Autism Spectrum Disorders: Topography of Economic Costs & Burden of Care

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Disclosures

- No commercial disclosures
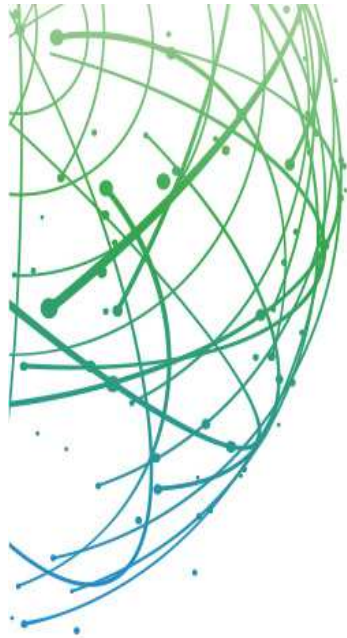- Funding support from NIH, Grand Challenges Canada and Bill and Melinda Gates Foundation

Objectives

- To describe a topography of care costs of ASD
- To describe related QoL, Medical and Mental Burden
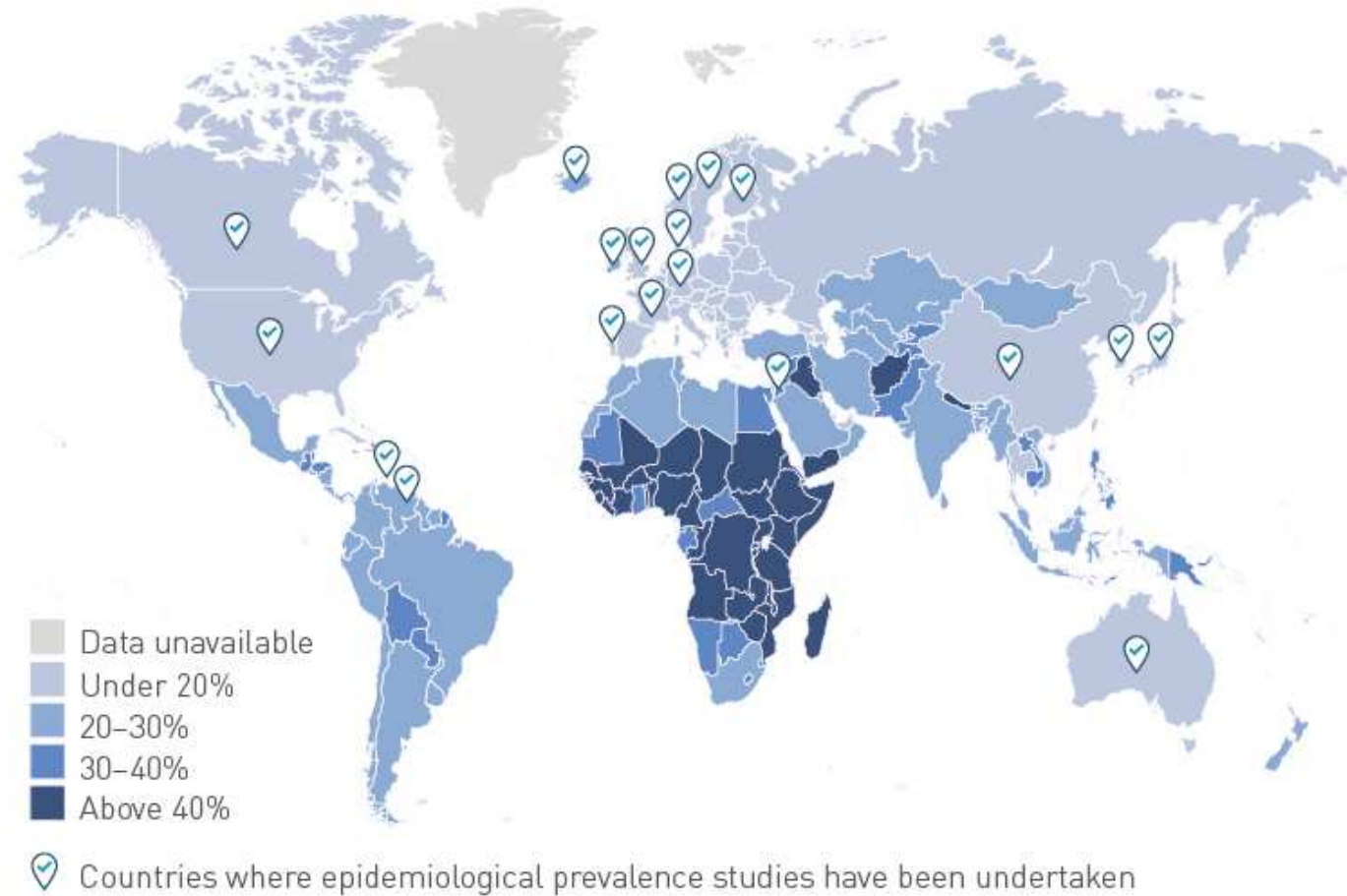- To have time for discussion

Before we begin: 70 percent of the global population live on less than 8 € per day – *World Bank Report*

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PERCENT POPULATION UNDER 15 Y BY COUNTRY AND LOCATIONS OF ASD PREVALENCE

Data unavailable
Under 20%
20–30%
30–40%
Above 40%

Countries where epidemiological prevalence studies have been undertaken

WISH Autism Report, 2016

- The economic impact associated with ASD is substantial and growing

- Lifetime cost of caring for an individual with ASD is ~$2.2 million in the US and £1.5 million in the UK

- Figures drop to $1.4 million in the US and £0.92 million in the UK for ASD without co-morbid ID/IDD
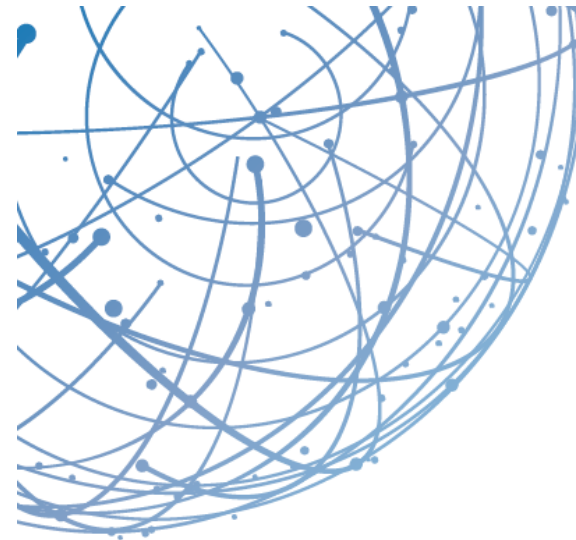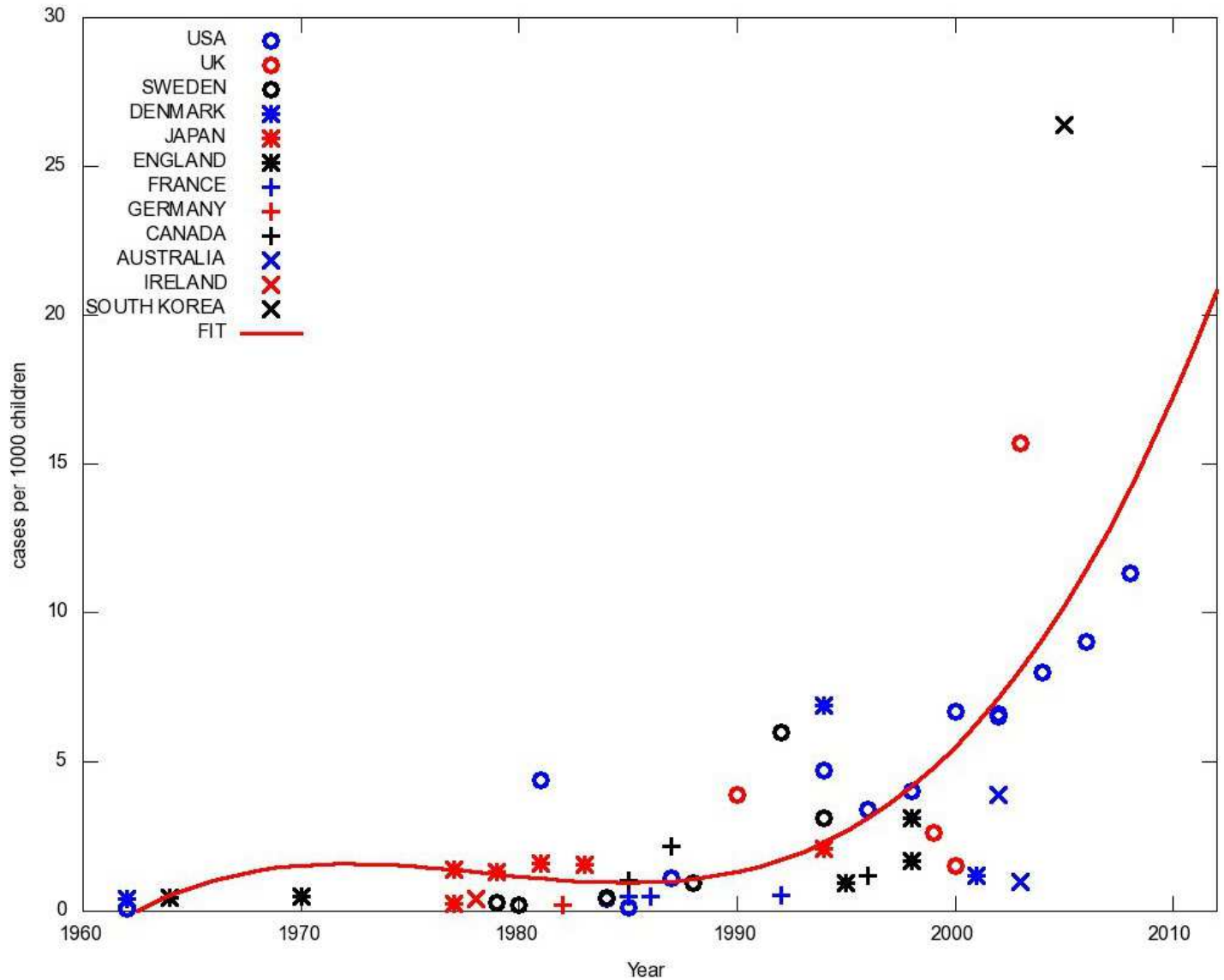
AUTISM
A GLOBAL FRAMEWORK FOR ACTION

Report of the WISH Autism Forum 2016

Kerim M Munir
Tara A Lavelle
David T Helm
Didi Thompson
Jessica Prestt
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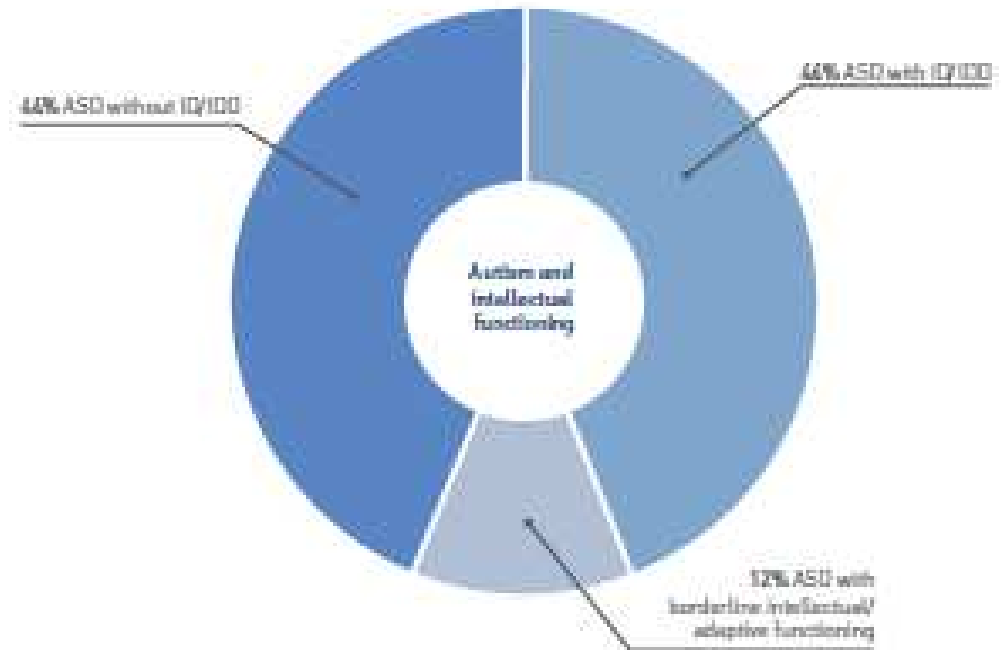**HARVARD MEDICAL SCHOOL**
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Autism Spectrum Disorder Prevalence (By Country)

Joint Cost of ASD and ID/DD

- Comorbidity with ID/DD compound ASD costs
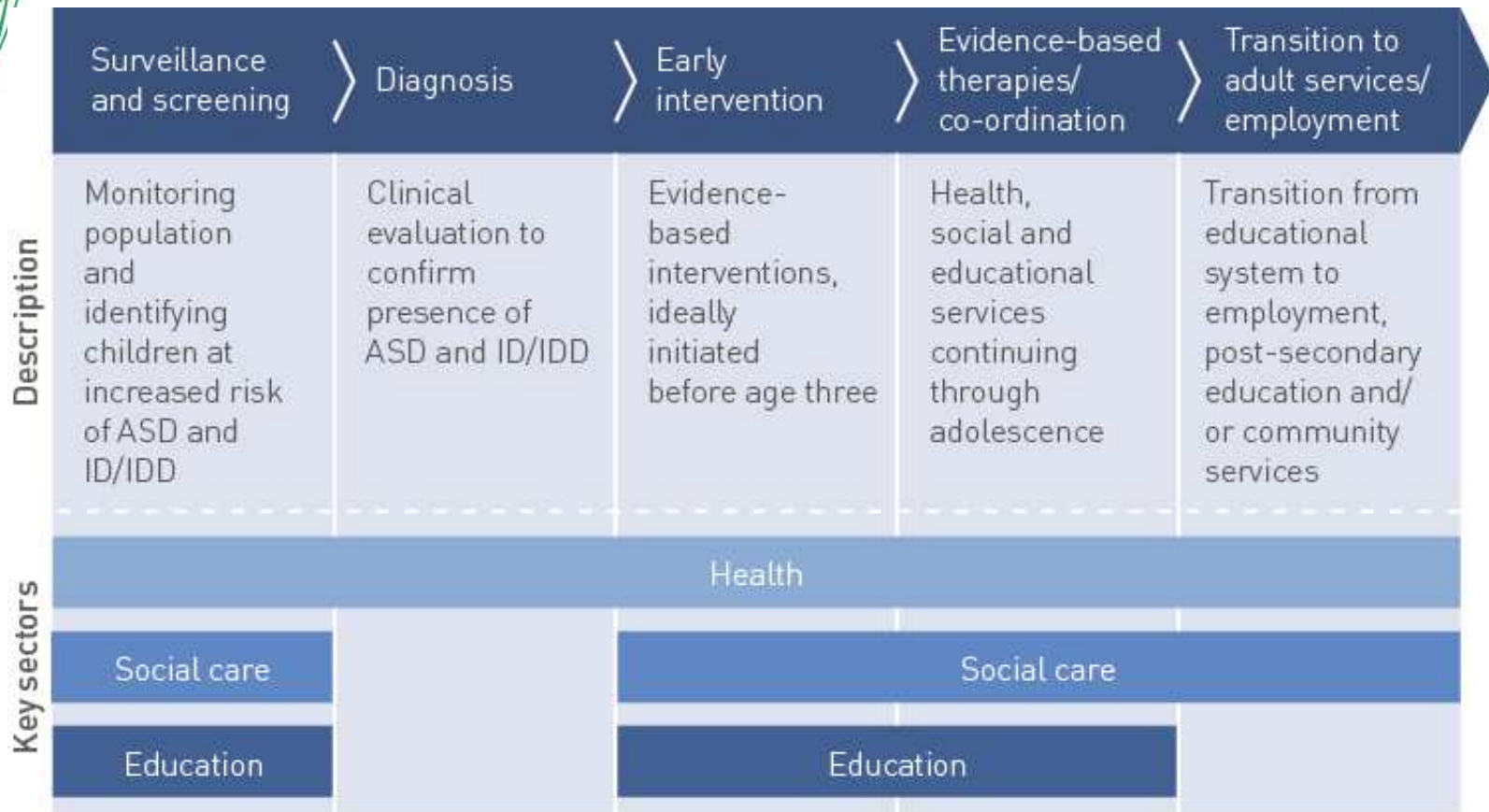- Estimates of overlap between ASD and ID/DD vary
- Is differentiation scientifically and morally justifiable
-

44% ASD without IQ/ID

44% ASD with IQ/ID

Autism and intellectual functioning

12% ASD with borderline intellectual/adaptive functioning

Source: Baxter et al. (2015)[a]

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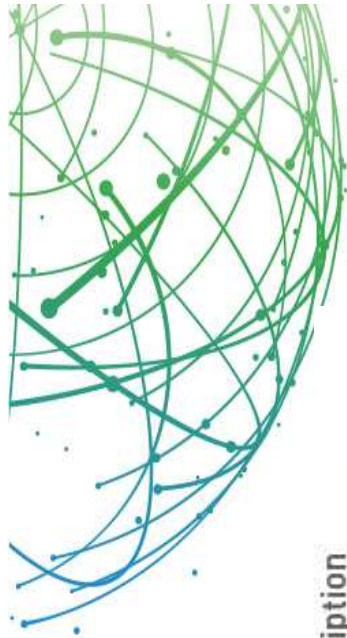
AUTISM AND INTELLECTUAL DEVELOPMENTAL DISORDERS – JOURNEY ACROSS THE LIFESPAN

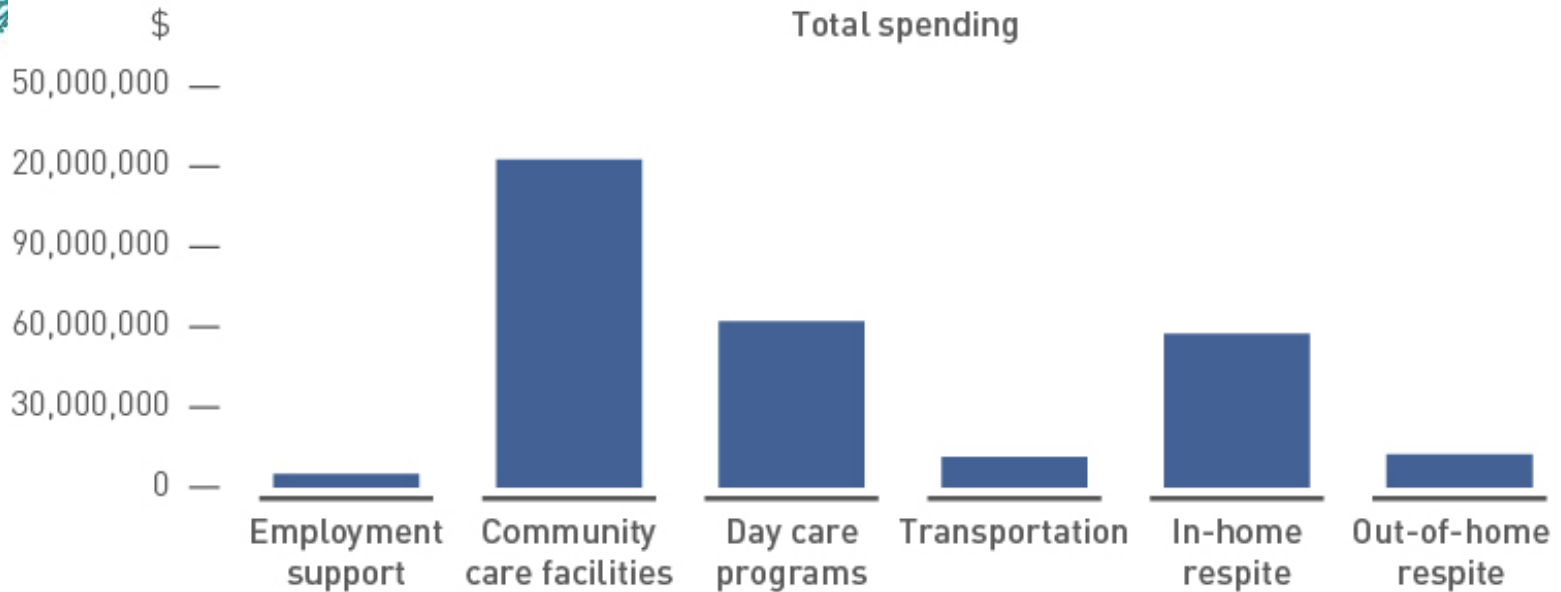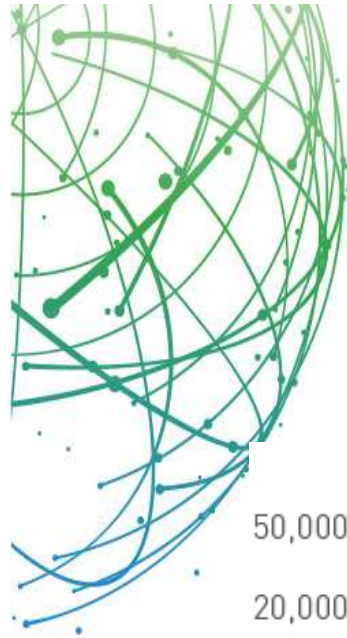|	Surveillance and screening	Diagnosis	Early intervention	Evidence-based therapies/ co-ordination	Transition to adult services/ employment
Description	Monitoring population and identifying children at increased risk of ASD and ID/IDD	Clinical evaluation to confirm presence of ASD and ID/IDD	Evidence-based interventions, ideally initiated before age three	Health, social and educational services continuing through adolescence	Transition from educational system to employment, post-secondary education and/ or community services
Key sectors	Health				
	Social care		Social care		
	Education		Education		

Significance

- Care requires long-term interventions presenting a lifelong burden on individuals, families, and societies
- Early intervention reduce lifetime costs – despite health cost peaking at diagnosis and EI
- CDC surveillance data report median age of diagnosis as later than 2 years
- Comorbid conditions increase costs
- Resource allocation is critical at times of financial austerity
- Care requires multi-agency tasks
- Data-based services are needed to provide joint decision-analytic tools to track prevalence, care and cost analyses

Economic Impact on US

- Economic total impact $268 billion based on:
  - **DIRECT MEDICAL**
  - **NON-MEDICAL**
  - **PRODUCTIVITY COSTS**
- 0.9 - 2% OF GDP
- Total cost expected to rise to $461 billion from 0.99 – 3.6 z5 of (ranging from 0.99 - 3.6 percent of GDP by 2025.
- Costs on par with recent estimates for diabetes
- Costs exceed that for heart disease, stroke and hypertension –significantly higher non-medical v. direct medical costs.

AUTISM CARE COSTS: NON-MEDICAL SPENDING ON ASD BY CALIFORNIA DEPARTMENT OF DEVELOPMENTSL SERVICES

Total spending

$

	Value
50,000,000	
20,000,000	
90,000,000	
60,000,000	
30,000,000	
0	

Employment support · Community care facilities · Day care programs · Transportation · In-home respite · Out-of-home respite

Calculating Cost

Estimating "annual adjusted costs" for an adult or a child with ASD:

$$(P + SP + S + M + C_{MD})$$

P = Production loss of the individual and family with an ASD diagnosis

SP = Support costs

S = School costs, mainly addition and specialist staff

M = Medical costs

C_{MD} = Missed diagnosis costs

Assumptions

- Several assumptions regarding productivity costs / impact of a child's diagnosis on parent employment:
  - *Time taken out from current employment for treatment visits is accounted for, but reduced employment of parents to care for a child with ASD is not taken into account*

Cost Offset of Diagnosis

- Early Diagnosis = Early intervention + Better social behaviors + Less reliance on special education

- Improvement in ASD benefit families, increases productivity of parents and affected individuals and benefits society

- Gains maximal when diagnosis is early: ~ ages 2 - 4.

Cost Offset Associated With Early Start Denver Model for Children With Autism

Zuleyha Cidav, PhD, Jeff Munson, PhD, Annette Estes, PhD, Geraldine Dawson, PhD, Sally Rogers, PhD, David Mandell, ScD

Objective: To determine the effect of the Early Start Denver Model (ESDM) for treatment of young children with autism on health care service use and costs.

Method: We used data from a randomized trial that tested the efficacy of the ESDM, which is based on developmental and applied behavioral analytic principles and delivered by trained therapists and parents, for 2 years. Parents were interviewed about their children's service use every 6 months from the onset of the intervention to follow-up (age 6 years). The sample for this study consisted of 39 children with autism who participated in the original randomized trial at age 18 to 30 months, and were also assessed at age 6 years. Of this sample, 21 children were in the ESDM group, and 18 children were in the community care (COM) group. Reported services were categorized and costed by applying unit hourly costs. Annualized service use and costs during the intervention and post intervention for the two study arms were compared.

Results: During the intervention, children who received the ESDM had average annualized total health-related costs that were higher by about $14,000 than those of children who received community-based treatment. The higher cost of ESDM was partially offset during the intervention period because children in the ESDM group used less applied behavior analysis (ABA)/early intensive behavioral intervention (EIBI) and speech therapy services than children in the comparison group. In the post-intervention period, compared with children who had earlier received treatment as usual in community settings, children in the ESDM group used less ABA/EIBI, occupational/physical therapy, and speech therapy services, resulting in significant cost savings in the amount of about $19,000 per year per child.

Conclusion: Costs associated with ESDM treatment were fully offset within a few years after the intervention because of reductions in other service use and associated costs.

Establishing Cost Difference between Identified vs. Non-Identified ASD Children

- Closest approximation for C_{MD} is the difference in costs between those children identified and treated early in their development vs. those not identified and/or treated until later in childhood or even adolescence and adulthood.

- Method: identify subgroup of group who receive a diagnosis of ASD shortly after their parents suspect it vs. subgroup of children who had their diagnosis formally confirmed much later.

National Differences in Disability Policies/Entitlements

- Each country has a unique story to tell

- Let's take the example of Australia:
  - State and Territory Governments primarily responsible for supporting disability services (including ASD) and not the Commonwealth.
  - Families with ASD children receive a 'finite' amount of Commonwealth funding up to the child's 7th birthday for early intervention.
  - Age 7 onwards, therapies and services outside of school largely parent-funded on top of medical and non-medical costs.

Areas of Expense for Families with Children with ASD

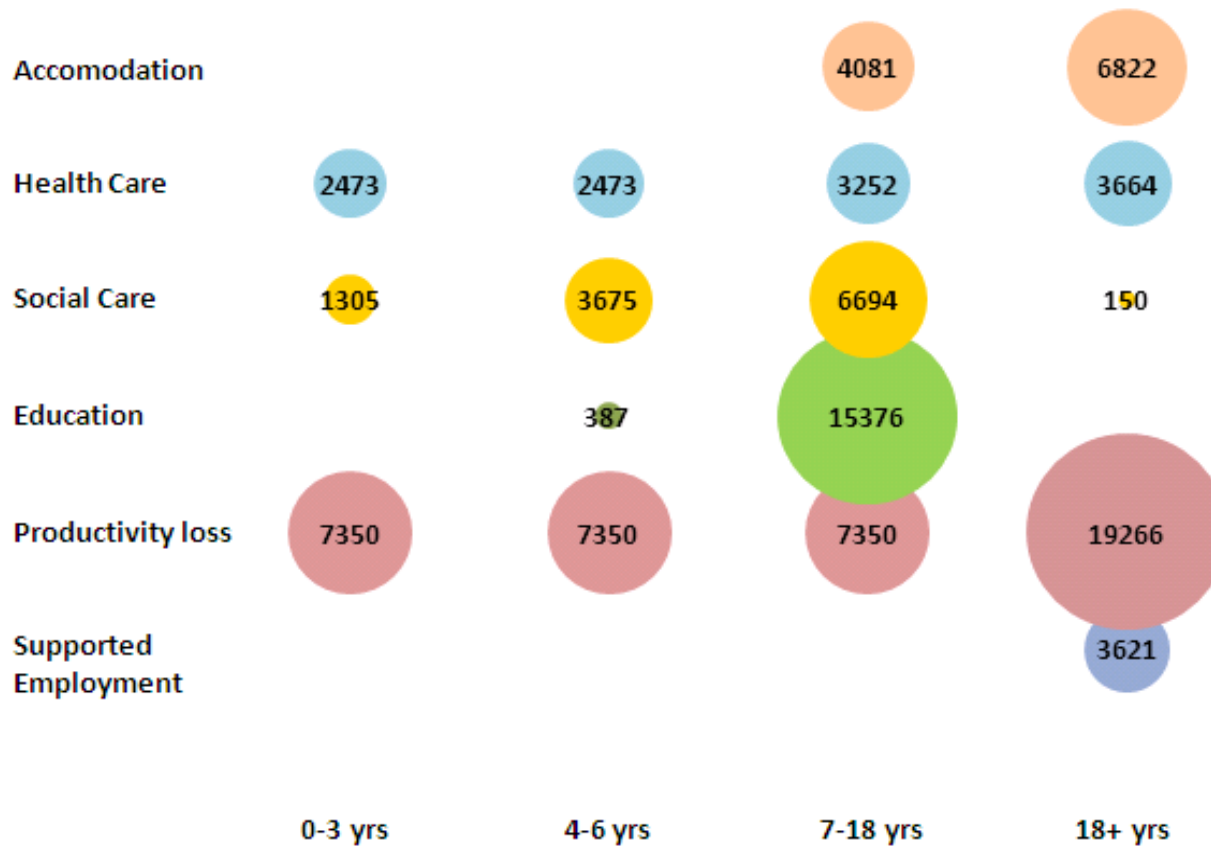| Direct Medical	Direct Non-Medical	Indirect
Physicians/dentists	Childcare	Caregiver lost productivity
Pharmaceuticals	Respite care	Family quality of life
Therapeutic services/interventions	Home improvement	
Alternative/complimentary therapies	Special education	
Emergency room/hospitals	Support services for other family members	
Home healthcare		

Autism Costs in Germany

- Model used assumed prevalence rate of ASD of 1%, and prevalence rate of ID/DD in individuals with ASD of 50%.

- Model focused on ASD without ID/DD ('high functioning ASD') as limited data was available over the full spectrum.

- Lifetime costs of care for individuals with ASD in Germany amounted to about 70% of UK lifetime costs.

- Education and parental productivity constituted main cost drivers in childhood.

- Additional costs of ASD calculated for age groups 0-3, 4-6, 7-18, 18+ years (2012 prices):
  - **Accommodation**
  - **Health and social care**
  - **Education**
  - **Productivity loss (for both individuals with autism and their parents) and**
  - **Supported employment.**

ASD Cost w/o ID/IDD

- <u>Special education</u> for children aged 7-18 (25% of total); <u>parental productivity loss</u> for pre-school children (12% of the total) were the main costs during childhood.

- <u>Individual productivity loss</u> was the largest cost for adults (58% of the total). The percentage of adults with ASD without employment might be reduced in the future as companies in Germany are now recruiting people on the spectrum for jobs.

- <u>Lifetime costs</u> of caring for a person with ASD w/o ID/DD was estimated at €766,865, based on an average life expectancy of 70 years for people with ASD.

Economic cost of autism in Germany (IQ >70, in € per person/year)

	0-3 yrs	4-6 yrs	7-18 yrs	18+ yrs
Accomodation			4081	6822
Health Care	2473	2473	3252	3664
Social Care	1305	3675	6694	150
Education		387	15376	
Productivity loss	7350	7350	7350	19266
Supported Employment				3621

Bachmann, Buescher & Knapp, preliminary data

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Germany-UK Comparison

- As already mentioned, <u>In UK, the distribution of costs within each age group was similar to German figures</u>, but lifetime costs of care in Germany amounted to ~70% of lifetime costs for UK for ASD w/o ID/DD. Lets revisit this:

- Although German health and social care system is regarded as quite highly priced and resource-intensive, further research is needed to investigate whether these results are due to fundamental differences in health and social care systems, or if other forces apply:

- One possibility is <u>greater awareness of ASD w/o ID/DD in UK</u> and <u>different pathways towards diagnosis and treatment</u>, contributing to these observed differences.

Economic cost of autism in the UK
Knapp, et al Autism (2009)

- Data on prevalence; level of ID/DD; place of residence; average annual costs of services and supports; and opportunity costs of lost productivity

- <u>Cost of supporting children with ASD were 2.7 billion each year</u>

- <u>Cost of supporting adults with ASD were 25 billion each year</u>

- Lifetime costs for someone with ASD with ID/DD was estimated at ~1.23 million, and for someone with ASD without ID ~0.80 million

UK Annual Costs

	Economic cost	Research spend	UK annual figures
Children and adolescents with autism	£32.1bn	£4m	Autism
Adults with autism	£29bn	0.29m	Adults with autism

Comparing Costs of ASD in UK and US
Buescher et al JAMA Pediatrics (2014)

- Mean annual medical, non-medical, and indirect economic costs and lifetime costs were measured for individuals with ASD separately with and without ID/DD in the US and UK

- Cost of supporting an ASD individual with ID/DD during the lifespan was $2.4 million in the US and $2.2 million in the UK.

- Cost of supporting an individual with an ASD without ID/DD was $1.4 million in the US and $1.4 million in the UK

- <u>Largest cost components for children were special education services and parental productivity loss</u>.

- <u>During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs</u>.

- <u>Medical costs were much higher for adults than for children</u>

Table 4. Mean Annual Costs per Capita for Adults (≥18 Years of Age) by Level of ID, Disaggregated by Cost Component

Cost Category	UK Costs per Year (2011), £		US Costs per Year (2011), $	
	With ID	Without ID	With ID	Without ID
Accommodation	41 512	0[a]	36 161[b]	18 080[b]
Education	2619	3307	0[a]	0[a]
Employment support	290	0[a]	705	352
Services[c]				
Medical	5142	16 044	27 159	13 580
Nonmedical	2871	3610	11 387	5693
Productivity loss				
Individual with ASD	25 644	21 797	10 718	10 718
Parents	1477	1477	1896	1896
Family expenses	873	1712	0[a]	0[a]
Benefits	5671	0	0[a]	0[a]
Total costs, £ ($) for United Kingdom and $ for United States	86 099 (126 430)	47 947 (70 406)	88 026	50 319

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability.

[a] No data available.

[b] Assumed to be zero.

[c] In the United Kingdom, medical services are not separate from residential care. Adults with ID frequently are in government-sponsored residential care, the costs of which include medical care costs. Adults without ID are served in the community and therefore have higher observed medical care costs.

Mean Annual Costs per Capita for Adults (≥18 Years of Age) by Level of ID, Disaggregated by Cost Component

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Societal Cost of Autism

The lifetime per capita incremental societal cost of autism in US was $3.2 million.

Table 1. Age-Specific and Lifetime per Capita Incremental Societal Costs of Autism*

Age Group, y	Average Per Capita Cost per Age Group			Total Per Capita Cost
	Direct Medical	Direct Nonmedical	Indirect	
3-7	35 370	10 805	43 066	446 203
8-12	6013	15 708	41 138	314 297
13-17	5014	13 550	38 453	285 082
18-22	2879	10 720	36 090	248 446
23-27	1574	27 539	51 740	404 260
28-32	1454	23 755	35 757	304 828
33-37	1389	20 492	30 852	263 662
38-42	1283	17 676	29 132	240 457
43-47	1440	15 248	26 600	216 439
48-52	1447	13 152	24 531	195 650
53-57	1290	11 292	17 776	151 790
58-62	1218	9489	0	53 535
63-66	1027	7908	0	35 738
Total lifetime costs	305 956	978 761	1 875 667	3 160 384

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

Ganz et al., *Arch Pediatr Adolesc Med* (2007)

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Annual cost of services for children with autism averages more than $17,000 per child each year, non-health expenses accounted for more than 60 percent of this costs

Lavelle et al., *Pediatrics* (2014)

TABLE 4 Summary of the Regression-Adjusted Difference in Costs for Children With ASD Compared With Children Without ASD

Category	Total costs,[a] $	95% CI	Out of pocket costs[a], $	95% CI
Health care	3020	1017 to 4259	182	−6 to 299
Total aggregate non–health care	14 061	4390 to 24 302	−112	−715 to 749
School	8610	6595 to 10 421	−462	−3496 to 189
ASD-related therapy and other family-coordinated services	350	−76 to 972	81	−318 to 523
Time	5089	−1672 to 11 936	—	—

[a] Adjusted for child gender, age, race/ethnicity, insurance status, household income, geographic region, urban/rural classification, and the presence of a comorbidity not related to ASD.

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Mean annual member costs for hospitalizations ($550 vs. $208), clinic visits ($1373 vs. $540), and prescription medications ($724 vs. $96) were more than double for children with ASD compared with children without ASD.

Croen et al., *Pediatrics* (2006)

TABLE 3 Average Total Costs ($) of Health Care Services for Children With ASDs and Control Children Enrolled in the Northern California KP From July 2003 to June 2004

	Children With ASDs			Control Children			ASD/Control Ratio, Ratio of Means	P
	Mean	Median	SD	Mean	Median	SD		
Annual total of health care costs per member								
Outpatient clinic costs, total	1373	712	2666	540	278	1525	2.5	<.0001
Pediatrics	358	231	440	232	140	324	1.5	<.0001
Psychiatry	611	0	1533	77	0	550	8.0	<.0001
Neurology	24	0	125	2	0	37	11.9	<.0001
Other clinic visits[a]	292	0	1297	179	0	1120	1.6	<.0001
Inpatient hospital costs	411	0	5097	140	0	2663	2.9	<.0001
Psychiatric	169	0	2185	14	0	398	12.4	<.0001
Nonpsychiatric	242	0	4554	126	0	2623	1.9	.03
Outpatient hospital costs	139	0	852	68	0	861	2.0	<.0001
ED costs	67	0	280	52	0	196	1.3	.0001
Medication costs	724	79	1761	96	11	931	7.6	<.0001
Psychotherapeutic agents[b]	601	0	1464	24	0	221	24.8	<.0001
Antiinfective agents	22	0	243	14	0	86	1.6	<.0001
Analgesics/antirheumatic agents	3	0	36	2	0	30	1.3	.19
Gastrointestinal agents	6	0	66	2	0	40	2.9	<.0001
Respiratory/allergy agents	30	0	308	15	0	97	2.0	<.0001
Total	2715	1058	6742	896	335	3679	3.0	<.0001

[a] "Other" includes visits to the following outpatient departments: allergy, adult primary care, alternative medicine, anesthesia, dermatology, obstetrics/gynecology, occupational medicine, ophthalmology, orthopedics, physical medicine, physical therapy, rehabilitation therapy, surgery, substance abuse, urgent care, and urology.
[b] Includes β-adrenergic blockers, antiadrenergic agents, antihypertensive combinations, benzodiazepine anticonvulsant agents, miscellaneous anticonvulsant agents, antidepressants, antianxiety agents, antipsychotic agents, miscellaneous psychotherapeutic agents, and amphetamines.

Estimated Effect of ASD Status: Parental Employment

- Mothers of children with ASD earn 35% ($7,189) less than the mothers of children with another health limitation and 56% ($14,755) less than the mothers of children with no health limitation. Cidav et al., *Pediatrics* (2012)

	I. Parental Employment[a]			II. Parental Work Hours[b]			III. Parental Earnings[c]		
	Mother	Father	Family	Mother	Father	Family	Mother	Father	Family
Child has another health limitation	1.75%	−0.95%	3.52%	1.87	−1.47	−0.65	7189[d]	6125	10 416[d]
	$P = .31$	$P = .73$	$P = .23$	$P = .43$	$P = .45$	$P = .80$	$P = .03$	$P = .14$	$P < .001$
Child has no health limitation	5.64%[d]	2.68%	9.02%[d]	6.55[d]	−0.32	5.15[d]	14 755[d]	7858	17 763[d]
	$P < .001$	$P = .34$	$P < .001$	$P < .001$	$P = .87$	$P = .04$	$P < .001$	$P = .06$	$P < .001$
Child has ASD	ref.	ref.	ref.	ref.	ref.	ref.	ref.	ref.	ref.

ref, reference group.

[a] Logit model is used to estimate dependent variables of whether the child's mother is employed, whether the child's father is employed, or whether both parents employed. Marginal effects are reported. All regressions include parent's age, education, rated health, an indicator of 2-parent household, number of children, number of children aged <6, family size, other family income, child's age and rated health, and indicators of whether child is a boy, Hispanic, black–non-Hispanic, white–non-Hispanic, has limitations in activities of daily living/instrumental activities of daily living, lives in an MSA, lives in the Northeast, lives in the Midwest, lives in the West, and year.

[b] Tobit model is used in estimating dependent variables mother's hours of work, father's hours of work, and sum of mother's and father's hours of work per week. Coefficients represent marginal effects. All regressions include covariates listed above.

[c] Tobit model is used to estimate dependent variables mother's earnings, father's earnings, and sum of mother's and father's earnings per year. Coefficients represent marginal effects. All regressions include covariates listed above.

[d] Estimated coefficients are found to be significantly different at $p = .05$.

Loss of Income in Households with Child with Autism

Montes et al., *Pediatrics* (2012)

TABLE 3 Estimated Loss of Income Associated With Having a Child With ASD

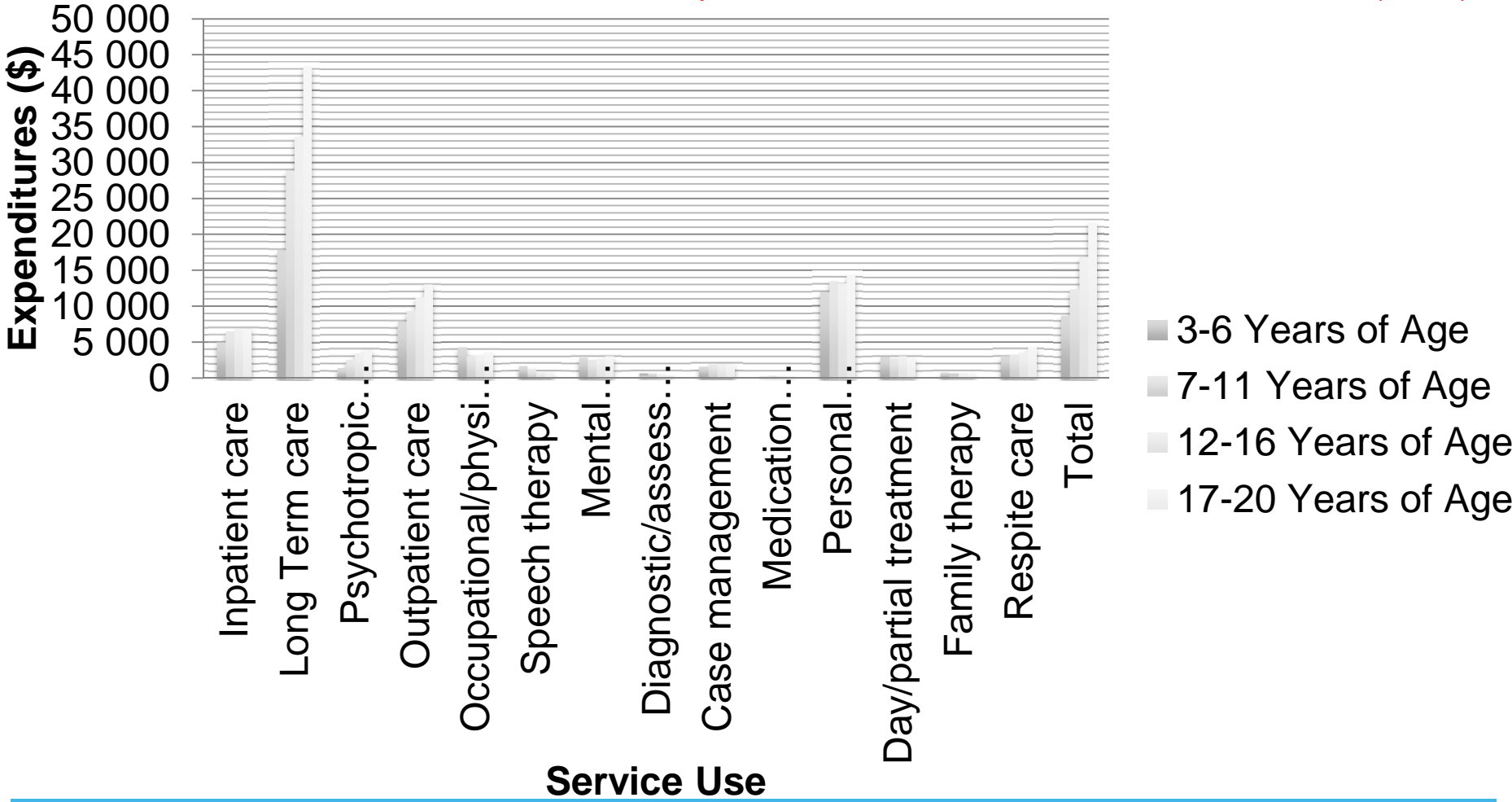| Variable	Annual Household Income (in 2005 $)[a]		
	All Households (Validation)[b]	Households With Child With Autism[c]	Households With Child With Other Disabilities[d]
Expected based on model	$53 500.45[b]	$51 693.25[c]	$48 573.06[d]
Reported	$53 420.35	$45 486.55	$47 480.25
Loss of income (difference)	$80.10	$6206.70	$1092.81

[a] Income distributions censored at $101 000.

[b] Covariates were evaluated at the average values for the sample.

[c] Covariates were evaluated at average values for families with children with autism but with no autism present.

[d] Covariates were evaluated at average values for families with children with other disabilities but with no disability present.

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Service use and expenditures across use by age group

Children with autism had significantly (p <0.001) higher mean physician visits over 12 months

Gurney et al., *Arch Pediatr Adolesc* (2006)

Table 4. Data for Physician Visits in the Past 12 Months as a Measure of Health Care Use Among Children With and Without Autism, From the National Survey of Children's Health*

Variable	Children With Autism (n = 324 000)†	Children Without Autism (n = 61 100 000)†
No. of visits for preventive care		
0	16.4	25.0
1-2	56.3	60.9
3-5	19.4	12.2
≥6	7.9	1.9
Mean (95% CI)	3.89 (3.57-4.21)	2.51 (2.49-2.53)
No. of hospital emergency department visits		
0	70.3	83.4
1	19.7	11.7
≥2	10.0	4.9
Mean (95% CI)	0.18 (0.12-0.23)	0.10 (0.09-0.10)
No. of nonemergency visits		
0	29.5	42.0
1	16.3	19.8
≥2	54.2	38.2
Mean (95% CI)	2.80 (2.44-3.16)	1.56 (1.54-1.58)

Abbreviation: See Table 2.
*Data are adjusted for sex, primary language, age, insurance, and household educational attainment. $P<.001$ for the difference between the 2 groups for all variables.
†Data are given as the percentage of each group and are based on sampling fractions and weighted extrapolation from parent report of 483 children with autism and 84 789 children without autism.

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Burden of ASD:
Quality of Life, Medical and Mental Health

GBD by World Regions: Globally, <u>autism</u> disorders accounted for more than 58 DALYs per 100,000 population and <u>other ASDs</u> accounted for 53 DALYs per 100,000.

Table 1. *Estimated DALYs for autistic disorder, by sex and GBD world region in 2010*

Baxter et al., *Psychological Medicine* (2015)

Region	Females DALYs	Females Rate per 100 000	Females 95% UI	Males DALYs	Males Rate per 100 000	Males 95% UI	Persons DALYs	Persons Rate per 100 000	Persons 95% UI
Asia Pacific, high income	26 769	29.5	19.8–41.4	75 229	86.1	59.3–121.2	101 997	57.3	39.5–80.1
Asia Central	12 116	29.6	19.7–42.1	34 011	86.7	59.1–125.2	46 128	57.6	39.3–81.7
Asia East	207 483	30.8	19.5–46.1	657 311	90.8	54.9–137.5	864 794	61.9	38.9–89.9
Asia South	225 718	28.8	19.1–40.6	696 418	84.0	56.6–118.9	922 136	57.2	38.8–80.0
Asia South East	93 615	30.5	20.8–43.8	268 615	88.5	59.2–126.4	362 230	59.4	40.4–83.4
Australasia	3848	29.5	19.7–40.8	11 026	85.7	58.8–122.3	14 873	57.4	39.4–80.0
Caribbean	6148	28.1	18.5–40.2	17 452	80.8	53.1–117.1	23 599	54.3	36.1–77.4
Europe Central	17 316	28.3	18.5–40.9	47 396	82.0	55.3–118.6	64 712	54.4	36.9–76.5
Europe Eastern	31 266	28.1	18.0–41.6	79 484	83.0	53.4–120.1	110 750	53.5	35.0–75.7
Europe Western	52 517	24.8	16.7–34.9	147 582	72.3	49.7–100.0	200 099	48.1	32.8–66.7
Latin America, Andean	7497	28.1	18.4–40.3	22 167	82.7	54.6–121.3	29 634	55.4	37.7–79.4
Latin America, Central	32 466	27.8	18.1–39.9	92 308	80.9	53.2–116.8	124 774	54.0	36.0–76.4
Latin America, Southern	9397	30.6	19.8–44.5	25 916	87.9	57.8–128.5	35 313	58.7	39.5–84.0
Latin America, Tropical	28 917	28.3	17.6–43.7	81 703	82.2	52.1–125.1	110 620	54.8	35.4–80.9
North Africa/Middle East	63 911	29.3	19.8–41.7	192 119	84.3	57.3–118.0	256 031	57.4	39.1–79.6
North America, high income	61 798	35.9	23.9–50.4	177 666	105.9	71.3–148.7	239 463	70.5	47.8–97.8
Oceania	1507	31.0	19.9–45.9	4574	90.3	58.4–133.0	6081	61.2	40.5–88.1
Sub-Saharan Africa Central	14 353	29.6	19.3–43.9	41 222	85.9	55.4–123.2	55 575	57.6	38.6–81.2
Sub-Saharan Africa East	53 435	30.0	20.1–42.3	151 894	85.8	57.1–120.6	205 329	57.8	38.8–81.3
Sub-Saharan Africa South	10 598	29.8	19.4–43.8	29 964	85.9	56.3–124.8	40 562	57.5	38.4–82.7
Sub-Saharan Africa West	49 480	29.7	19.2–42.7	145 909	86.3	57.1–125.9	195 390	58.2	39.2–83.1
Global	1 010 150	29.6	20.3–40.6	2 999 970	86.3	58.9–121.3	4 010 120	58.2	40.1–81.1

DALYs, Disability-adjusted life-years; GBD, Global Burden of Disease Study; UI, uncertainty interval.
Rounding of numbers may not add up to the 'Total'.

Mean Health-Related Quality of Life (HRQoL) scores of the 286 children with ASD assessed were significantly lower than those of healthy populations.

Kuhlthau et al., *J Autism Dev Disord* (2010)

Table 2 Mean PedsQL total scores and subscale scores for ASD sample and healthy and chronic health condition normative populations

	ASD sample	Healthy sample[a]		Chronic health condition sample[a]	
		Mean (SD)	p-Value[b]	Mean (SD)	p-Value
Parent-proxy report					
Total	65.2 (15.9)	82.3 (15.6)	<0.001	73.1 (16.5)	<0.001
Physical health	74.6 (19.6)	84.1 (19.7)	<0.001	77.0 (20.2)	0.080
Psychosocial health	59.9 (16.8)	81.2 (15.3)	<0.001	71.0 (17.3)	<0.001
Emotional functioning	66.4 (20.0)	81.2 (16.4)	<0.001	71.1 (19.8)	<0.001
Social functioning	50.6 (23.6)	83.1 (19.7)	<0.001	75.1 (21.8)	<0.001
School functioning	63.8 (21.0)	78.3 (19.6)	<0.001	65.6 (20.8)	0.238

PedsQL scores range from 0 to 100, with 100 representing the best possible quality of life. (*NOTE: Reviewer #4 asked us to clarify what scores mean, so I added this edit...I don't know if he is looking for more information than this, but I am assuming that this is what he means.)

[a] Data from Varni et al. (2003). The PedsQL[TM] as a pediatric population health measure: feasibility, reliability, and validity. *Ambulatory Pediatrics, 3*, 329–341

[b] Because of multiple comparisons, the p-value for significance for this table is 0.004

Mothers of a child with autism were highly stressed and more likely to report poor or fair mental health than mothers in the general population, even after adjustment for the child's social skills and demographic background

Montes et al., *Pediatrics* (2007)

TABLE 3 Multivariate Analyses of Maternal Functioning

Parameter	Unadjusted OR (95% CI)	Adjusted OR (95% CI)[a]
Maternal health		
Overall health (poor/fair)	1.29 (0.65–2.57)	1.60 (0.80–3.21)
Mental and emotional health (poor/fair)	2.74 (1.45–5.18)[b]	2.42 (1.31–4.45)[b]
Maternal Stress		
Child is harder to care for than most children	13.33 (8.64–20.59)[c]	7.57 (4.47–12.82)[c]
Parent gives up her life to meet child's needs	3.11 (2.03–4.77)[c]	3.77 (2.43–5.87)[c]
Parent–child relationship		
Relationship is very close	1.27 (0.62–2.56)	5.20 (2.05–13.20)[b]
Talk about important things with child	0.27 (0.18–0.40)[c]	0.44 (0.29–0.67)[c]
Angry at child	1.17 (0.80–1.71)	0.54 (0.34–0.85)[b]
Child bothers mother a lot	2.26 (1.33–3.84)[b]	1.18 (0.73–1.93)
Coping and support		
Coping very well with parenting	0.88 (0.61–1.27)	1.84 (1.28–2.65)[b]
Has someone to talk about parenting	1.40 (0.84–2.35)	1.14 (.55–2.38)
Disagreement style		
Keeps opinions to oneself	1.22 (0.79–1.89)	1.34 (0.83–2.14)
Discusses calmly	1.02 (0.66–1.57)	1.43 (0.93–2.20)
Argues heatedly	0.82 (0.48–1.39)	0.52 (0.27–1.01)
Hits or throws things	1.04 (0.63–1.73)	0.63 (0.30–1.34)

[a] OR for families with a child with autism compared with families with a child without autism, adjusted for demographic variables and child's social skills. Demographic variables include age, gender, race, Hispanic ethnicity, poverty, education, and 2-parent family.
[b] $P < .01$.
[c] $P < .001$.

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Siblings of children with ASD participated in fewer extracurricular activities than those with Typically Developing (TD) siblings. Children with TD siblings had higher enjoyment scores in relaxation activities than children with siblings with ASD.
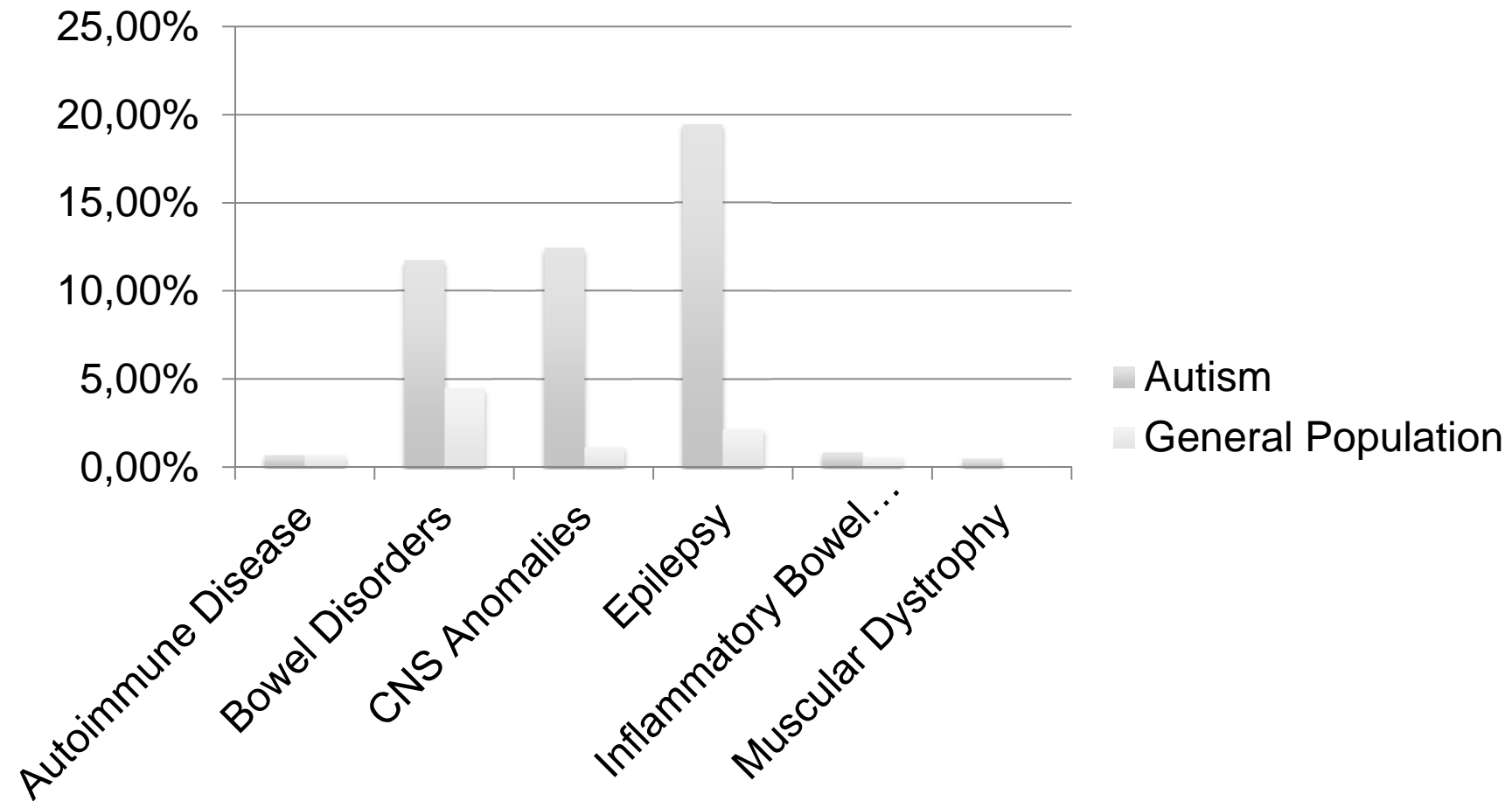(*p <0.05)

Wingston et al., *Dev Neurorehabil* (2017)
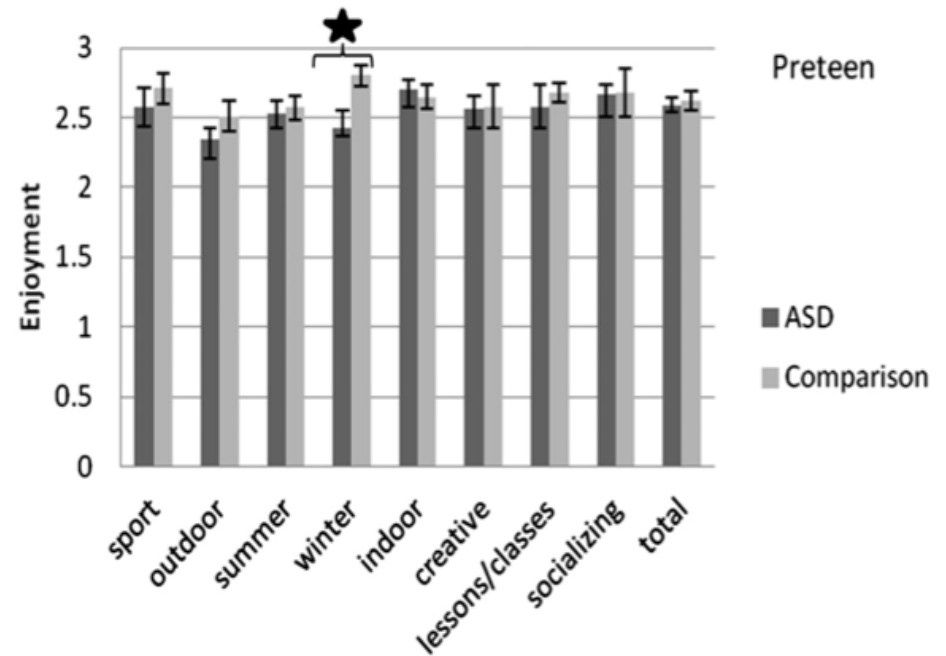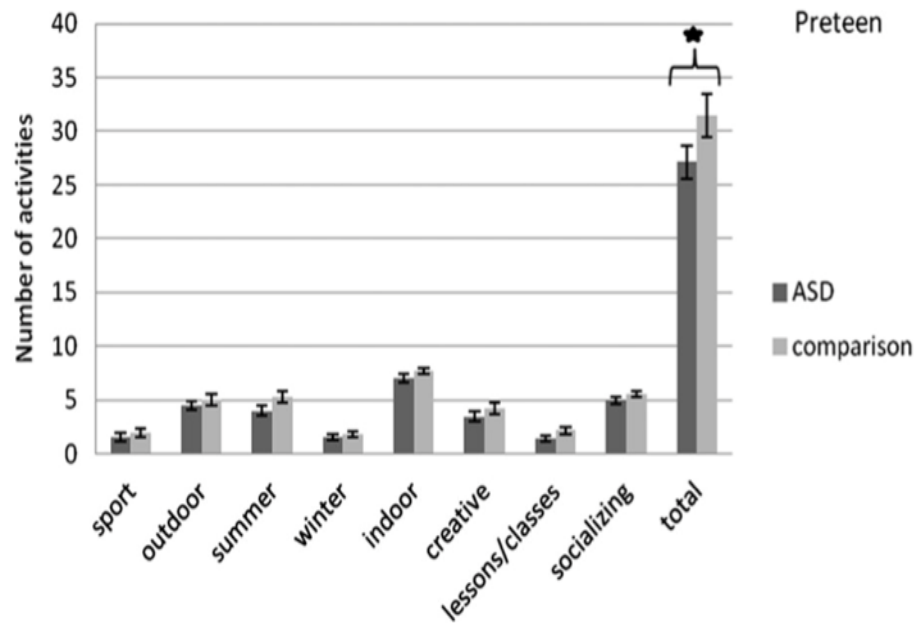
All comorbities have a significantly different proportion in the ASD population (p< 0.0001 by Chi-square) except for the autoimmune diseases (from which IBD and DM1 were excluded and are shown separately on the chart) for which p <0.5.

Adopted from Kohane et al., *PLoS ONE* (2012)

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Prevalence of Psychiatric Comorbidities in Psychiatrically Referred ASD and Non-ASD Youth (3-17 Years of Age)

Joshi et al., *J Autism Dev Disord* (2012)
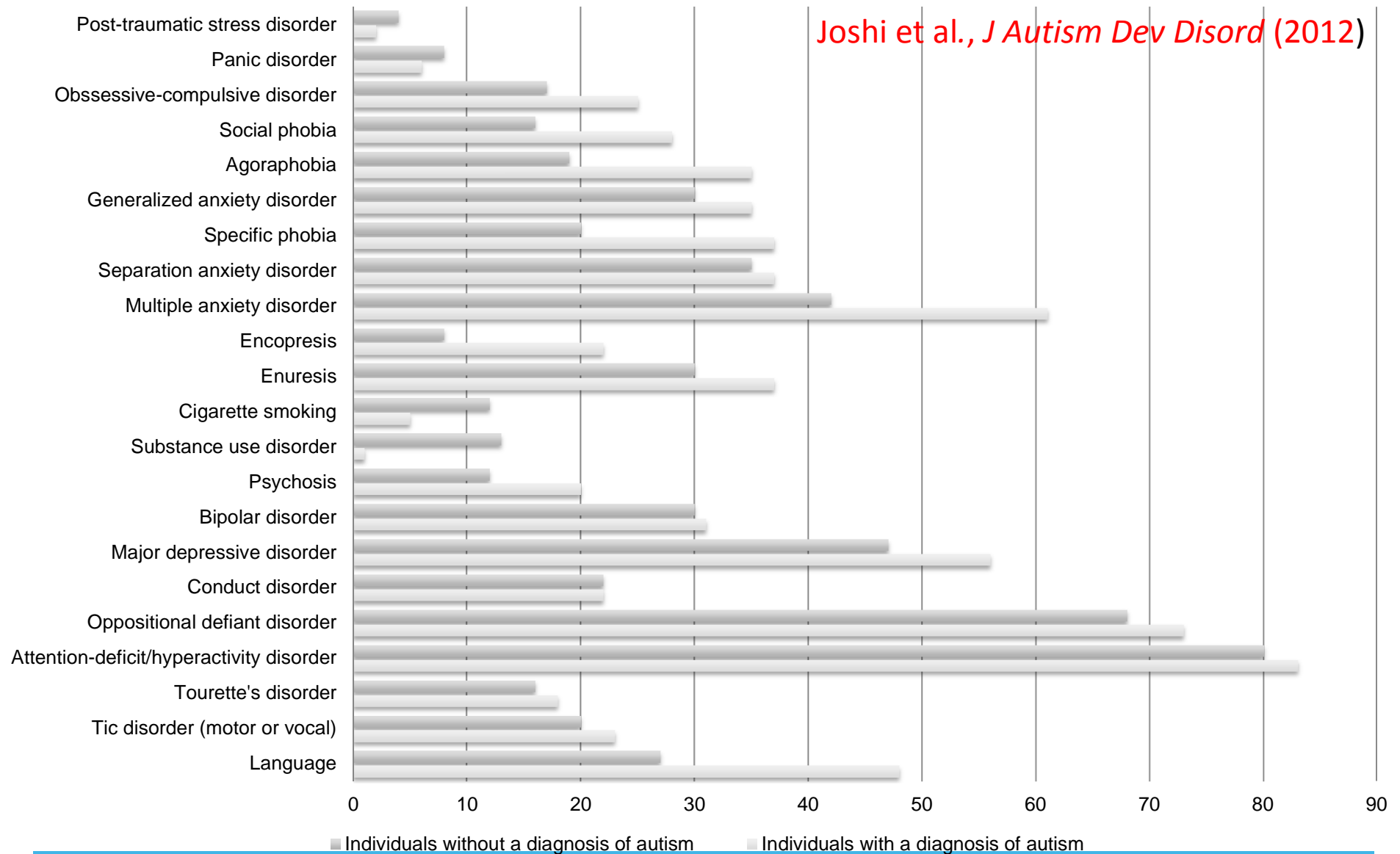
Premature mortality was markedly increased in ASD owing to a multitude of medical conditions.

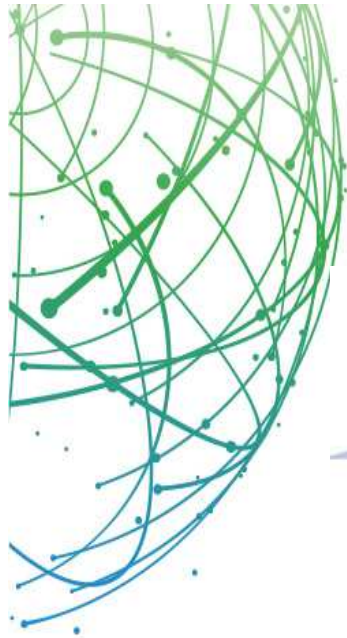Hirkoski et al., *Br J Psychiatry* (2016)

Table 3 Risk for all-cause mortality for the entire autism spectrum disorder (ASD) group, as well as separately for females and males, and low-functioning ASD and high-functioning ASD groups

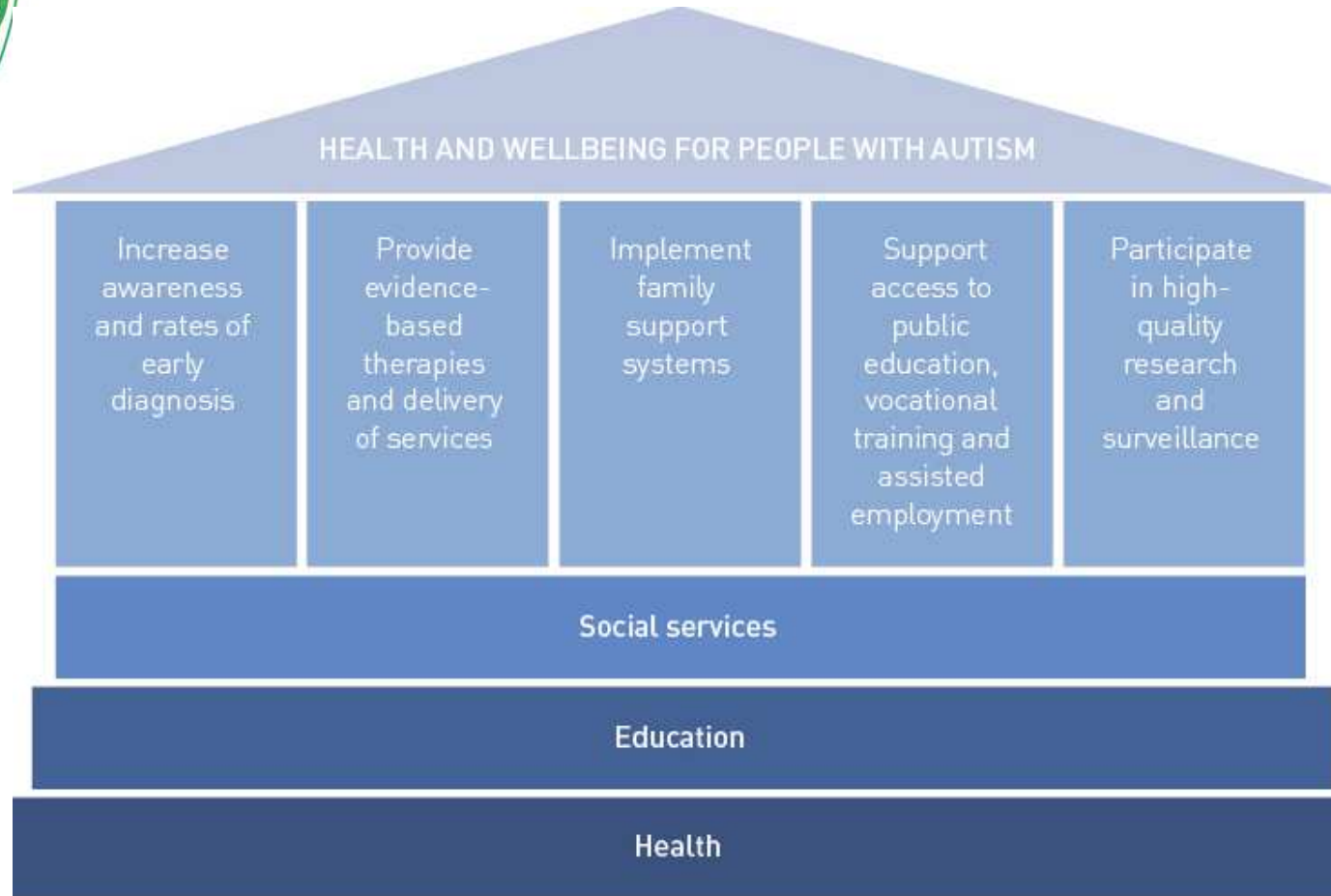|	Controls Number of deaths (%)	ASD OR (95% CI) Number of deaths (%)	Low-functioning ASD OR (95% CI) Number of deaths (%)	High-functioning ASD OR (95% CI) Number of deaths (%)
Total	24 358 (0.91)	2.56 (2.38–2.76) 706 (2.60)	5.78** (4.94–6.75) 169 (2.71)	2.18 (2.00–2.38) 537 (2.57)
Females	11 693 (1.39)	2.24 (1.99–2.51) 296 (3.51)	8.52 (6.55–11.08) 61 (3.00)	1.88 (1.65–2.14) 235 (3.67)
Males	12 665 (0.69)	2.87* (2.60–3.16) 410 (2.19)	4.88 (4.02–5.93) 108 (2.57)	2.49 (2.22–2.80) 302 (2.08)

ASD, autism spectrum disorder; OR, odds ratio; CI, confidence interval.
*Partial likelihood ratio test for interaction effect ASD × gender, $P = 0.001$.
**Partial likelihood ratio test for model selection (low-functioning ASD/high-functioning ASD), $P < 0.001$.

Conclusion

- The substantial direct and indirect economic costs associated with ASD as well as its social, medical and mental health burdens emphasize the need to continue to search for early, cost effective interventions

- The distribution of economic costs effect across many different service systems and raises the question about coordination of services and sectors

PLATFORMS AND PILLARS OF CARE

HEALTH AND WELLBEING FOR PEOPLE WITH AUTISM

| Increase awareness and rates of early diagnosis | Provide evidence-based therapies and delivery of services | Implement family support systems | Support access to public education, vocational training and assisted employment | Participate in high-quality research and surveillance |

Social services

Education

Health

Merci!