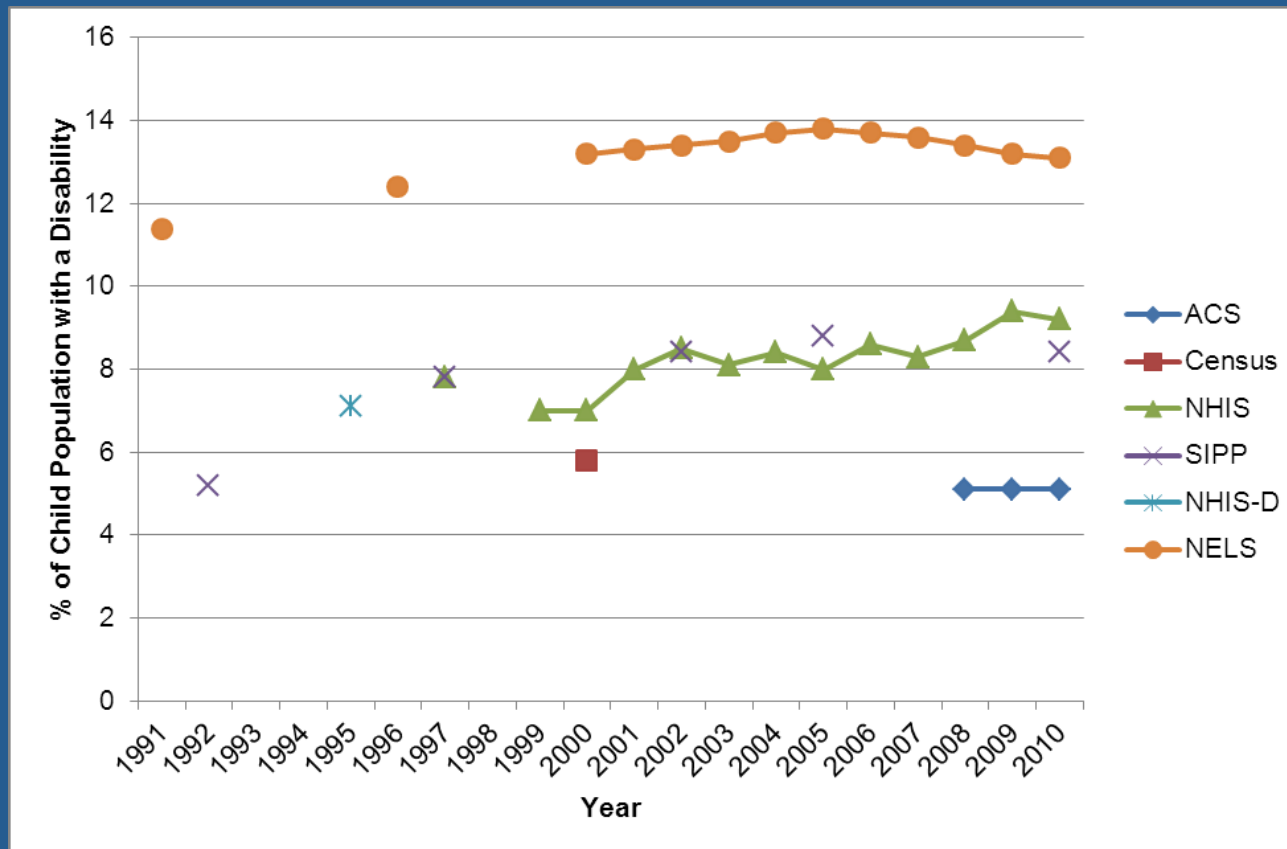
■ Children With Disabilities, 5-9%

■ Children Without Disabilities, 91-95%

Sources:

- 2010 American Community Survey
- 2010 National Health Interview Survey
- 2010 Survey of Income & Program Participation

Trends in Prevalence of Children with Disabilities



American Community Survey (ACS); Census 2000 (Census); National Health Interview Survey (NHIS); Survey of Income & Program Participation (SIPP); National Health Interview Survey on Disabilities (NHIS-D); National Education Longitudinal Study (NELS)

Children with Disabilities Use More Health Care Services

Average Annual Rates		
Measure	Children with Disabilities	Children without Disabilities
Prescribed Medication	6.2	1.8
Physician Visits	4.6	1.9
Allied Health Professional Visits*	3.0	0.6
Emergency Room Visits	0.25	0.13
Hospital Discharges Per 1000	97	23
Hospital Days Per 1000	464	55

*Non-physicians refer to physical therapists, psychologists, nurse practitioners, physicians assistants, etc.
 Source: 1999-2000 Medical Expenditure Panel Survey (MEPS)

Concerns about
Healthcare Quality
for Children with Disabilities

Concerns about Healthcare Quality

There is virtually no information about health care quality for children with disabilities.

However, the following sources suggest that there may be significant problems with care quality:

- Case reports
- Data from adult settings



Medical Care Often Inaccessible
to Disabled Patients (2007)

The New York Times

Disabled Patients Win Sweeping Changes
From HMO (2001)

The Boston Globe

2 flagship hospitals to upgrade accessibility:
Millions pledged for improvements (2009)

Clinical Anecdotes



“...Hospital staff have no real understanding of [children with behavioral impairments] and how their worlds work.

I try to impress upon [the Attending] how extraneous noise, light, human movement, and the absence of a communication partner could sabotage the medical objective.

[The Attending], however, is not listening and has no questions, only directives.”

*Sarabeth Broder-Fingert, Resident Physician
Academic Pediatrics 2012;12:469-470*

Family Experience



- “...Parents know the needs of their child best. They are with them 24 hours a day, 7 days a week. We need to be comfortable with the doctors we need for our child’s care and to obtain appropriate equipment and services.”

Wells N, Krass M, Anderson B, et.al. The Family Partners Project Report to Families. Family Voices. Unpublished manuscript. Boston, MA.

Disparities in Quality of Care Received by Adults with Disabilities vs. Those Without

Measure	Those Who Face Limitations When Doing Basic Activities	2008		2002	
		%	SE	%	SE
Difficulty getting care when needed	No	4.4	0.2	5.0	0.2
	Yes	11.4	0.7	12.9	0.8
Dissatisfaction with care received	No	8.7	0.3	10.3	0.3
	Yes	10.3	0.6	12.8	0.6

Source: 2011 National Healthcare Disparities Report, Agency for Healthcare Research and Quality.

The Importance of Developing CWDA

CWDA: It's the Right Time

We have:

1. An internationally recognized definition of “disabilities.”
2. Estimates for the prevalence of children with disabilities.
3. Evidence that children with disabilities use healthcare more than those without.
4. Significant concerns about the quality of care received by children with disabilities versus those without.
5. Federal interest in health care quality for children with disabilities

CWDA Development

- **ICD9 Code Classification**

- 5 step process combining independent and group processes
- 5 expert pediatricians in CWD
- At least 2 reviewers per code
- 20 specialty pediatricians
- >800 literature searches/citations

- **CWDA Triangulation**

- Medical Chart Abstraction
- Parent Survey

ICD9 Code Classification

Chance of being a disability	Number of codes	% of Medicaid-insured children who are CWD *	# of Medicaid children with ICD9 diagnosis*
≥90-100%	250	1%	86,327
≥75-100%	451	3%	229,261

*states included in Medicaid claims data: AZ, IN, KS, KY, MO, NJ, NM, VA, WI

To Target Surveys for Assessing Healthcare Quality for Children with Disabilities



Questions?
Comments?

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