The Patient Center Medical Home: Bridging Child-Oriented to Adult-Oriented Care for Children and Young Adults with Disabilities

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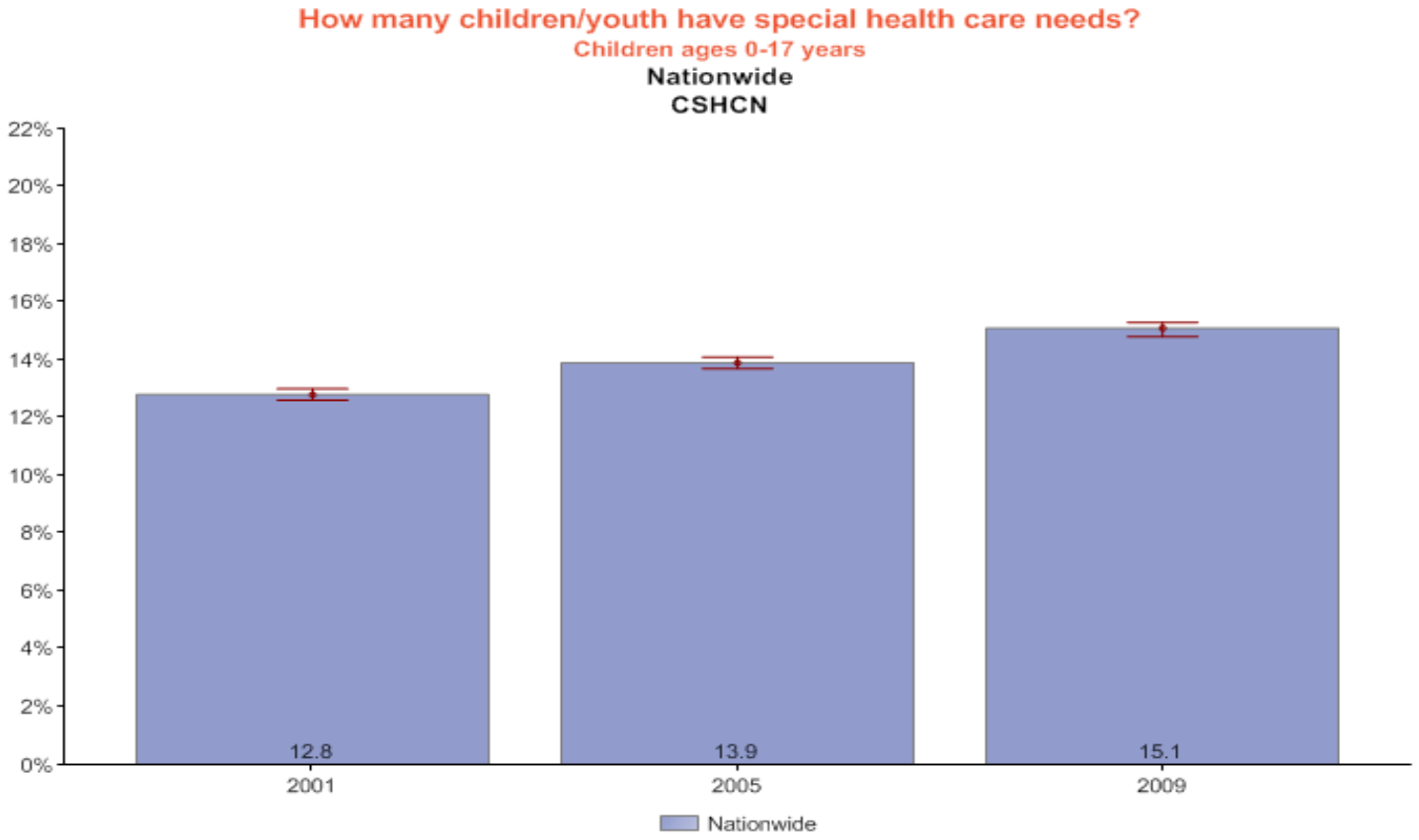
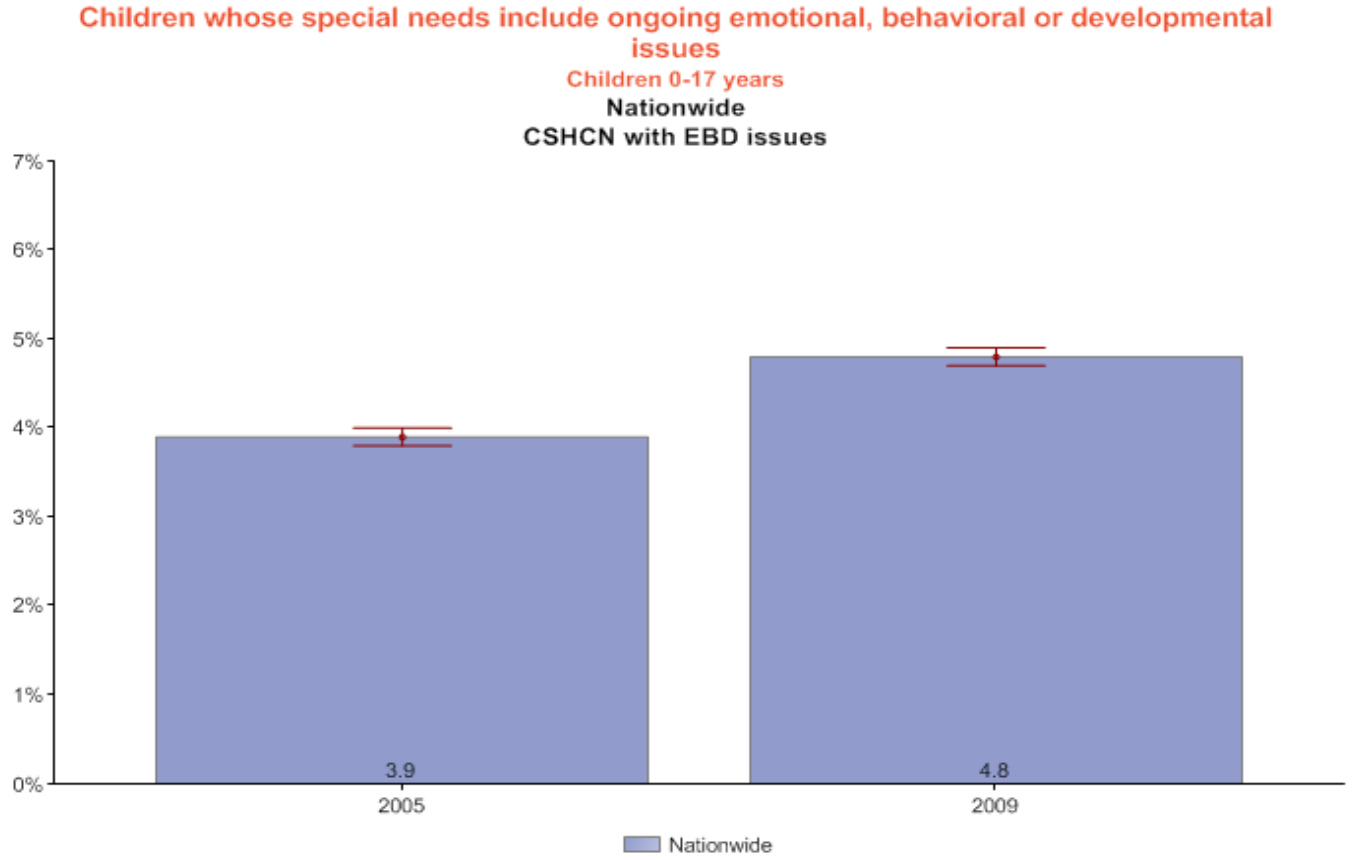
Prevalence of Children with Special Health Care Needs: US



2009/10 National Survey of Children with Special Health Care Needs; childhealthdata.org

Prevalence of Children with Special Health Care Needs with Behavioral Issues: US



2009/10 National Survey of Children with Special Health Care Needs: childhealthdata.org

Prevalence of Children in Need in the UK

- 2011:
- 390,300 children, equivalent to a rate of 343.3 per 10,000 children
- Total of 736,400 episodes of need

Transitioning and Health Care

- "An increasing number of chronically ill children are surviving into young adulthood. With over 85 percent of children with chronic illnesses (Betz, 1999) and 90 percent of those with disabilities (Bloomquist et al., 1998) surviving into adulthood, there is a growing need for specialised care to ensure a seamless transfer and transition from children's to adult health care services. There is also a need for greater attention towards transition within mental health services for 16 to 18 year olds."

From the perspective of health care providers

- Need "health care providers to have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity."

U.S. Department of Health and Human Services. 2005. Office of the Surgeon General. *Surgeon General's call to action to improve the health and wellness of persons with disabilities*. Rockville, MD.

US outcomes: health care from physician's perspective

- "A total of 57% of the general pediatricians reported that it was easy to communicate with an adult provider to transition their young adult patients to adult-based care, and 62% of internists reported that it was easy to communicate with a pediatric provider about transitioning."

Okumura, M.J., E.A. Kerr, M.D. Cabana, M.M. Davis, S. Demonner, and M. Heisler. 2010. Physician Views on Barriers to Primary Care for Young Adults with Childhood-Onset Chronic Disease. *Pediatrics* 125:e748

US: Satisfaction with Care

Variable	CSHCN with ASD %	CSHCN with other EBD problems %	Other CSHCN %
Any unmet need for specific care services	30.9	25.4	12.3
Any unmet need for family support services	19.3	10.7	1.8
Child had delayed or foregone care	13.8	12.2	6.8
Child had no usual source of care	5.6	7.0	5.2
Child had no personal physician or nurse	5.7	7.2	6.2
Difficulty receiving referrals	31.2	27.1	18.1

Kogan, M.D., B.B. Strickland, S.J. Blumberg, G.K. Singh, J.M. Perrin, and P.C. van Dyck. 2008. A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005-2006. *Pediatrics* 122:6:e1149-e1158.)

Institutional Bias

- "Historically, people with disabilities have been severely disadvantaged in accessing private health insurance … Medicaid's institutional bias…perhaps kept too many people with disabilities in nursing homes, despite clear consumer preference for and the cost-effectiveness of community living."
- 2011: 221 children in secure homes in UK
  - Locked environment
  - Restrict personal liberties

Kuo et al 2011; education.gov.uk

Benefits of community living

- Community-based services are "critical for optimal medical, developmental, and service outcomes."

Transition Barriers

- 2 distinct health care systems
- Organization of care
- Effective communication
- Physical barriers
- Social barriers
- Disease-specific barriers
- Lack of awareness

The Affordable Care Act

- "The Affordable Care Act advances community living by extending the Money Follows the Person program, improving the Medicaid home-and-community based services (HCBS) option, and creating new options and incentives making it easier for states to provide HCBS– including Community First Choice."

UK: National Health Services

- 2 sections:
- Primary Care
  - ‘frontline’
  - Independent contractors
- Secondary Care
  - ‘Acute Health Care’

Medical Homes in the UK

- "In 2001, the United Kingdom's National Health Services contracted with general practitioners to provide medical home services to patients. By 2005 these contracts had improved the quality of care. The rate of improvement further accelerated when financial incentives were added in 2005."

Rosenthal TC. The medical home, access to care, and insurance: a review of evidence. *Pediatrics*. 2004;113(5)(Suppl.):1493-1498

Medical Homes in the UK

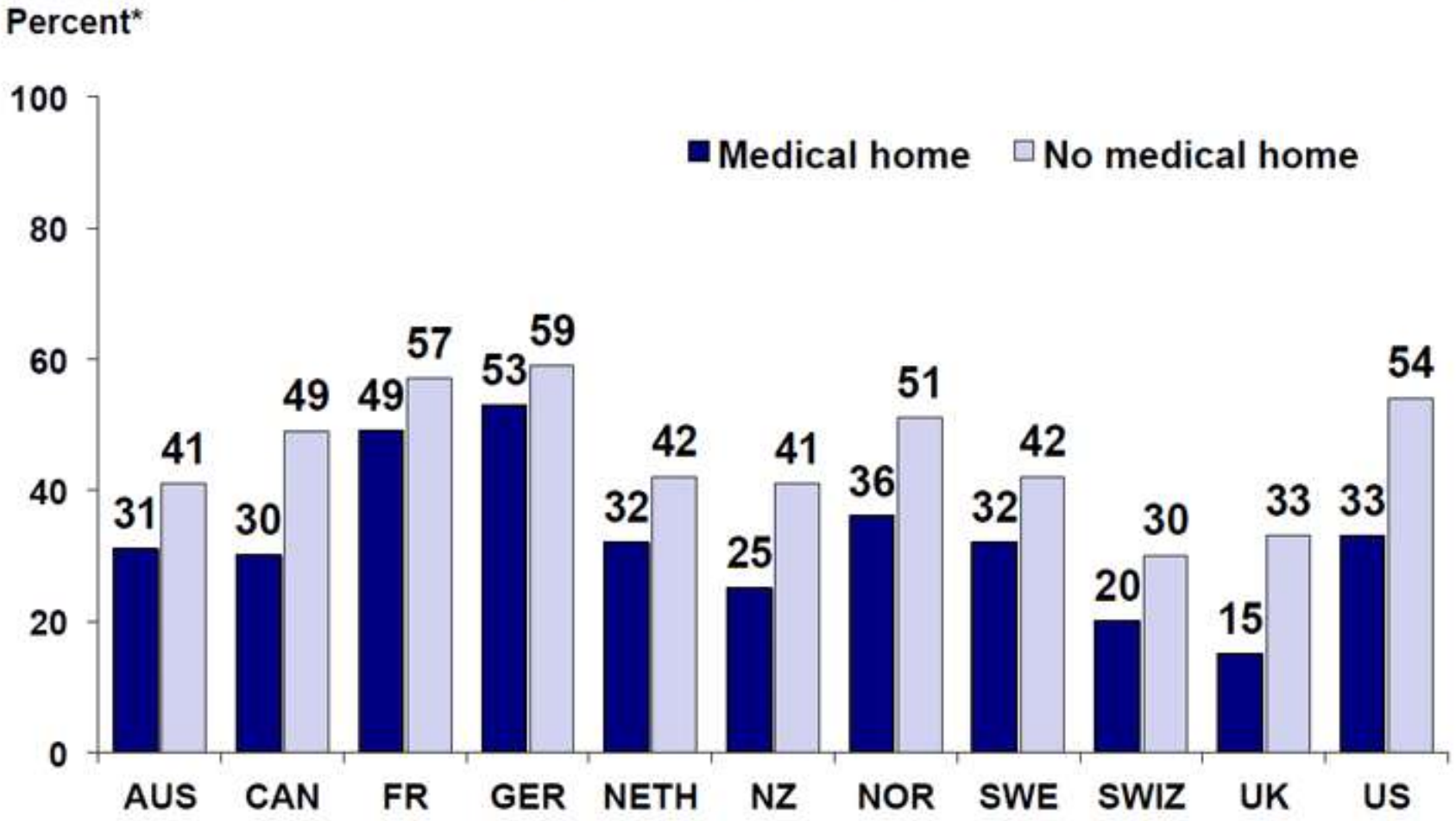
- "Across the diverse healthcare systems included in the study, patients who were connected to a medical home in general had more positive care experiences, including better support for managing chronic conditions, better communication, and better care coordination."

www.healthcareitnews.com/news/medical-homes-prove-worth-us-and-abroad

Medical Homes in the US

- American Academy of Pediatrics:
- The medical home is “an approach to providing comprehensive primary care” that “facilitates partnership between patients, physicians, and families”

Experienced Coordination Gaps in Past Two Years, by Medical Home



* Test results/records not available at time of appointment, doctors ordered test that had already been done, providers failed to share important information with each other, specialist did not have information about medical history, and/or regular doctor not informed about specialist care.

Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries.

Medical Home Data: CSHCN

Medical Home for Children with Special Health Care Needs, by Age: 2005-2006

(Age: All; Access to a Medical Home: All)

United States	Percent	
Age	Had Medical Home	Did Not Have Medical Home
Ages 0-5	50.4%	49.6%
Ages 6-11	47.4%	52.6%
Ages 12-17	45.2%	54.8%

Medical Home for Children with Special Health Care Needs, by Income Level: 2005-2006

(Income Level: All; Access to a Medical Home: All)

United States	Percent	
Income Level	Had Medical Home	Did Not Have Medical Home
0-99% of Federal Poverty Level (FPL)	34.0%	66.0%
100-199% of FPL	41.2%	58.8%
200-399% of FPL	51.1%	48.9%
400% of FPL or Higher	56.3%	43.7%

Lifespan Approach/Team Approach

- Group patients with similar needs
- Discuss changing health needs and critical care issues
- Team setting: learn from encounters and consolidate resources
- Improved care outcomes
- Cost effective
- Improved patient and provider communications

Lifespan Approach/Team Approach

- "Youth with lifespan-oriented providers were more likely than youth with child-only providers to have discussed changing health needs in adulthood and adult health insurance…these associations persisted after adjusting for demographics."
- Medical homes have proven to be cost-effective and considering the efficiencies and sustained access to resources and therapies over the patient's lifetime, savings for CSHCN would even be greater.

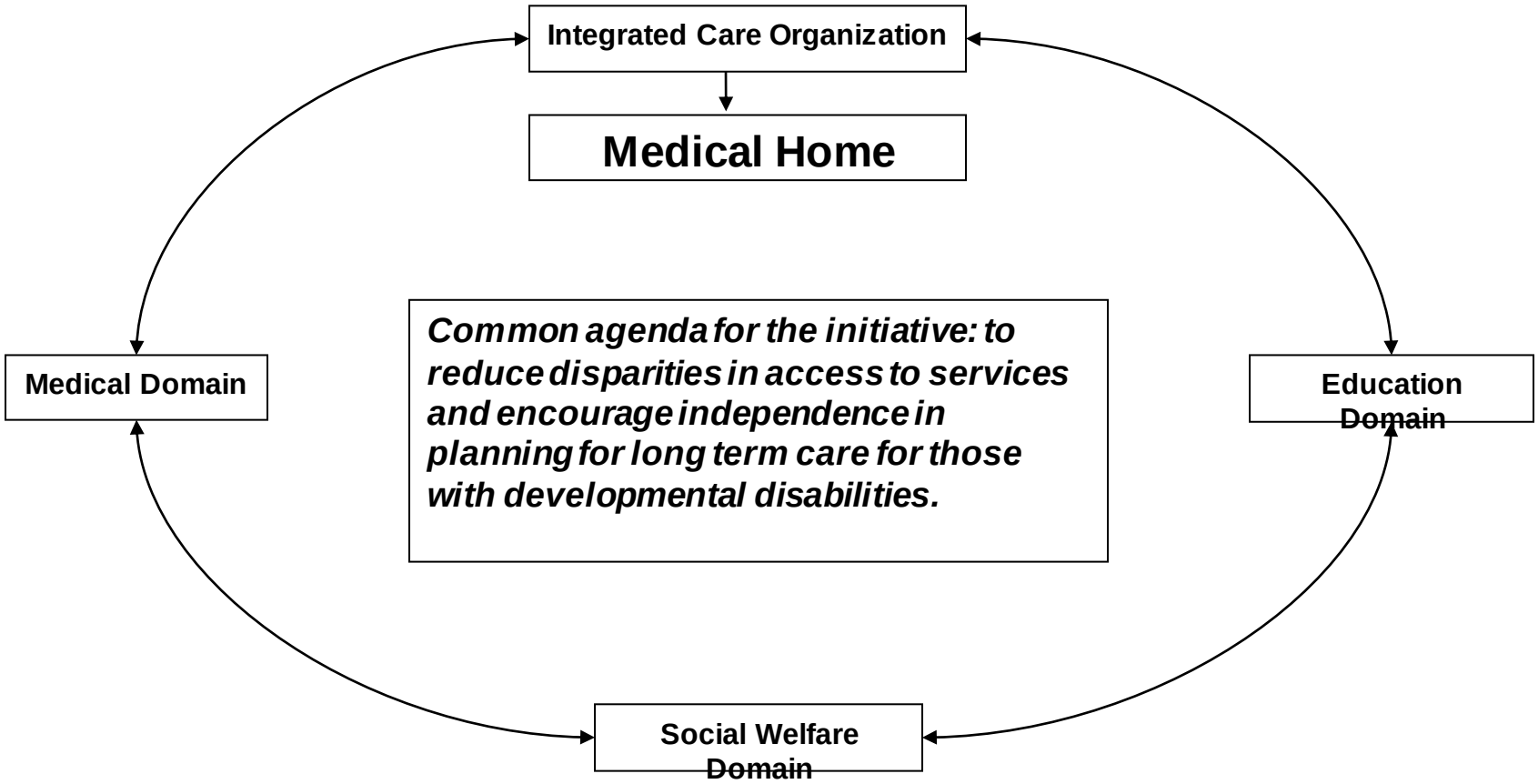
Nishikawa et al 2011; Kogan et al, 2008; Palsbo & Digo , 2010.

Ideal model for future care

- Practices consisting of healthy patients and special health care patients
- Flexibility in transition services
- Direct access to specialty care
  - "medical homes should not become barriers to specialty access"

Rosenthal TC. The medical home, access to care, and insurance: a review of evidence. *Pediatrics*. 2004;113(5)(Suppl.):1493-1498

Holistic Framework



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