

Disability Names and Numbers: Challenges and Opportunities in Nosology, Epidemiology, and Equity/Disparity

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Workshop on Ensuring Quality & Accessible Care for Children
with Disabilities and Complex Health and Educational Needs

National Academies of Sciences, Engineering and Medicine
Washington, DC

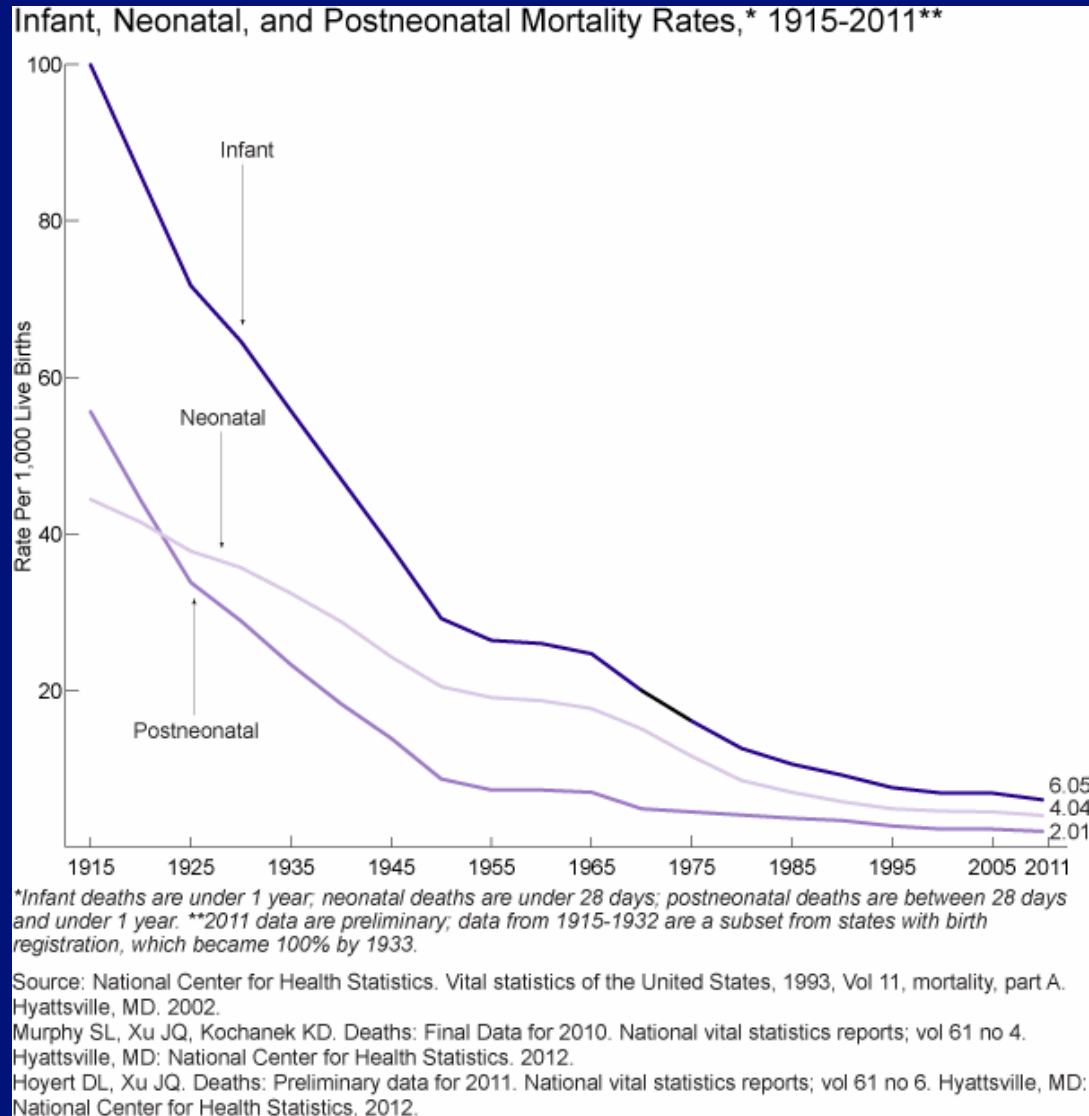
December 9, 2015



Overview

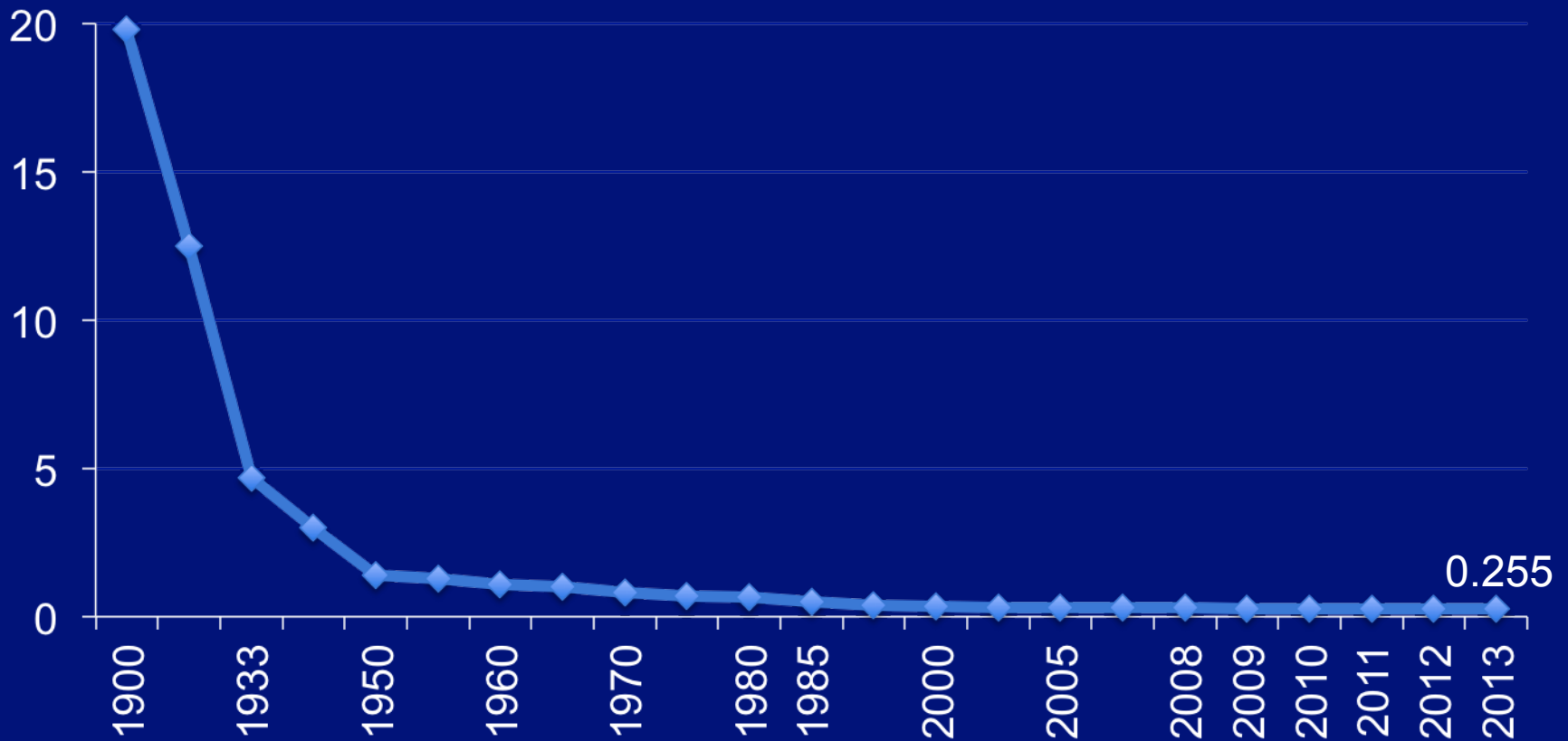
- Trends in the prevalence of disabilities and complex needs among US children, and their relationship to reductions in child mortality
- Two schools of thought affect policies and programs for children with special needs: social contract theory and utilitarianism
- Current gaps in knowledge, research priorities
- Societal benefits of including children with disabilities and complex needs in all programs and policies

Decline in Infant Mortality, United States, 1915-2011 (from 10% to 0.6%)

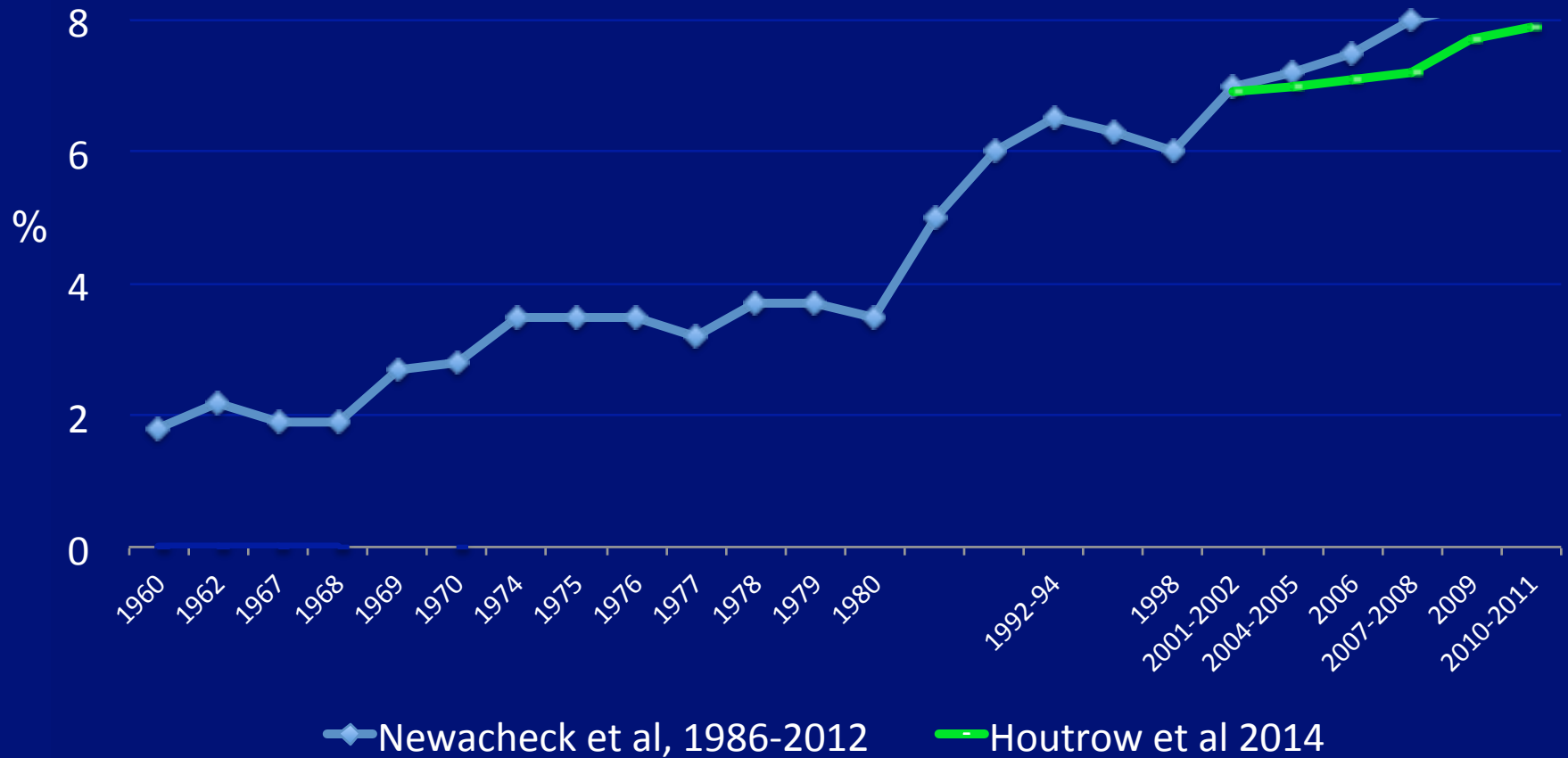


Similar Decline in Child Mortality, United States, 1910-2013

Deaths per 1,000 Children Ages 1-4 Years



Rise in the % of Children with Activity Limitations Due to Health, Ages 0-17 Years, Based on Parent Reporting, U.S. National Health Interview Survey, 1960-2011



Haflon N, et al, The changing landscape of disability in childhood.
The Future of Children, 2012; 22(1):13-42.

Much of the Rise in the Prevalence of Disability is Likely Due to Increasing Life Expectancy for Conditions Such as Down Syndrome

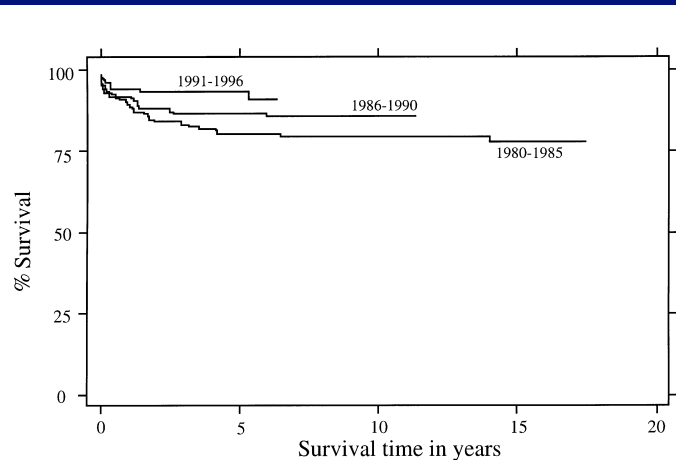
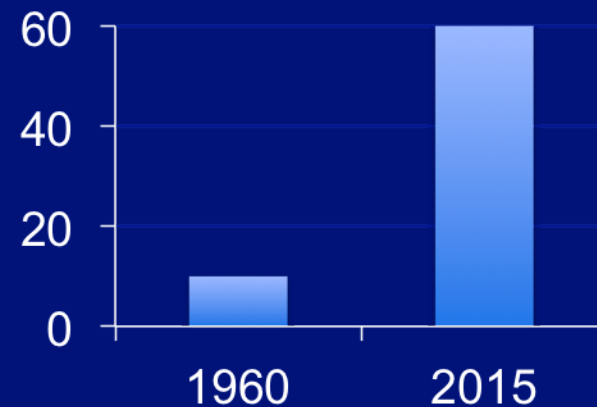


Figure 3. Livebirths of Down's syndrome, Western Australia, 1980-96: survival by birth cohort.

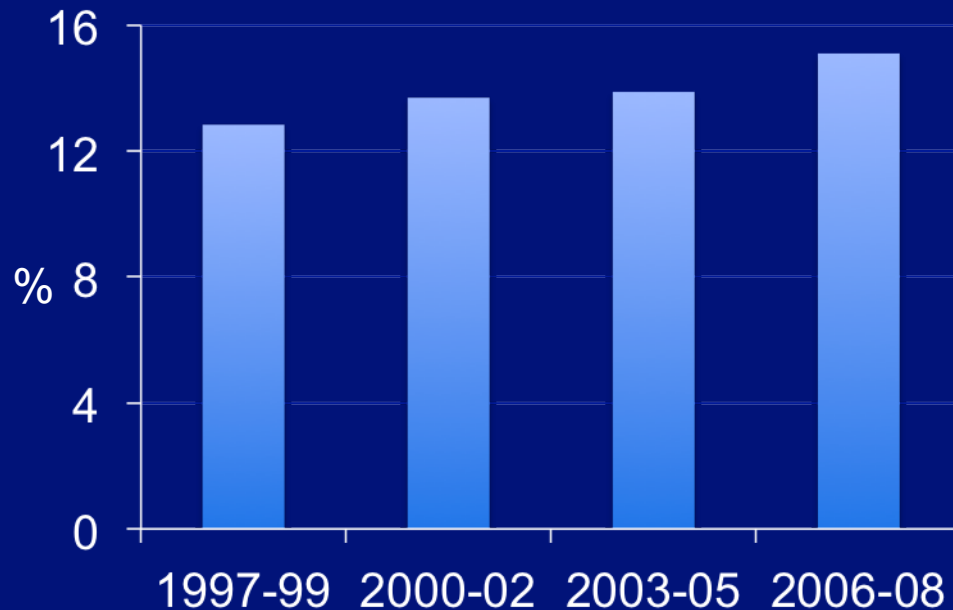
Estimated Life Expectancy (Years)



<http://www.ndss.org/Down-Syndrome/Down-Syndrome-Facts/>
<http://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>

Leanard S, et al, *Paediatric and Perinatal Epidemiology*, 2000; 14:163-71.

Rising % of Children with Developmental Disabilities in the U.S., based on parent report, ages 3-17, National Health Interview Survey



Greatest increases in autism and ADHD.

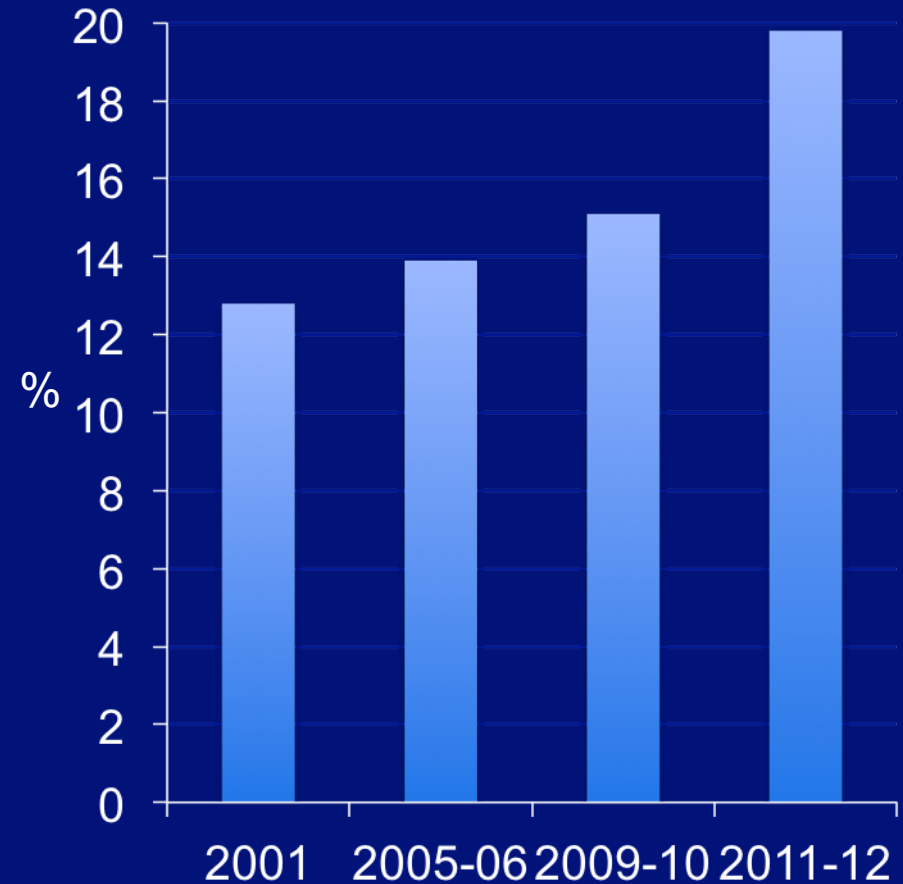
Survey Questions

- Has a doctor or health professional ever told you that [child] had any of the following conditions?
 - ADHD
 - Autism
 - Cerebral Palsy
 - Mental Retardation
 - Other developmental delay
- During the past 12 months, has [child] had any of the following conditions?
 - Seizures
 - Stuttering or stammering
- Additional questions about hearing, vision, learning disability.

% of Children with Special Health Care Needs (CSHCN) in the U.S., parent report, ages 0-17, National Survey-CSHCN

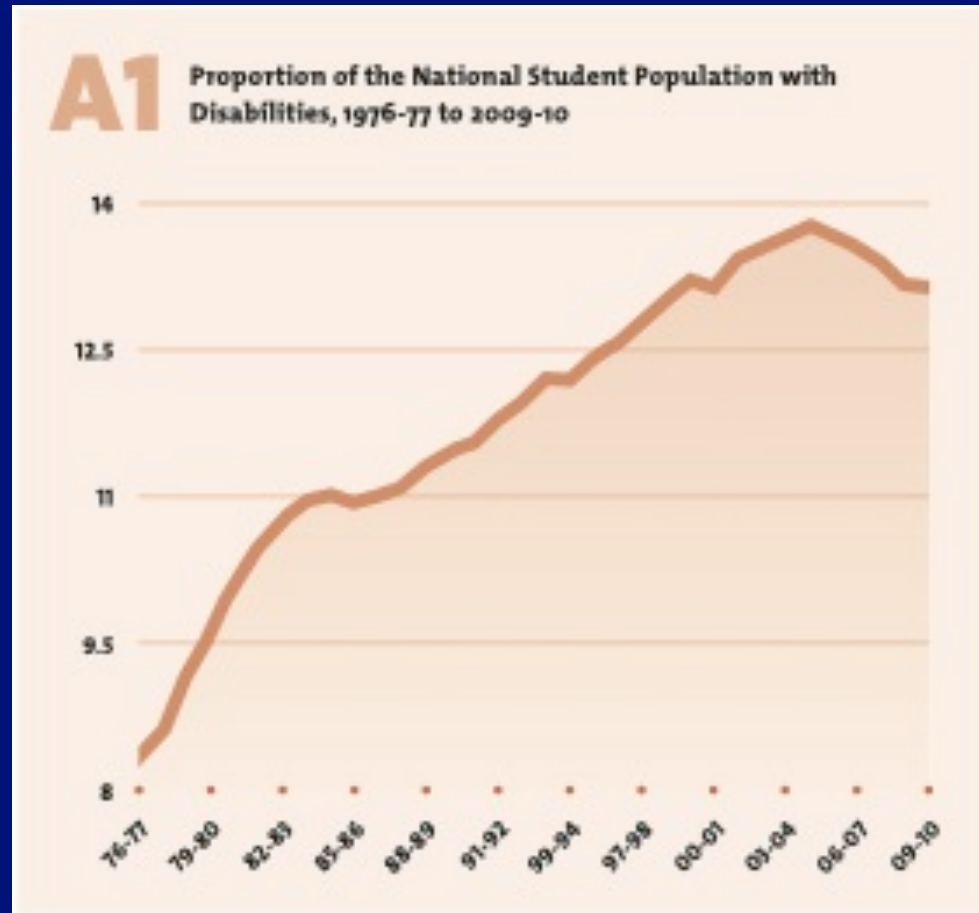
CSHCN Screener

1. Does your child currently need or use **medicine prescribed by a doctor?**
2. Does your child need or use more **medical care, mental health, or educational services** than is usual for most children of the same age?
3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
4. Does your child need or receive **special therapy**, such as physical, occupational, or speech therapy?
5. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or receives **treatment or counseling?**



Bethell CD, et al, *Ambulatory Pediatrics*, 2002; 2(1):38-48

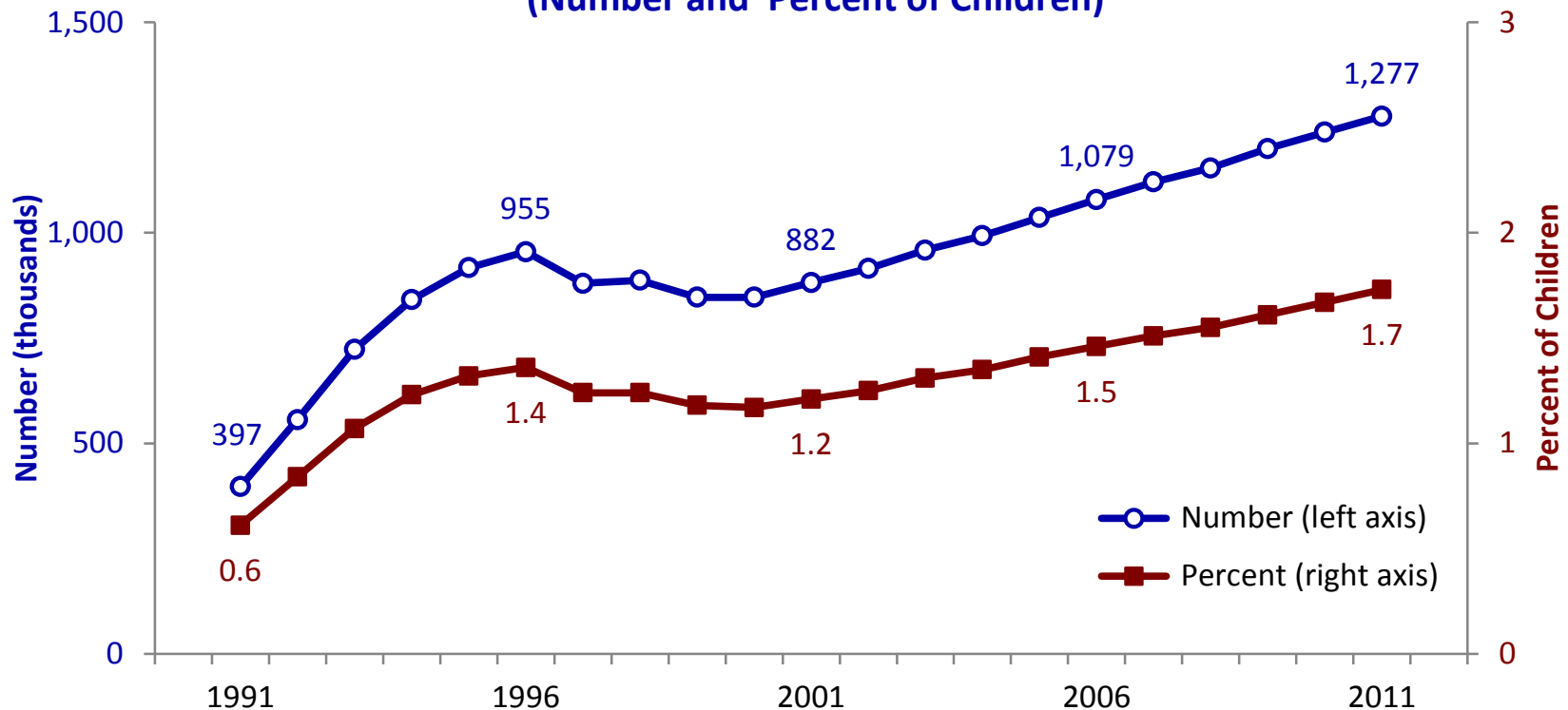
Special Education Enrollment in the US Increased from ~8% in the 1970s to ~13% Today



Scull J, Winkler AM, Shifting Trends in Special Education, Fordham Insitute, 2011
http://edex.s3-us-west-2.amazonaws.com/publication/pdfs/ShiftingTrendsInSpecialEducation_7.pdf

The number of children with disabilities receiving SSI more than tripled between 1991 & 2011

**Figure 1. Child Recipients of SSI Benefits: 1991-2011
(Number and Percent of Children)**

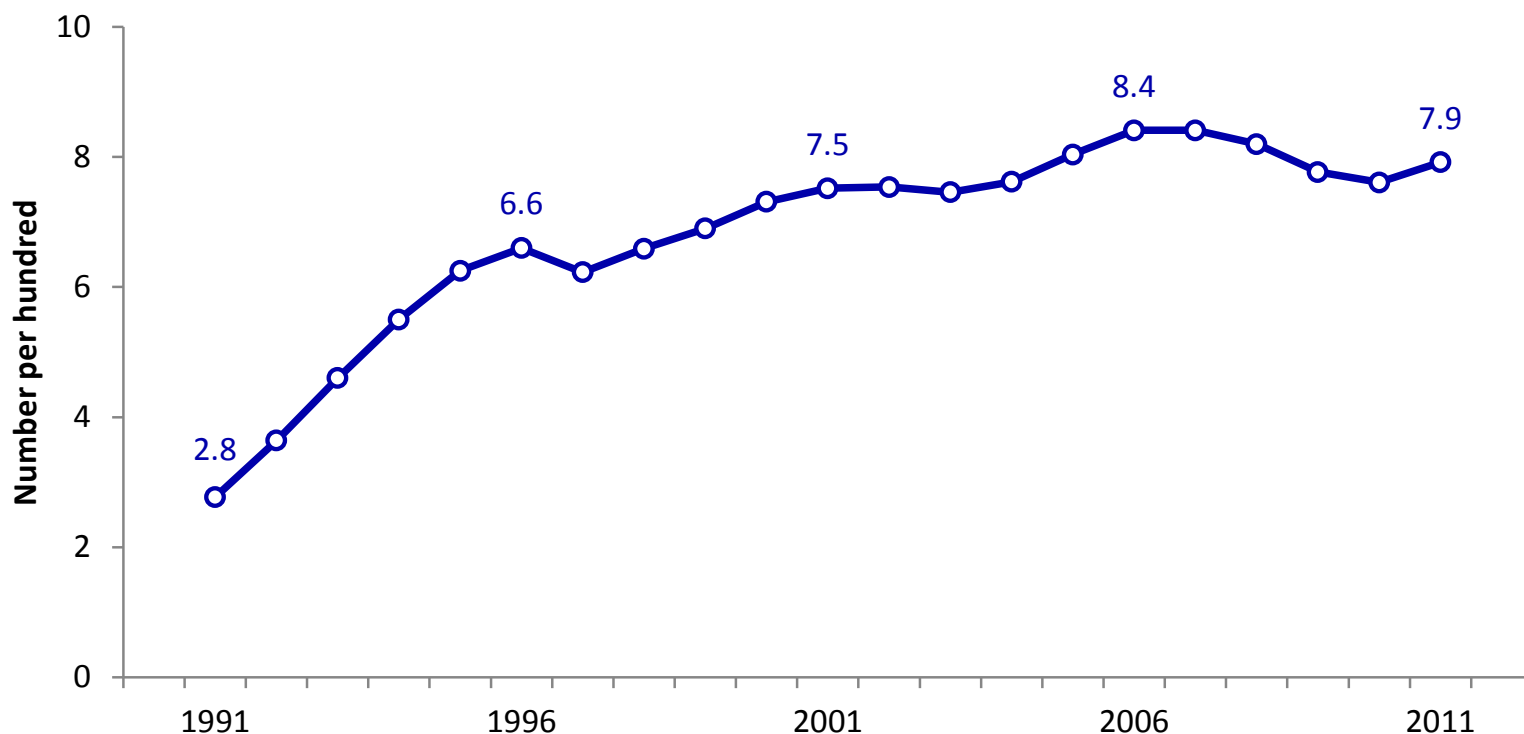


Note: These data are as of December of each year.

Source: U.S. Census Bureau, Population Estimates Branch, and Social Security Administration, *SSI Annual Statistical Report*;

% of children in poverty who received SSI disability benefits also increased

Figure 2. Number of Child SSI Recipients per Hundred Poor Children: 1991-2011

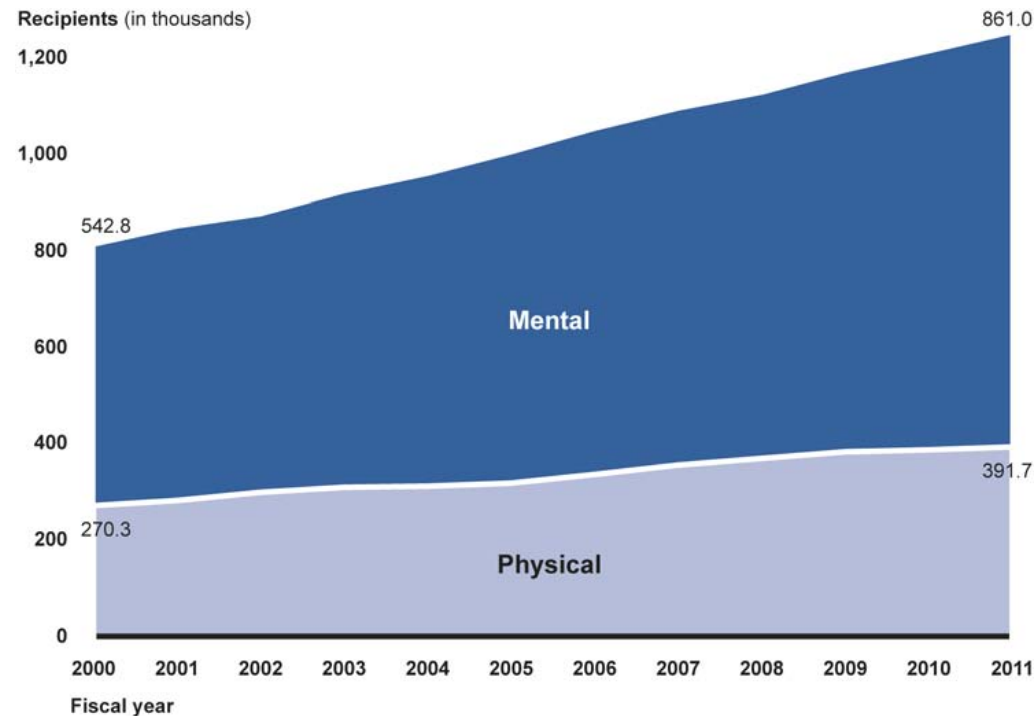


Note: These data are as of December of each year.

Source: U.S. Census Bureau, Poverty Statistics Branch, and Social Security Administration, *SSI Annual Statistical Report*; calculations by ASPE.

Increase in Number of Children with Disabilities Receiving SSI, 2000-2011, Due Mostly to Increases in Mental Disorders

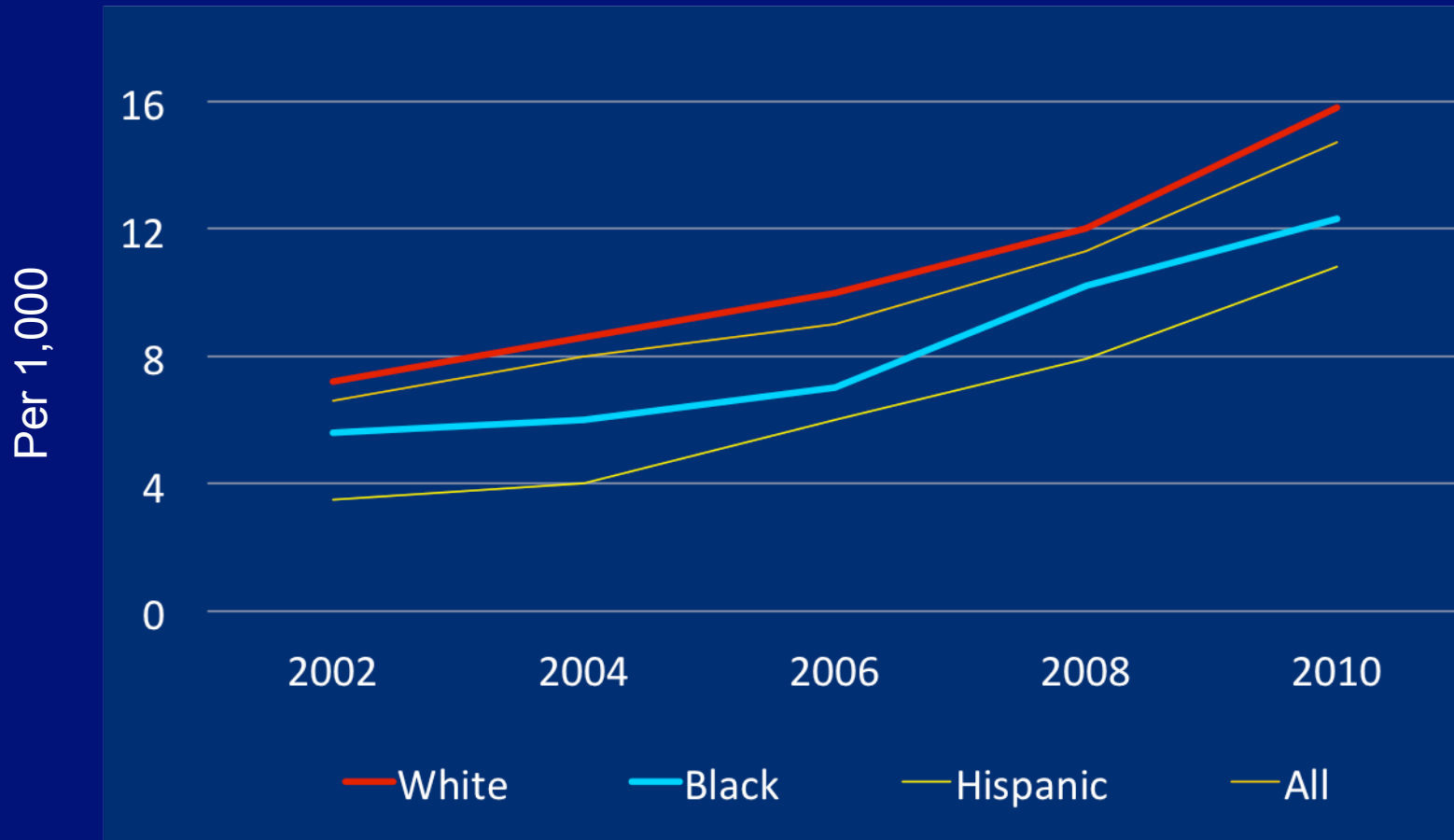
Figure 4: Number of Children under Age 18 Receiving Federally Administered SSI Payments, by Mental and Physical Impairment Group, December 2000 through December 2011



Source: GAO analysis of SSA data from the Supplemental Security Record.

Note: This figure does not include those diagnostic groups that SSA reported as "unknown." SSA data showed that as of December 2000, "unknowns" totaled 33,042 children (4 percent of all children), and as of December 2011, 24,443 children (2 percent of all children).

Rising Prevalence of Autism Spectrum Disorder

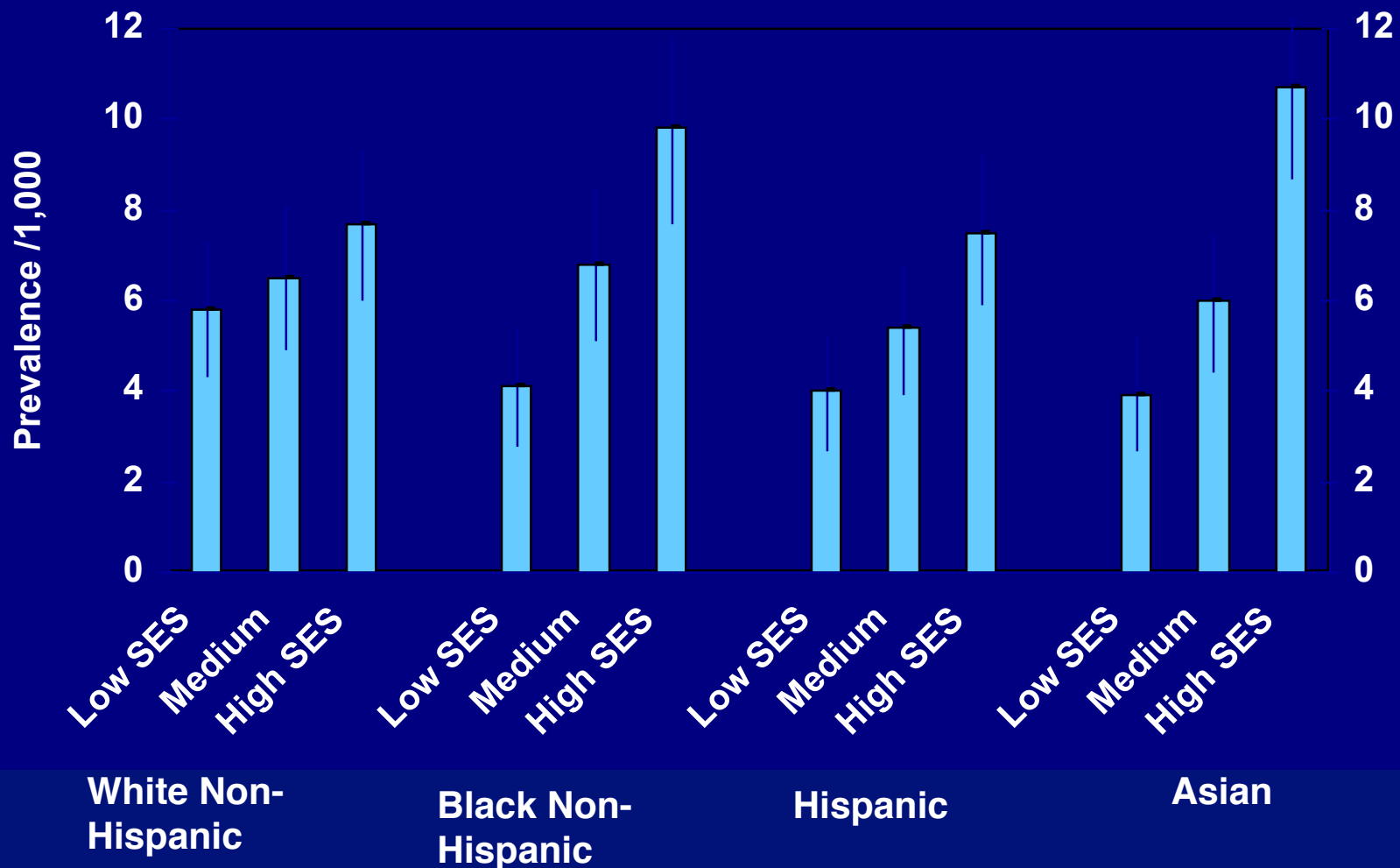


Prevalence of Autism Spectrum Disorder per 1,000 8 Year-Old Children in the U.S., *MMWR*, 2014

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

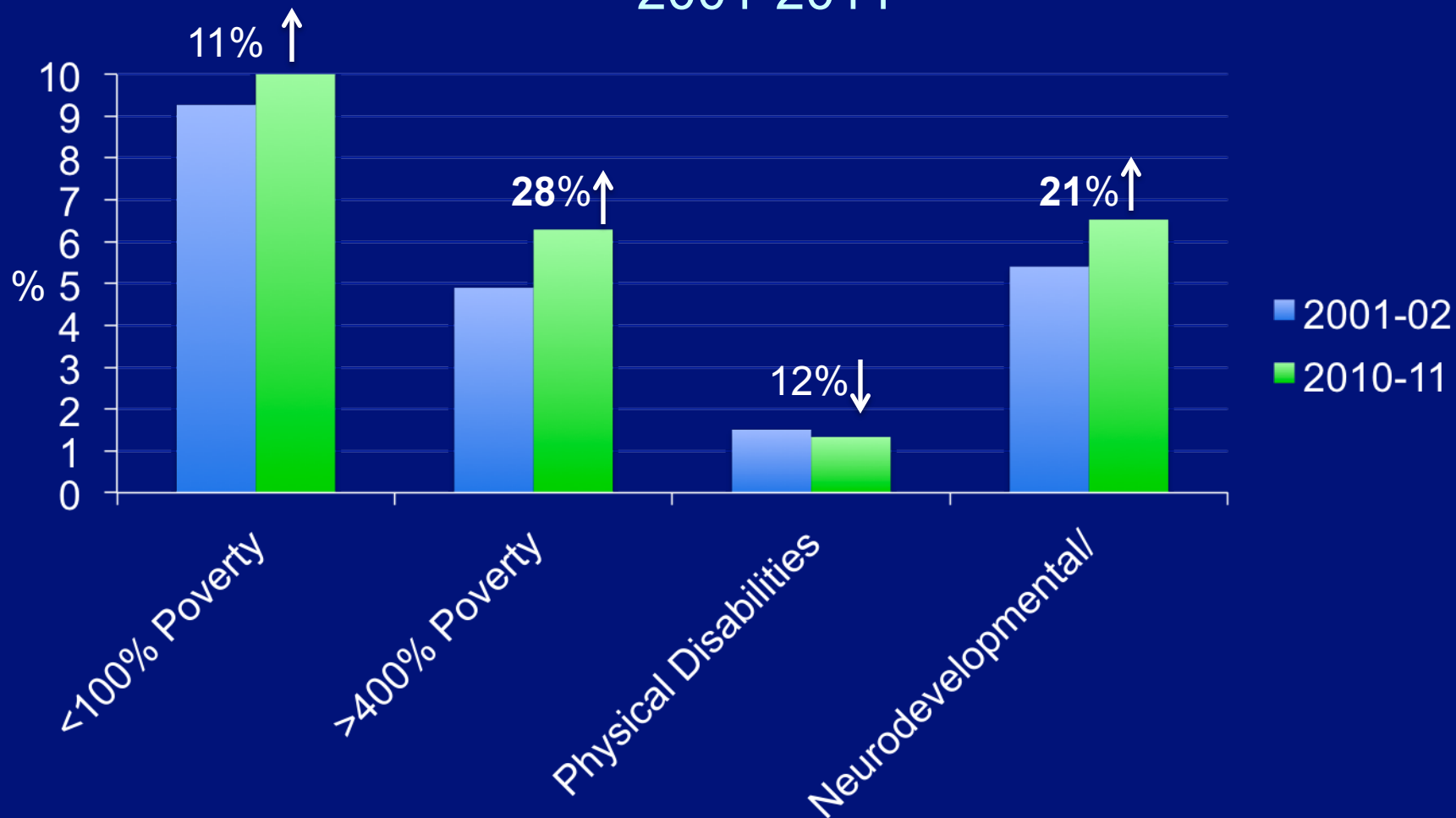
PLoS One 2010

Maureen S. Durkin^{1,2,3*}, Matthew J. Maenner^{1,3}, F. John Meaney⁴, Susan E. Levy⁵, Carolyn DiGuseppi⁶, Joyce S. Nicholas⁷, Russell S. Kirby⁸, Jennifer A. Pinto-Martin⁹, Laura A. Schieve¹⁰



Based on ADDM data from 12 U.S. states, population of 557,689 8-year-old children in 2002, including 3,680 with ASD.
SES = Socioeconomic Status

Changes Over Time in the % of US Children with Disability (Activity Limitations), National Health Interview Survey, 2001-2011



Houtrow A, et al, Changing trends of childhood disability, 2001-2011. *Pediatrics*, 2014; 134(3):530-8.

Two Traditions of Thought have Shaped Policies for Children with Disabilities and Complex Health and Educational Needs

Utilitarianism	Contractarianism
Bentham (1748-1832), James Mill (1773-1836) John Stuart Mill (1806-1873) Cost effectiveness: How can we allocate limited resources to maximize happiness and wellbeing for the population overall? A system with high inequality, health disparities and suffering of a minority, including people with disabilities may be acceptable if it produces maximum benefit for the population overall. Greatest good for the greatest number (efficiency).	Hobbs (1588-1679), the social contract Kant (1724-1804), the golden rule Rawls (1921-2002), under a veil of ignorance, rational people will choose policies that benefit the least advantaged [people with disabilities/complex health/educational needs]. A just society is one that rational, self-interested individuals would pick to gain protection, in exchange for some loss of freedom. Greatest benefit to the least advantaged members of society.

Utilitarianism and Child Disability, 18th Century England

“In answer to the Inquiry of the Sub Committee by Mr Collingwood I am to desire to let them know that Idiots can't be nursed at the usual price of other Children in this Neighbourhood. Those we have are in ye Hospital & a great trouble, You may be sure to us. Happy indeed hitherto we are that the Children don't mimic them. If you sh'd send them we'll send them to the Nurses that will take the most Care of them at the lowest price, but don't approve of taking more into the House.”

June, 1765, *London Foundling Hospital*

(Levene, Alysia, Childcare, Health and Mortality at the London Foundling Hospital, 1741-1800 (Manchester: Manchester University Press, 2007), pp. 165)

Courtesy of Walton Schalick, MD, PhD

The World Health Organization's Utilitarian Approach to Disability: Disability Adjusted Life Years (DALYs)

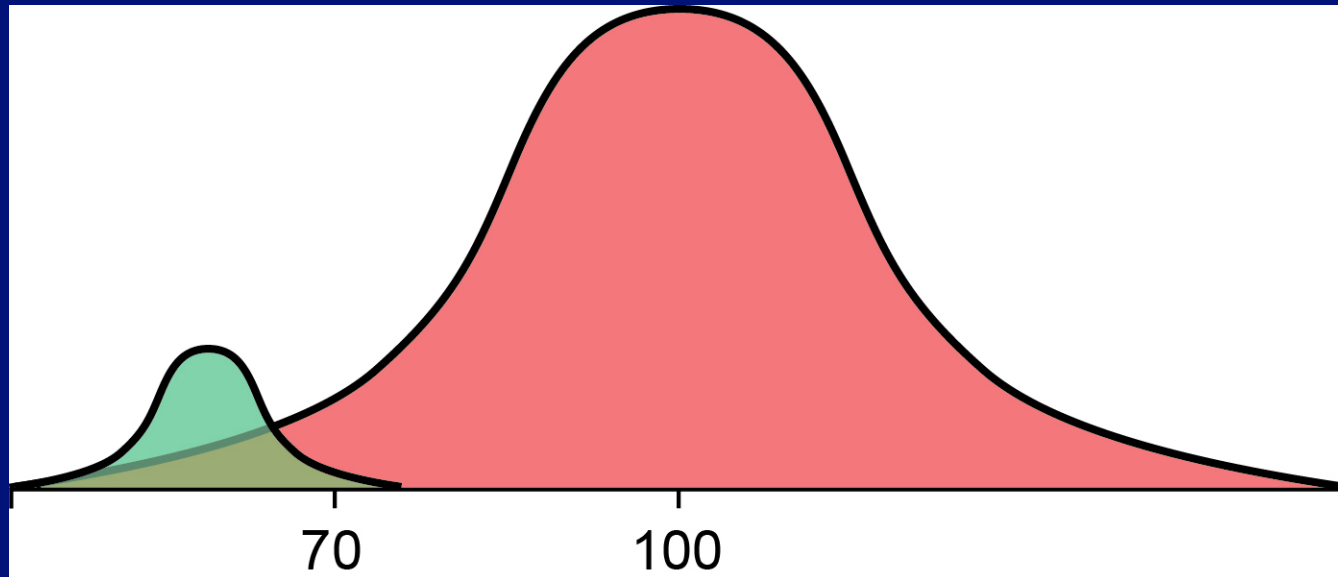
DALYs are based on the person trade-off (PTO) technique to estimate the social value of different health states and interventions

PTO1—the first person trade-off question

You are a decision maker who has enough money to buy only one of two mutually exclusive health interventions. If you purchase intervention A, you will extend the life of 1000 healthy [non-disabled] individuals for exactly one year, at which point they will all die. If you do not purchase intervention A, they will all die today. The alternative use of your scarce resources is intervention B, with which you can extend the life of n individuals with a particular disabling condition for one year. If you do not buy intervention B they will all die today; if you do purchase intervention B, they will die at the end of exactly one year.

“Allocative efficiency”:
how can we use limited resources to prevent the maximum number of DALYs ?

Conceptualization of Child Development: 2 Distributions

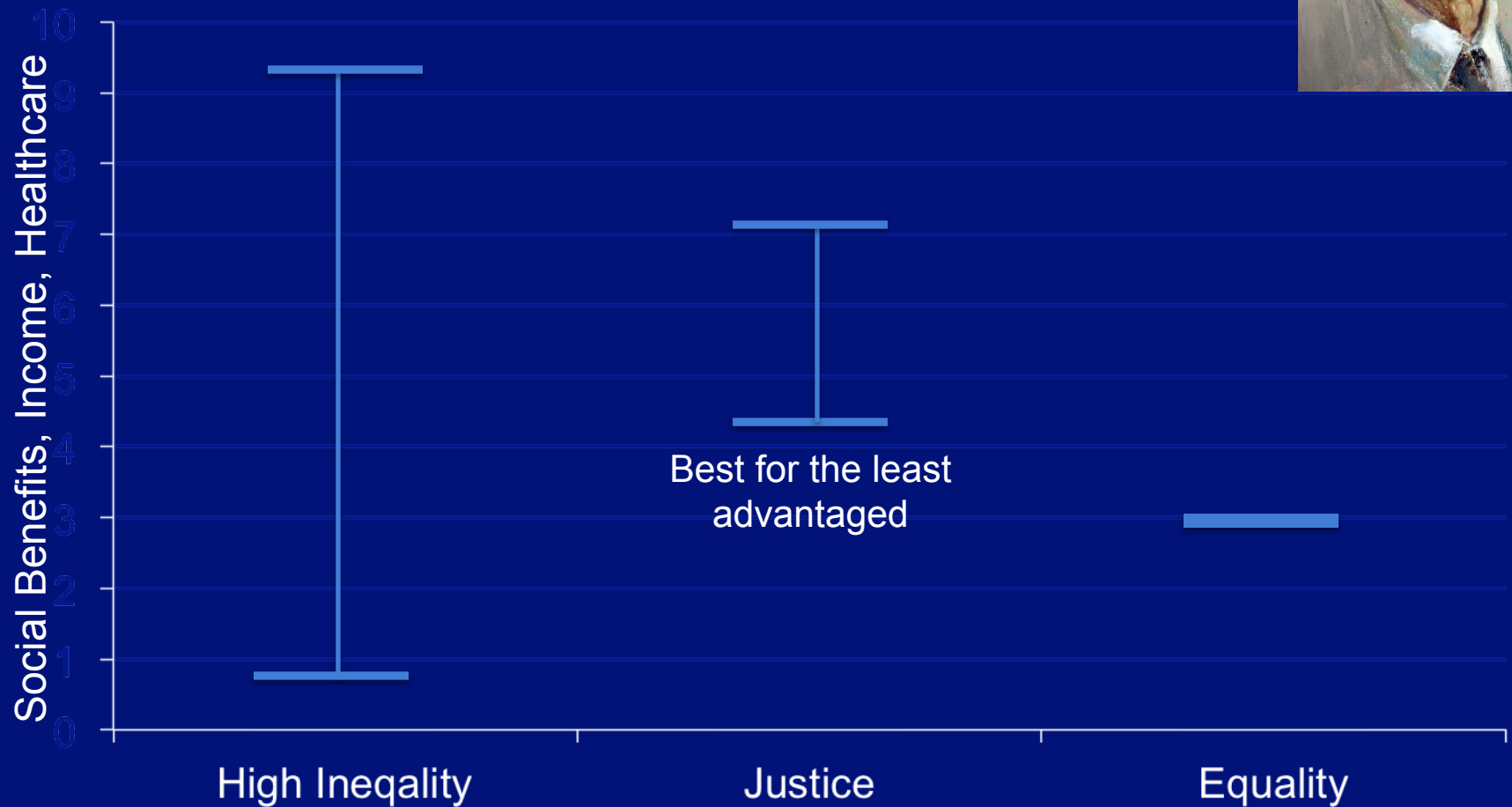
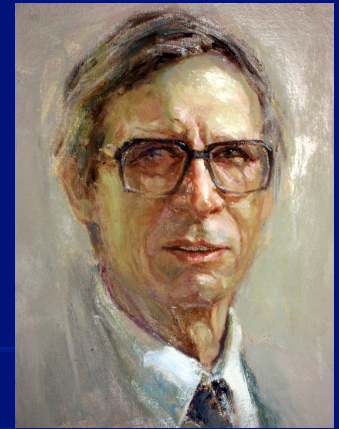


Distributions of developmental test scores:

General population

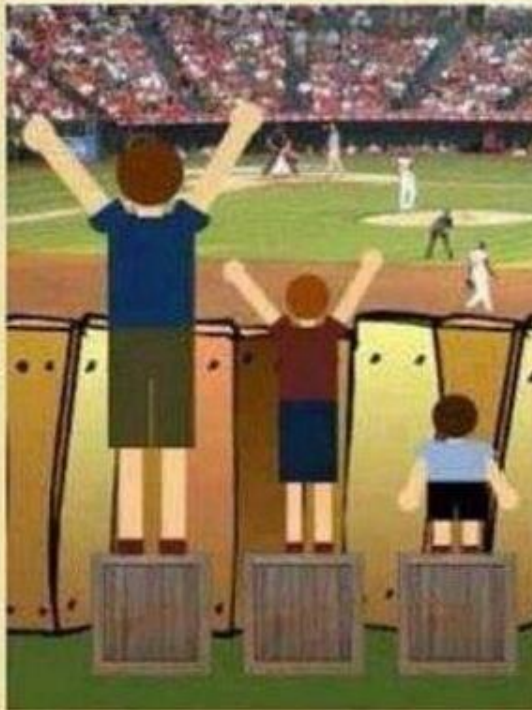
Individuals with known or identified disabilities

Rawl's Theory of Justice: Alternative Distributions of Resources

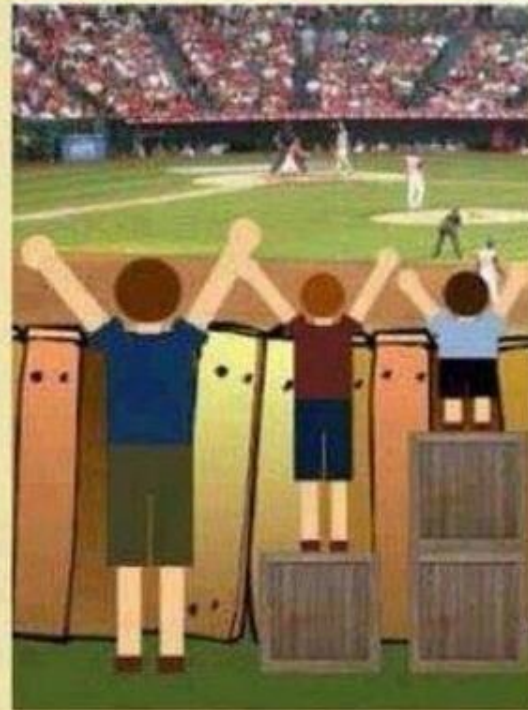


Distributive Justice

Equality doesn't mean Justice



This is Equality



This is Justice

The Children's Charter: The White House Conference on Child Health and Protection, 1930

- *V. For every child health protection from birth through adolescence, including: periodical health examinations and, where needed, care of specialists and hospital treatment;*
- *XIII. For every child who is blind, deaf, crippled, or otherwise physically handicapped, and for the child who is mentally handicapped, such measures as will early discover and diagnose his handicap, provide care and treatment, and so train him that he may become an asset to society rather than a liability. Expenses of these services should be borne publicly where they cannot be privately met;*

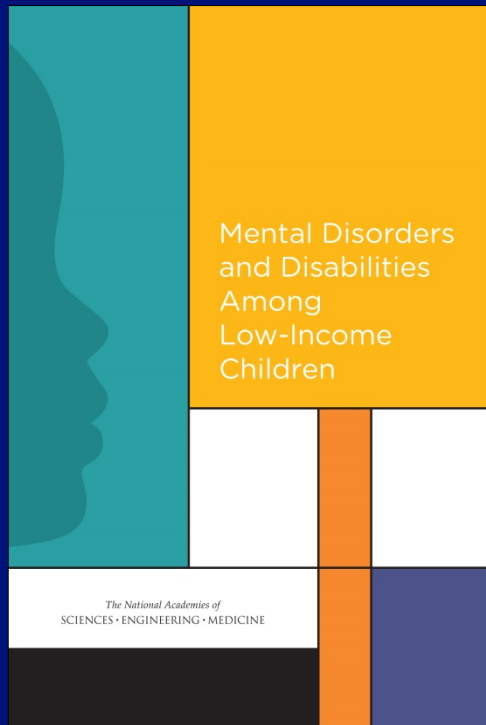
“CHILDREN ARE our most precious possession. The Children's Charter was written by 3,500 experienced men and women, after many months of study. It condenses into few words the fullest knowledge and the best plans for making every child healthier, safer, wiser, better and happier. These plans must be constantly translated into action. ...”

--- Herbert Hoover

Additional Examples of “Contractarianism” in U.S. Policies for Children with Disabilities and Complex Health and Educational Needs

- Supplementary Security Income (SSI) for children with disabilities, SSA 1974 Amendment
- Individuals with Disabilities Education Act (IDEA), 1975, 1990
- Americans with Disabilities Act (ADA), 1990

A 2015 Expression of the “Contractarian” Approach to Child Disability



“Children with disabilities in the United States, particularly those with mental, emotional, or behavioral disorders, are deserving of the highest level of planning and implementation for family support programs. Both at-risk families and society as a whole stand to benefit.”

-- Thomas F. Boat, M.D., *Preface*

National Academies of Sciences, Engineering, and Medicine. 2015.
Mental disorders and disabilities among low-income children.
Washington, DC: The National Academies Press.

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

International Contractarian Policies:

U.N. Conventions on the Rights of the Child (CRC) and on the Rights of Persons with Disabilities (CRPD)

- CRC Art 23, Sec 1: “A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self reliance and facilitate the child’s active participation in the community.”
- CRPD Art 27: “...Recognize the right of persons with disabilities to work...”
- Paradigm Shift: Persons with disabilities not viewed as *objects* of charity, medical treatment or social protection, but as *subjects* with rights.



ICF

International
Classification of
Functioning,
Disability
and Health

ICF-CY

International
Classification of
Functioning,
Disability
and Health

Children &
Youth
Version



World Health
Organization

ICF

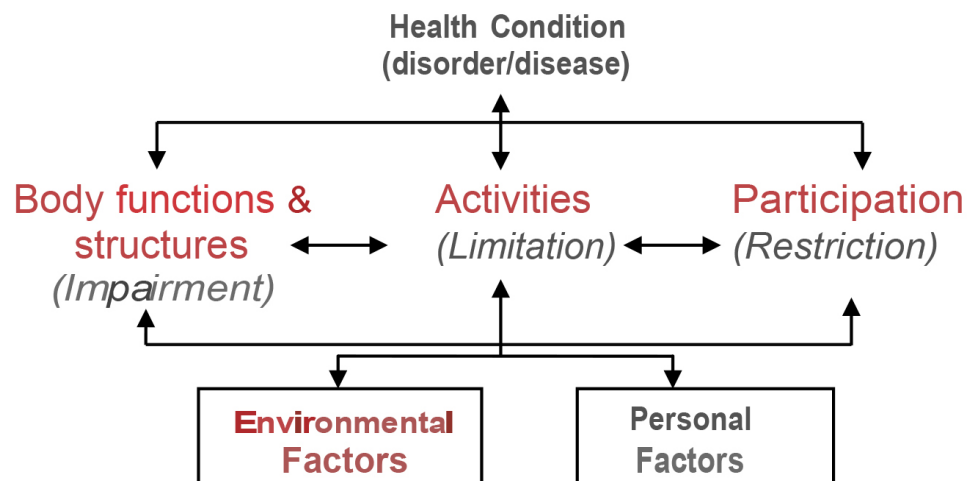
International
Classification of
Functioning,
Disability
and Health

Short version



World Health Organization
Geneva

ICF: Interaction of Concepts



The World Health Organization's "Contractarian" Approach to Disability: interventions to improve functioning and participation of children with disabilities are as important as primary prevention.

Contrasting Definitions of Disability

- ADA, Title V: a physical or mental impairment that substantially limits one or more major life activities of an individual, expected duration not <6 months
 - SEC. 12102. [Section 3], <http://www.eeoc.gov/laws/statutes/ada.cfm>
- SSI: a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months” (SSA, 1997), <http://www.nap.edu/read/21780/chapter/5#35>
- CSHCN: consequence-based, need for or use of healthcare or special education for chronic conditions, ...
<http://www.childhealthdata.org/browse/survey/results?q=2625&r=1>

Arguments for a Contractarian and Inclusive Approach to Children with Disabilities and Complex Health and Educational Needs

- Investments in children with special needs benefit all people
- Inclusive education benefits all children
 - Empathy, compassion, appreciation of diversity
- Utilitarian benefit – interventions to improve health, functioning & participation of children with special needs will save money in the long run, across the lifecourse
- Potential to reduce health & economic disparities
- Morally, it's the right thing to do.

Barrier-Free Designs & Technology Enhance Participation of People with Physical and Sensory Disabilities, and Benefit Everyone



... so all people, including those with disabilities, can interact with electronic devices more easily and independently.

Power wheelchair with augmented communication device

... so that technology products and services can be enjoyed by everyone.



Hand-held wireless device sends text messages to hearing aids



Web Accessibility initiative

<http://www.w3.org/WAI/>

Barrier-Free Technology Coming of Age

<http://trace.wisc.edu/>

Gaps in Knowledge, Research Priorities

- How to quantify, classify and monitor levels of disability, functioning, and complex health and education needs at the population level
- How to incentivize innovations and inclusive, high quality care in the context of healthcare reform
- How to ensure access to care for those in greatest need

Main Points

- Improvements in survival and economic development are associated with increases in the prevalence of disability and special needs, which now affect up to 20% of US children
- Investing in children with disabilities and complex needs reduces disparities and benefits everyone
- Need for greater attention to the functional and participation dimensions of disability, and their multiple determinants (beyond the medical model)

References

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