

The Costs of Autism in the United States

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IACC Full Committee
July 16, 2010

Introduction

Context

- Much policy activity recently involving insurance coverage
- Large financial & non-financial burdens for families and society
- Considerable resources are used to treat & support children (& adults) with autism
- Individuals with autism (& especially their caregivers) experience lost productivity

Context

- It is important to know what these costs are, when they are incurred, and by whom.
- It is important because it contributes to the general knowledge base on the costs of different health conditions, it is important because it helps autism advocacy groups do their jobs, and it is important because understanding the costs of autism will help us understand the how to best allocate our scarce resources to support individuals with autism and their families.

Context

- Because different current and future treatment strategies vary in effectiveness and costs, understanding how total costs due to autism are distributed across the life cycle will help us to make better decisions about investing in treatment and prevention activities.
- Understanding who suffers the financial burden of autism, and when, will help us balance the costs of treatment, and extending insurance benefits to treatments, against the potential reductions in other contemporaneous and future costs.

Objective

- The objective is to estimate the costs of caring for individuals with autism.
- Estimates of costs are important for policy
- Raise awareness
- Cost = value of prevention
- Point out gaps in knowledge

Problem

- Not much is known about those costs and less has been published.

Problem

- Compared with other health conditions (chronic and acute), there has been little research on the costs associated with autism (US).
- More work to be done.

Where are the Autism Economists?

“Governmental and nongovernmental funders must make choices in distributing scarce research resources; these choices can be between disparate areas of health or involve deciding how to allocate funds between different approaches to a specific condition. This allocation of research funds to particular fields of study is influenced by many factors...

...Usually, however, funding bodies do not have access to quantitative estimates of the value of a specific advance: this is the territory of micro- or health- economics.”

A. J. Bailey. *Autism Research* 2: 245, 2009

Methods

Components of Cost

- Direct Medical
 - Physician, Therapy, Medication
 - Dental, Travel
- Direct Non-Medical
 - Child care, Adult care, Respite care
 - Special Education, Supported Employment
- Indirect
 - Own and parental lost productivity



Cost of Illness Approach

- Ideally would like to use an incidence-based approach
 - Costs closely estimates the value of prevention
- Data requirements are formidable
 - Requires longitudinal/prospectively collected data
- Approximate by applying prevalence-based data to a synthetic cohort
 - Cross-sectional approximation to longitudinal data



Perspective

- Autism's impact felt:
 - Families
 - Communities
 - Employers
 - Insurers
 - Local, State, Federal governments
- Require a broad perspective
 - Societal Perspective
 - As recommended by the Panel on Cost-Effectiveness in Health and Medicine



Direct Costs

- Source materials
 - Published, non-published reports
- Cost data or use data (\times price) converted to 2003 US dollars
- Costs computed for high & low functioning individuals
- Sex-age-specific



Indirect Costs

- Human capital approach
- Used age-sex-specific data on average earnings, benefits, value of household services
- Combined with life- and work-expectancies to estimate lost lifetime productivity



Incremental Costs

- Cost of illness approach only tabulates incremental costs
- I.e., costs specific to condition that are over and above costs non associated with the condition”
 - Need to subtract non-autism costs
 - When applicable, non-autism-related estimated from national survey data



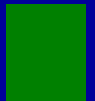
Present Value

- Per capita costs computed for each age from 3 to life expectancy in constant 2003 dollars
 - Future earnings were inflated using CBO estimates of productivity growth rates
 - Costs discounted back to present value (2003) using 3% discount rate
- Per capita present value (PV) lifetime cost



Total Costs

- Per capita PV lifetime costs multiplied by number of 3-year olds with autism
- # 3-year olds with autism = # 3-year olds (4 million; from Census) \times prevalence (27.5 per 10,000)



Methods Recap

- Estimates of direct costs by age & severity
- Estimates of indirect costs by age & severity & sex (differential wages)
- Discounted
- Multiply by assumed cohort size

= Total Lifetime Costs

Questions??

Results

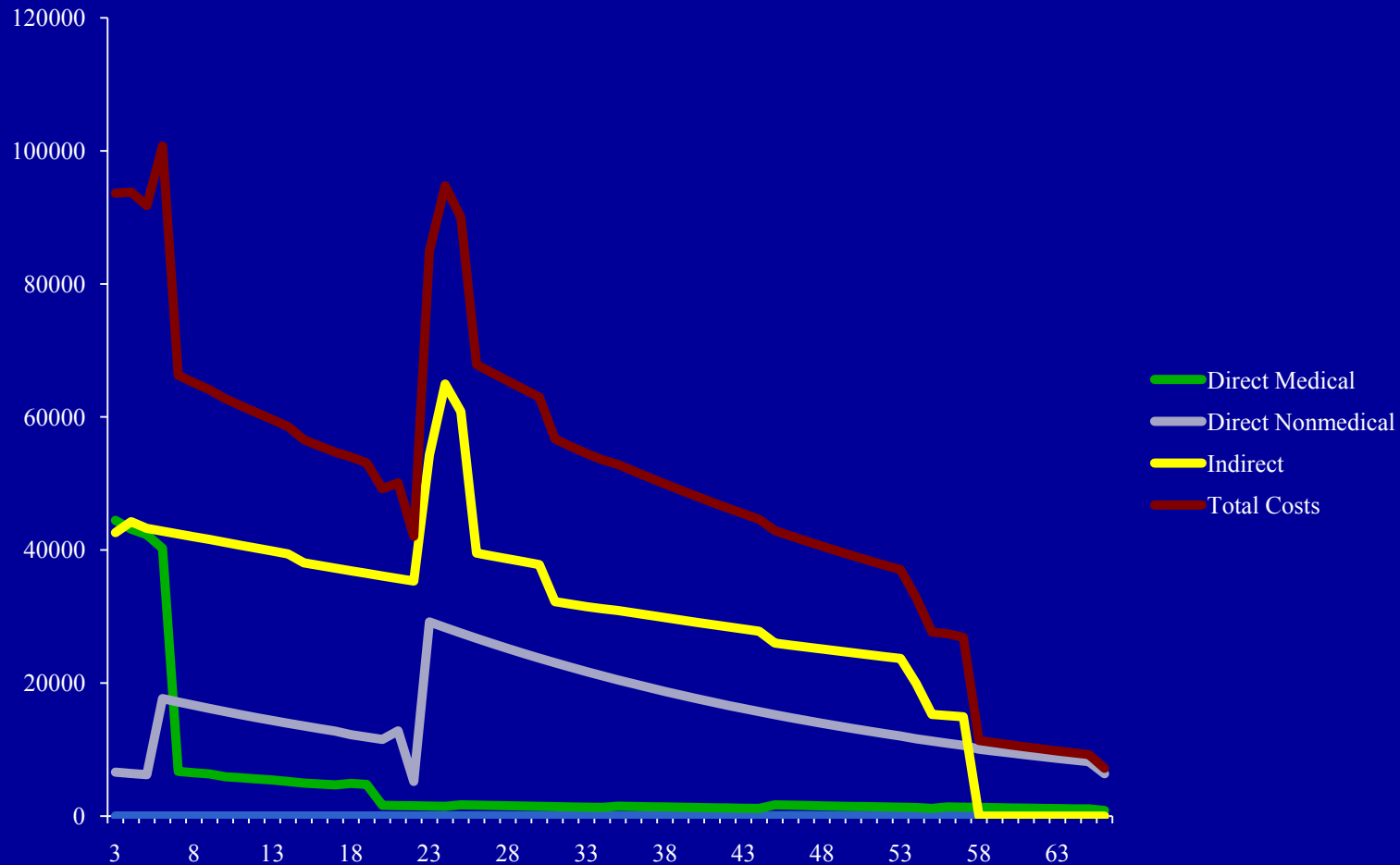
Summary

	Per Capita Lifetime	TOTAL (Millions)
Direct Medical	\$305,956	\$3,366
Direct Non-Medical	\$978,761	\$10,766
Indirect	\$1,875,667	\$20,632
TOTAL	\$3,160,384	\$34,764

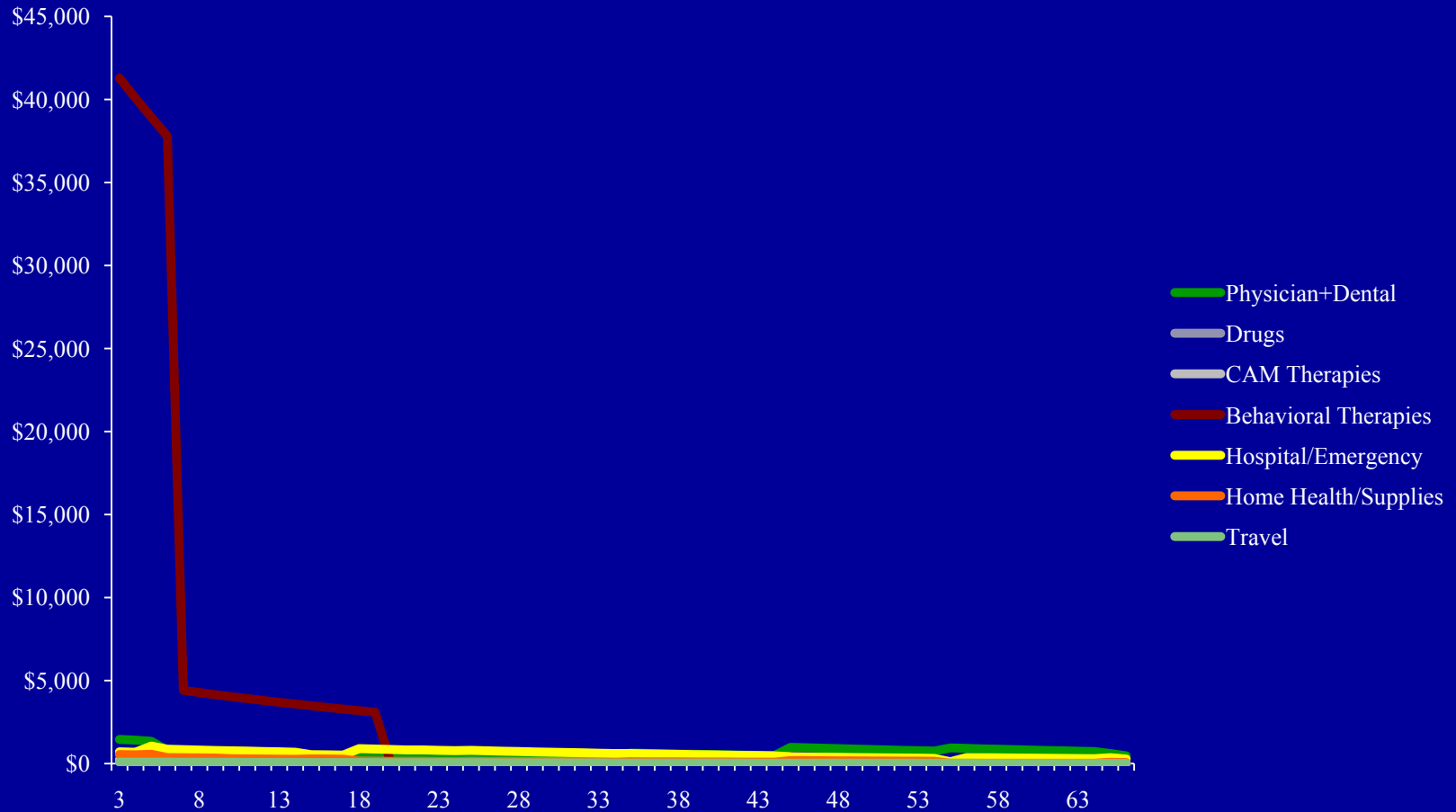
Age Distribution of Costs

Age	Per Capita Costs				Total National (Millions)
	Direct Medical	Direct Nonmedical	Indirect	Total	
3-7	\$35,370	\$10,805	\$43,066	\$446,203	\$4,908
8-12	\$6,013	\$15,708	\$41,138	\$314,297	\$3,457
13-17	\$5,014	\$13,550	\$38,453	\$285,082	\$3,136
18-22	\$2,879	\$10,720	\$36,090	\$248,446	\$2,733
23-27	\$1,574	\$27,539	\$51,740	\$404,260	\$4,447
28-32	\$1,454	\$23,755	\$35,757	\$304,828	\$3,353
33-37	\$1,389	\$20,492	\$30,852	\$263,662	\$2,900
38-42	\$1,283	\$17,676	\$29,132	\$240,457	\$2,645
43-47	\$1,440	\$15,248	\$26,600	\$216,439	\$2,381
48-52	\$1,447	\$13,152	\$24,531	\$195,650	\$2,152
53-57	\$1,290	\$11,292	\$17,776	\$151,790	\$1,670
58-62	\$1,218	\$9,489	\$0	\$53,535	\$589
63-66	\$1,027	\$7,908	\$0	\$35,738	\$393

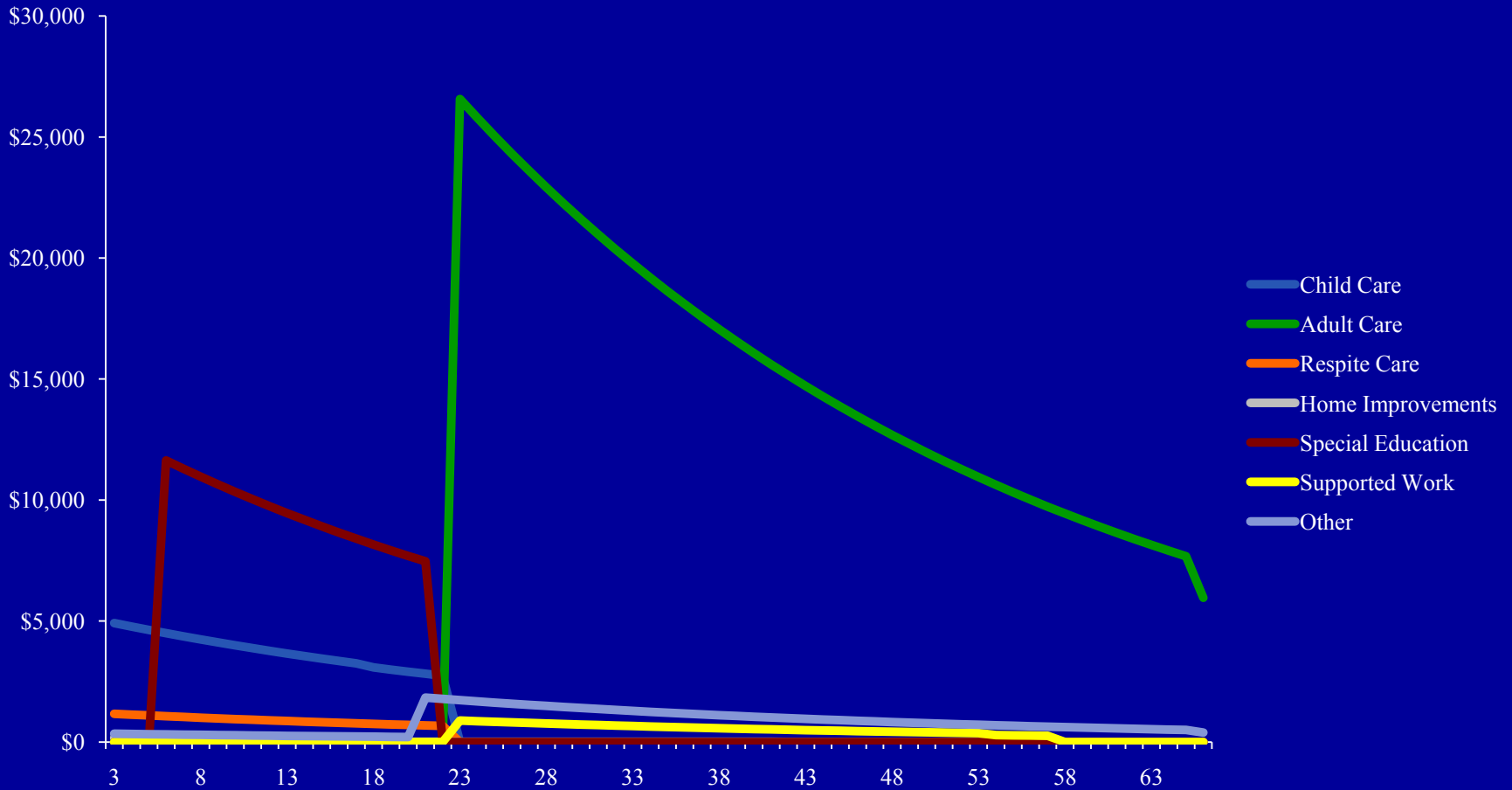
Age Distribution of Costs



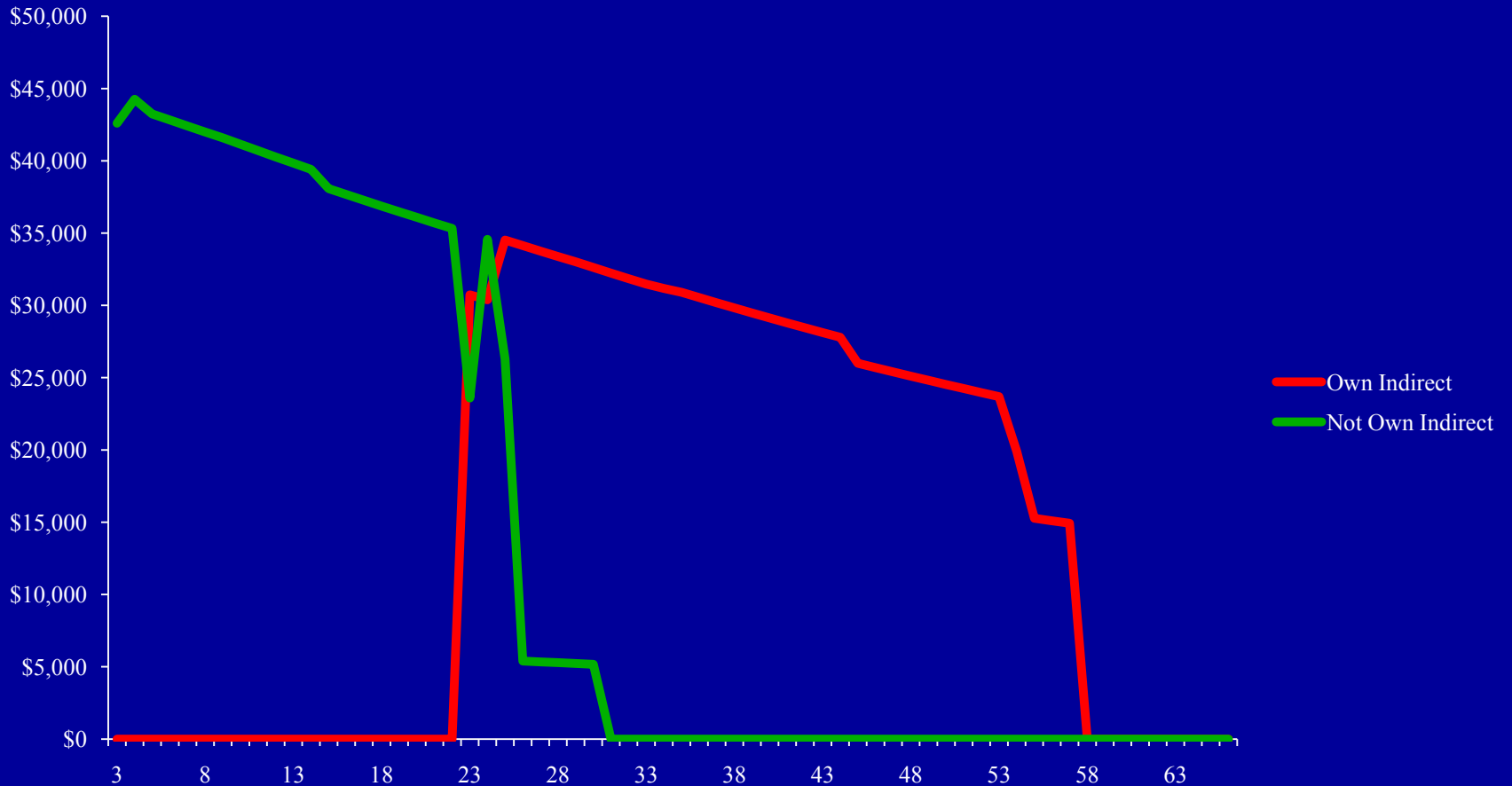
Age Distribution of Medical Costs



Age Distribution of Nonmedical Costs



Age Distribution of Lost Productivity



Sensitivity Analyses

	Lower Bound	Upper Bound	Total Cost: Lower	Total Cost: Upper
Prevalence	10 per 10,000	60 per 10,000	12.6 billion	75.8 billion
% Low Disability	25%	75%	35.8 billion	34.0 billion
Discount Rate	2%	5%	42.2 billion	25.7 billion
Cost of Adult Care	-25%	+25%	32.9 billion	36.6 billion
Own Lost Productivity	-25%	+25%	29.4 billion	40.1 billion
(Baseline = 34.7 billion)				



Discussion

Discussion

- Autism is expensive
- Autism is a disorder of childhood *and* adulthood
- People with autism spend twice as much as the typical American over their lifetimes and spend 60% of those extra direct medical costs > 21 years

Discussion

- One of the first attempts at a comprehensive estimation of the societal costs of autism
- Far from perfect
- Many assumptions
- Relies on sometimes old data
- Health care technologies and standards of care have changed (and will change)

Discussion

- Most likely an underestimate:
 - Legal costs
 - Lost productivity of others
 - Value of physical/mental stress on caregivers and other family members
 - Full cost of alternative/complementary therapies and diets
 - Value of changes in reproductive behaviors (including costs of genetic tests/counseling)
 - Immunization avoidance behaviors

Discussion

- Lacks estimates of advocacy and research
- For example, the National Institutes of Health research budget for autism has grown from \$22 million in Fiscal Year 1997 to \$70 million in Fiscal Year 2003.

But...

- These estimates are consistent with the few other reports (UK, Autism Society newsletter)
- Roughly equivalent to costs for:
 - Mental retardation (\$51 billion; 103/10,000)
 - Anxiety (\$47 billion; 12.6/10,000)
 - Schizophrenia (\$33 billion; 1.1/10,000)
- ~5% of the health component of GDP (689 B)

Next Steps

- More standardized approach to collect data on use and cost
- Out of pocket costs (including alternative therapies)
- Prospectively tracking the life experiences of children with autism and their families
- Enumerating multiple sources of costs and linking them together

Next Steps

- Providing families greater access to therapies that can help decrease the symptoms associated with autism and that can increase the likelihood of more easily entering mainstream society, whether it be in elementary school or in the labor force, may help decrease future disability and hence future costs.

“The cost of autism question from time to time occupies my thoughts. I am an extreme - I left Britain, used my US citizenship (I was born here) to access better services for my child. A costly and hidden exercise which is nonetheless played out in some variation by families all over the western world. Sadly, despite a large acquaintance with hundreds of families with kids with autism, every one I know except myself is now divorced...

...Too little attention has been targeted at the cost to society, let alone the individuals concerned.”

“I work for a variety of California school districts with programs for children with autism, and encounter some very thorny economic issues that I wonder if you've had experience with.”

“...I am a mother to two children, one of whom has autism... [he] is 6. He also has apraxia, has a severe receptive language delay and is nonverbal. (And he is amazingly beautiful with a heart of gold)...

...His father, my husband of 12-plus-years recently left us. He just packed up his bags and left one day last summer and he now lives in another state. He is a physician (yes, a physician), and we are in the middle of a divorce. My husband has offered the minimum amount of child support each month and does not want to be held responsible for my son's therapy payments because he considers the therapy „worthless’...”

Sources

- “Understanding Autism: From Basic Neuroscience to Treatment,” Edited by Steven O. Moldin and John L. R. Rubenstein to be published by the CRC Press/Taylor Francis Group (April 26, 2006).
- The lifetime distribution of the incremental societal costs of autism. *Arch Pediatr Adolesc Med.* 2007;161:343-349.

Thank You

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