



The lifetime social cost of autism: 1990–2029

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ABSTRACT

This cost of illness analysis computes a baseline and future estimate of lifetime social costs associated with autism spectrum disorder (ASD) for the 50 states in the United States (US). The number of cases of ASD are estimated, then multiplied by annual direct and indirect medical and non-medical costs identified in the peer-reviewed literature. This amount is then extrapolated across the number of years each cost type is expected to be incurred to calculate a total lifetime cost for each state in the US from 1990–2019, and to project future cost for 2020–2029. From 1990–2019, there have been an estimated 2 million new cases of (ASD), with social costs of more than \$7 trillion. If the future prevalence of ASD remains unchanged over the next decade, there will be an estimated additional 1 million new cases, resulting in an additional \$4 trillion to the United States in social costs, however if the rate of increase in prevalence continues, costs could reach nearly \$15 trillion by 2029. The financial burden of ASD is significant and identifying the modifiable causes of ASD has the potential to provide tangible benefits.

1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is behaviorally defined and includes impairments in social communication as well as stereotypical and/or repetitive and/or restrictive behaviors. Standard of care therapy for ASD commonly involves intensive (full-time) behavioral and educational therapy, with many children requiring life-long care, resulting in what others have characterized as substantial costs (e.g. Buescher, Cidav, & Knapp, 2014; Ganz, 2007; Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; Lavelle et al., 2014; Leigh & Du, 2015). There have been some attempts to estimate the social cost of ASD, and typically a standard method of ‘average per capita cost’ is the focus (Leigh & Du, 2015). Others like Buescher et al. (2014); Ganz (2007), and Leigh and Du (2015) have calculated the national social costs of ASD as a function of (a) the estimated number of affected individuals, (b) severity, (c) the age at diagnosis, and (d) associated expenses for treatment and care.

The present study, by carefully reviewing the prior published methods used to estimate the social cost of ASD, presents an applied national cost analysis at the individual state level utilizing methods found in earlier analyses. This new model, designed to be geographically specific (i.e., accounting for cost differences from state-to-state), provides a baseline estimate for incurred past, and a projected future estimate of the lifetime social costs of ASD for each state in the United States, and for the nation, beginning in 1990 and projecting out to 2029.

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1.1. Per capita annual and lifetime costs associated with autism

Having a diagnosis of ASD carries with it a lifetime of direct and indirect costs (de la Cuesta, 2009; Ganz, 2007; Horlin et al., 2014; Knapp, Romeo, & Beecham, 2009). Recently, a review by Rogge and Janssen (2019) distinguished between six types of ASD-related costs: medical and healthcare related service costs, therapeutic costs, (special) education costs, costs of production loss for adults with ASD, costs of informal care and lost productivity for family/caregivers, and costs of accommodation, respite care, and out-of-pocket expenses. Most models used to estimate the cost of ASD attempt to either (1) characterize the lifetime social costs (Buescher et al., 2014; Ganz, 2006, 2007; Ganz, 2008; Knapp et al., 2009; Leigh & Du, 2015) or (2) illustrate the cost savings or benefits of a particular intervention associated with avoided expenses from reduced needs and improved outcomes (Chasson, Harris, & Neely, 2007; Horlin et al., 2014; Jacobson, Mulick, & Green, 1998).

It is difficult to assess if there is general agreement regarding the social cost of ASD because the earlier published studies do not have a uniform method (unit of measure) for reporting costs and, most importantly, each study has its own inherent assumptions that influence the final cost estimate. We explored methods used to calculate social costs of ASD in a variety of international studies; however, estimated costs for other nations have less relevance to the United States due to worldwide social, cultural, and regional differences in expenses that can influence the per capita lifetime social cost associated with ASD. For example, in contrast to studies of western societies that identify the largest source of cost as special education for children (Järbrink, 2007; Leigh & Du, 2015), and lost productivity (Horlin et al., 2014) or care for adults (Buescher et al., 2014; Ganz, 2007; Knapp et al., 2009; Nydén, Myrén, & Gillberg, 2008); a study conducted in China found the largest cost associated with an ASD is early intervention and behavioral therapy, which can exceed the per capita income of as many as 20 % of urban and 38 % of rural Chinese families (Wang et al., 2012).

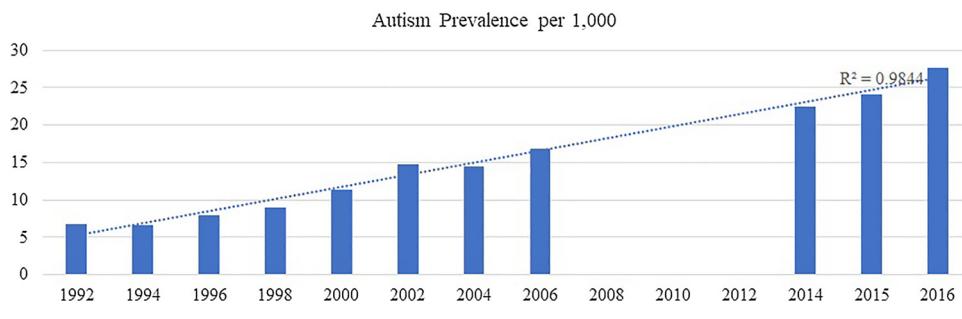
Despite the heterogeneity, previously conducted studies have several key methodological strengths, such as the identification of costs dependent on the age of the individual (Buescher et al., 2014; Ganz, 2007; Jacobson et al., 1998; Leigh and Du, 2015), an average annual per capita cost (Horlin et al., 2014; Järbrink, 2007; Nydén et al., 2008) or lifetime per capita cost (Ganz, 2007; Järbrink & Knapp, 2001; Knapp et al., 2009), extrapolation to a population based on prevalence of the disorder (Buescher et al., 2014; Ganz, 2007; Jacobson et al., 1998; Järbrink & Knapp, 2001; Knapp et al., 2009; Leigh & Du, 2015), apportionment of costs based on severity or ID (Buescher et al., 2014; Ganz, 2007; Horlin et al., 2014; Knapp et al., 2009; Leigh & Du, 2015), and analysis of alternate future scenarios (Leigh & Du, 2015). This study borrows these methodological strengths and applies them to United States population-based estimates of individuals with ASD.

1.2. Number of autism cases

Because national per capita cost is multiplied by the number of cases in a society to derive total social cost, the estimated prevalence of existing, and incidence of new cases of affected individuals is a key determining factor in aggregated social cost for a specific nation or state. Most studies of the social cost of ASD estimate the total number of cases of ASD by calculating the number of individuals expressed as the percentage of population affected, or prevalence (Buescher et al., 2014; Knapp et al., 2009; Leigh & Du, 2015). The most recent studies by Buescher et al. (2014) and Leigh and Du (2015) both applied the prevalence or rate of ASD reported by the Centers for Disease Control (CDC), which Buescher et al. (2014) considered the most reliable and accepted estimates. Others have constructed cohorts, allowing for the approximation of lifetime costs for age groups (Buescher et al., 2014; Ganz, 2007; Knapp et al., 2009; Leigh & Du, 2015), which is important when there is changing rate over time, as has been reported by Van Naarden Braun et al. (2015).

There has been some disagreement concerning whether the rate of ASD is static or changing over time. Fombonne (2005) examined studies from 14 countries and found that the best estimate for the rate of ASD is 0.6 %, and Baxter et al. (2015) explored studies with samples up to 27 years of age and identified a global rate of 7.6 per 1000 (0.8 %); neither of these global studies was able to definitively reveal a change in prevalence of ASD over time. In the United States in 2007, surveys of parents reporting a diagnosis indicated the prevalence of ASD was 110 / 10,000 (1.1 %) (Kogan et al., 2009). This is within the range of a national surveillance program for 8-year-old children in metropolitan Atlanta that showed a rate of 4.2 per 1000 (0.4 %) in 1996, and 15.5 per 1000 (1.6 %) in 2010 (Van Naarden Braun et al., 2015). The ADDM network reported a prevalence of 14.7 per 1000 (1.47 %) of children aged 8 in reporting year 2010 (ADDM Network Principal Investigators, 2014) and 16.8 per 1000 (1.68 %) for reporting year 2014 among 8-year-old children (Baio, Wiggins, & Christensen, 2018). The most recent estimates of the prevalence of ASD from the National Health Interview Survey (NHIS), which was conducted by the National Center for Health Statistics and designed to yield a nationally representative sample, were reported as 2.76 % (27.6 in 1000) in 2016 (Zablotsky, Black, & Blumberg, 2017). Recently, Nevison, Blaxill, and Zahorodny, (2018) analyzed temporal trends of ASD prevalence using constant age tracking and age-resolved snapshots and found a strong, statistically significant upward trend over time in the State of California, which realized an increase of 1,000 % between 1931 and 2012. This study also reported statistically significant increases in ASD prevalence over time in one-half of the states in the ADDM network.

In the United States, each state reports to the United States Department of Education, which reports to Congress the number of students served under the Individuals with Disabilities Education Act of 2004 (IDEA), including students served under the classification of an ASD. Mandell and Palmer (2005) found that these state-reported cases of ASD were associated with education related spending and the unique education system characteristics of each state. These state- reported numbers do not capture those in private and home schools, but to the extent the education system in each state remains the same, the change in ASD reported over time may be able to shed light on changes in prevalence.

**Fig. 1.** Prevalence of ASD Over Time.

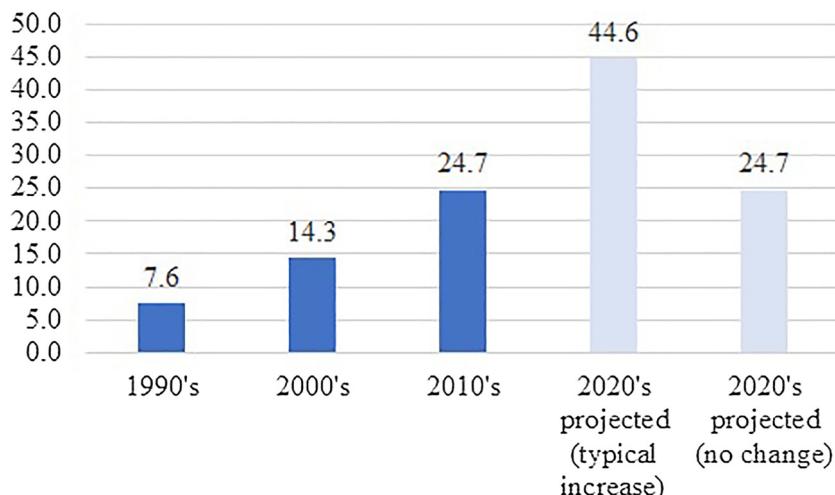
2. Methods

This study has two essential components: 1. Estimation of the number of cases of ASD for each state for each decade 1990–2019, and 2020–2029. 2. Estimation of the lifetime cost of ASD per person. To estimate the number of cases for each state, we computed an average national prevalence of ASD for each decade 1990–2019 using prevalence reported in [CDC \(2018\)](#) and [Zablotsky et al. \(2017\)](#) (also shown in [Fig. 1](#)), and applied it as a percentage to the total state-by-state, decade by decade population of children to estimate a number of individuals with ASD for each decade for each state. State decade estimates of the number of individuals with ASD were then multiplied by a lifetime per capita cost of the disorder based on reported annual average costs for additional medical and education needs, lowered productivity, and lower rates of independent living associated with an ASD. Like [Leigh and Du \(2015\)](#), we used scenario analysis to explore a base case of future percentage incidence identical to the prior decade, and an alternate scenario of increase in percentage incidence equal to the increase of past prevalence over the prior two decades using two separate data sources.

2.1. Total estimated cases of ASD

To calculate an estimated number of American children carrying an ASD diagnosis, we averaged the prevalence of ASD from federal monitoring programs, expressed it as a percentage, and applied it to the federal 2010 Census ([United States Census Bureau, 2019a](#)), and CDC WONDER population projections for the decades of 1990–2019 and 2020–2029 ([CDC WONDER Online Database, 2005](#)). CDC ADDM reported ASD prevalence per 1,000 for birth years between 1990 and 1999 are as follows: 6.7 (1992), 6.6 (1994), 8.0 (1996), and 9.0 (1998) for an average of 7.6 in 1,000 for United States children born in years 1990 – 1999. For the 2000s, reported prevalence by birth year was 11.3 (2000), 14.7 (2002), 14.6 (2004), and 16.8 (2006) ([CDC, 2018](#)) for an average prevalence of 14.4 in 1000 for birth years 2000 – 2009. The ADDM Network does not cover birth years 2010–2019 yet, so instead we applied the National Center for Health Statistics survey of ASD in children aged 3–17, which documented a prevalence of 22.4 (2014), 24.1 (2015), and 27.6 (2016) ([Zablotsky et al., 2017](#)), averaging to 24.7 for birth years 2010 – 2019. [Fig. 1](#) graphs the United States estimates based on the ADDM ([CDC, 2018](#)) and NHIS ([Zablotsky et al., 2017](#)).

For our base case future scenario 2020–2029, we assumed the future incidence of ASD will remain unchanged from the average prevalence of the prior decade 2010–2019, and as an alternate scenario, we projected a future incidence of ASD based on the average rate of prevalence increase for each study decade, 1990–2019, (i.e. 180.77 % increase per decade). As a third scenario, we apply the

**Fig. 2.** Average prevalence of ASD per 1000 calculated from data from [CDC \(2018\)](#) and ([Zablotsky et al., 2017](#)).

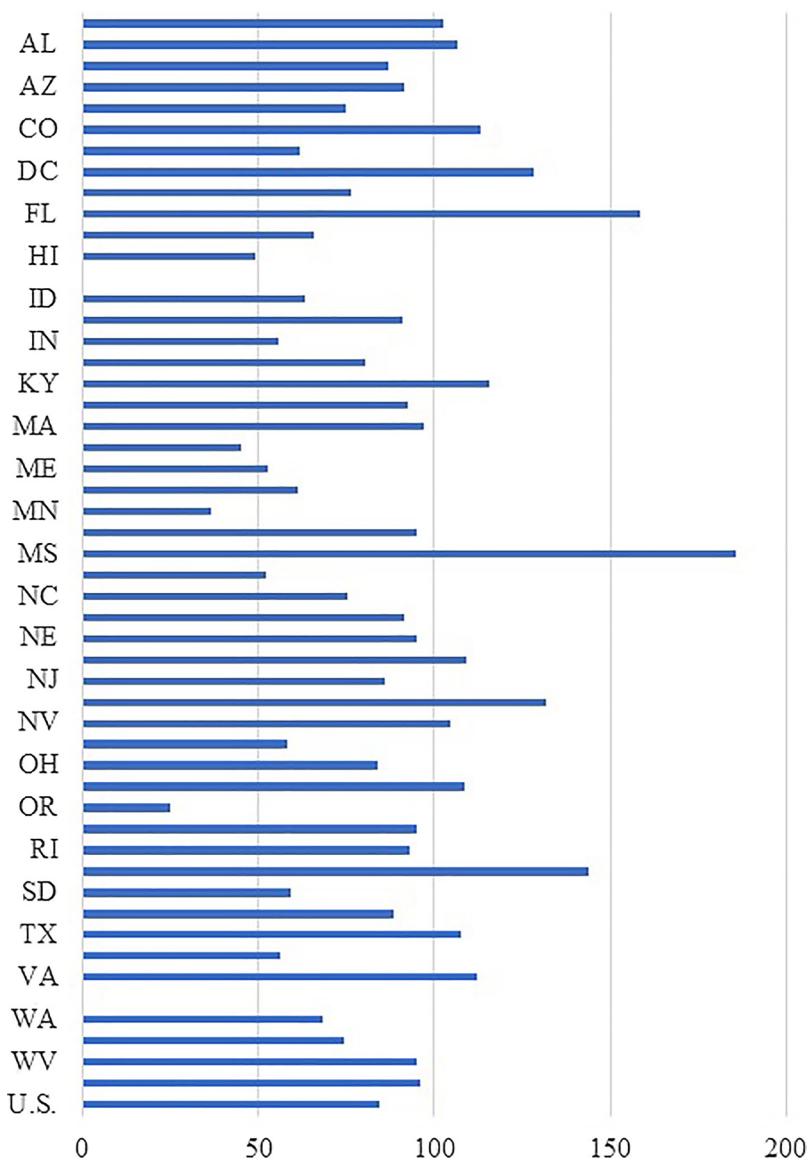


Fig. 3. Percent change in ASD 2008–2015 (United States Department of Education, 2017).

state-by-state rate of change between 2008 and 2015 from the United States Department of Education's 39th annual report to Congress on the implementation of IDEA, 2017 (United States Department of Education, 2017). Fig. 2 displays the decadal average prevalence of ASD and the projected future scenarios of incidence for the 2020's (24.7 per 1000 for a baseline of no change, and 44.6 per 1000, assuming the historical rate of increase continues). Fig. 3 shows our state-by-state change in ASD scenario based on 2008–2015 change as reported by states for IDEA (United States Department of Education, 2017). The change for Iowa was less than .05 % and not reported, and Vermont did not provide data, so a 0 % change from 2010 to 2019 is applied for these states for this scenario so that a conservative and reasonable national aggregate can be computed. Table 1 lists the total population of children from the Census and CDC population projections and provides our estimated number of children with ASD for each state for each study decade 1990–2019. Table 2 provides the three alternate future scenarios for 2020–2029, reported as whole numbers.

2.2. Application of estimates for lifetime per capita cost

Estimating the social cost of ASD is a complex undertaking because the treatment and care of affected individuals is fragmented, taking place in medical, educational, and residential settings (Leslie & Martin, 2007). Others like Järbrink (2007) and Lavelle et al. (2014) have focused on the cost for children, or the cost of a specific need for either an adult or child (e.g. Liptak, Stuart, & Auinger, 2006; Shimabukuro, Grosse, & Rice, 2008; Vohra, Madhavan, & Sambamoothi, 2017). Some of the cost for children or adults with an ASD can be found in government and non-profit organization reports related to a specific cost parameter (e.g. Chambers, Parrish, &

Table 1

Estimated Number of ASD Cases Based on Population and Average Prevalence for Each Decade 1990–2019.

State	Children Born				Estimated Autism Diagnoses		
	1990–1999	2000–2009	2010–2019	2020–2029	1990–1999	2000–2009	2010–2019
AL	663,126	613,186	594,849	618,790	5,040	8,830	14,693
AK	102,957	104,883	132,659	145,156	782	1510	3,277
AZ	910,246	909,395	1,229,605	1,487,522	6,918	13,095	30,371
AR	401,364	394,566	405,430	439,732	3,050	5,682	10,014
CA	5,414,870	5,037,172	6,096,218	6,206,327	41,153	72,535	150,577
CO	672,129	692,563	761,831	839,160	5,108	9,973	18,817
CT	491,099	424,677	466,796	455,493	3,732	6,115	11,530
DE	121,431	112,372	121,750	121,957	923	1,618	3,007
DC	64,960	58,760	65,276	58,145	494	846	1,612
FL	2,359,229	2,153,761	2,751,410	3,230,947	17,930	31,014	67,960
GA	1,399,683	1,381,946	1,603,712	1,801,993	10,638	19,900	39,612
HI	167,533	170,768	193,434	181,751	1,273	2,459	4,778
ID	232,314	242,967	250,213	269,901	1,766	3,499	6,180
IL	1,801,540	1,694,982	1,858,071	1,841,184	13,692	24,408	45,894
IN	927,686	878,896	907,911	949,875	7,050	12,656	22,425
IA	417,741	402,769	379,413	359,033	3,175	5,800	9,372
KS	402,705	407,939	399,047	392,373	3,061	5,874	9,856
KY	580,949	565,255	549,206	576,143	4,415	8,140	13,565
LA	633,615	620,622	641,217	645,405	4,815	8,937	15,838
ME	167,323	143,636	149,703	136,146	1,272	2,068	3,698
MD	785,270	731,356	924,920	968,761	5,968	10,532	22,846
MA	868,369	752,774	827,840	856,265	6,600	10,840	20,448
MI	1,414,815	1,234,070	1,390,491	1,332,435	10,753	17,771	34,345
MN	720,171	711,040	815,408	836,858	5,473	10,239	20,141
MS	432,867	416,628	395,721	393,531	3,290	5,999	9,774
MO	820,711	780,700	809,635	831,172	6,237	11,242	19,998
MT	127,848	123,188	120,147	113,272	972	1,774	2,968
NE	251,636	260,836	254,164	253,436	1,912	3,756	6,278
NV	365,773	370,555	503,795	618,599	2,780	5,336	12,444
NH	178,240	147,562	187,070	193,913	1,355	2,125	4,621
NJ	1,185,434	1,105,770	1,222,533	1,233,084	9,009	15,923	30,197
NM	291,552	288,289	279,372	252,816	2,216	4,151	6,900
NY	2,577,734	2,319,777	2,487,470	2,409,578	19,591	33,405	61,441
NC	1,290,695	1,267,985	1,476,349	1,750,081	9,809	18,259	36,466
ND	87,264	84,671	74,167	68,122	663	1,219	1,832
OH	1,598,381	1,468,745	1,504,189	1,462,851	12,148	21,150	37,153
OK	518,148	523,462	511,177	545,425	3,938	7,538	12,626
OR	497,413	474,770	564,057	628,944	3,780	6,837	13,932
PA	1,696,217	1,483,173	1,542,709	1,485,967	12,891	21,358	38,105
RI	143,870	117,888	140,482	133,381	1,093	1,698	3,470
SC	626,275	598,150	594,547	633,251	4,760	8,613	14,685
SD	111,588	115,152	108,756	108,589	848	1,658	2,686
TN	856,127	819,994	895,989	1,013,628	6,507	11,808	22,131
TX	3,765,007	3,856,707	4,547,455	5,130,534	28,614	55,537	112,322
UT	449,041	513,496	512,219	606,742	3,413	7,394	12,652
VT	83,649	66,606	75,378	71,773	636	959	1,862
VA	1,062,211	1,021,474	1,180,363	1,299,862	8,073	14,709	29,155
WA	900,361	869,534	977,872	1,099,440	6,843	12,521	24,153
WV	229,137	210,076	186,577	176,570	1,741	3,025	4,608
WI	775,136	727,060	767,196	742,678	5,891	10,470	18,950
WY	74,097	77,416	59,983	53,266	563	1,115	1,482
United States	42,717,537	40,550,019	45,495,782	48,061,857	324,653	583,920	1,123,746

Note. Population data from the 2010 United States Census ([United States Census Bureau, 2019a](#)) and CDC WONDER Online Database ([CDC WONDER Online Database, 2005](#)).

[Harr, 2002](#)). Recently, [Rogge and Janssen \(2019\)](#) developed a literature review of the economic costs of ASD, however no previous studies have developed a state-by-state estimate of the lifetime per capita cost, which is the goal of this study. Similar to others, we identified previously-published annual average per-capita incremental needs and costs above that of typical individuals conducted from 2000 to present, then multiplied each type of cost (medical, education, care, and productivity) by the number of appropriate years in childhood or adulthood similar to [Buescher et al. \(2014\)](#) and [Knapp et al. \(2009\)](#), to develop a per capita lifetime total cost on a state-by-state level.

To develop a state level estimate, we reviewed the literature for prior studies that estimated the cost of ASD associated needs, then inflated reported costs to 2019 dollars using the United States Department of Labor, Bureau of Labor Statistics Consumer Price Index Inflation Calculator, January to January adjustment. The calculator can be found at https://www.bls.gov/data/inflation_calculator.

Table 2

Estimated Number of ASD Cases for Each of Three Future Scenarios for 2020–2029.

State	Scenarios of Future Incidence		
	2020–2029 no increase in rate	2020–2029 consistent rate of increase	IDEA percent increase reported to congress compared to 2010–2019 estimates
AL	15,284	27,598	30,385
AK	3,585	6,474	6,645
AZ	36,742	66,343	58,131
AR	10,861	19,612	18,736
CA	153,296	276,802	263,660
CO	20,727	37,427	40,137
CT	11,251	20,315	18,655
DE	3,012	5,439	5,305
DC	1,436	2,593	3,683
FL	79,804	144,100	175,608
GA	44,509	80,369	65,637
HI	4,489	8,106	7,133
ID	6,667	12,038	10,099
IL	45,477	82,117	87,612
IN	23,462	42,364	34,894
IA	8,868	16,013	9,372
KS	9,692	17,500	17,781
KY	14,231	25,696	29,288
LA	15,942	28,785	30,472
ME	3,363	6,072	5,650
MD	23,928	43,207	33,126
MA	21,150	38,189	40,302
MI	32,911	59,427	55,433
MN	20,670	37,324	27,472
MS	9,720	17,551	27,915
MO	20,530	37,070	39,036
MT	2,798	5,052	4,514
NE	6,260	11,303	12,254
NV	15,279	27,590	25,460
NH	4,790	8,649	9,671
NJ	30,457	54,996	56,105
NM	6,245	11,276	15,982
NY	59,517	107,467	97,383
NC	43,227	78,054	63,888
ND	1,683	3,038	3,510
OH	36,132	65,243	68,437
OK	13,472	24,326	26,325
OR	15,535	28,051	17,443
PA	36,703	66,274	74,305
RI	3,295	5,949	6,707
SC	15,641	28,243	35,847
SD	2,682	4,843	4,282
TN	25,037	45,208	41,761
TX	126,724	228,822	233,518
UT	14,987	27,061	19,800
VT	1,773	3,201	1,862
VA	32,107	57,974	61,838
WA	27,156	49,035	40,674
WV	4,361	7,875	8,991
WI	18,344	33,123	33,086
WY	1,316	2,376	2,904
United States	1,187,128	2,143,559	\$2,108,713

[htm](#). We discuss the literature and data sources available to make transparent informed decisions on the average per-capita annual cost each of medical care, special education, adult care, and productivity loss, then multiply across number of years of need for a lifetime per-capita cost per affected individual. This is then multiplied by the number of estimated cases of ASD in each state and aggregated for a national estimate. Where possible, we applied the most up to date state-by-state cost data aggregated and reported by federal programs or public-private partnerships, non-profits, and foundations to produce an estimate of costs from needs that are being met.

2.2.1. Direct medical costs

The additional cost of medical care for individuals with an ASD has been reported in numerous studies that have documented the incremental cost reflective of a core set of medical needs. [Vohra et al. \(2017\)](#); [Lavelle et al. \(2014\)](#); [Shimabukuro et al. \(2008\)](#); [Ganz](#)

Table 3

Direct Medical Costs.

Incremental annual average per capita cost (2019 dollars)	Calculated expenses	Study dollars: Annual average per capita cost	Study dollar year	Adult / child	Author Reference
\$8,077	In and Outpatient Hospital Pharmacy Physician Non-physician Emergency care Other health care Home healthcare	\$6,132 (ASD) \$860 (typical) \$5,272 difference	1999	child	Liptak et al. (2006)
\$21,425 (excluded)	Physician Dental Pharmacy CAM Therapy Hospital/Emergency Home Health and Supplies Early Intensive Behavioral Intervention	\$15,466	2003	child	Ganz (2007)
\$6,497	In and Outpatient Hospitals Pharmacy Physician Non-physician Medical equipment Facility fees Diagnostic services Laboratory services Speech and Occupational Therapy when covered by insurance	\$4,110 low \$6,200 high \$4,690 (average amount above typical)	2003	Child (to age 21)	Shimabukuro et al. (2008)
\$3,852	In and Outpatient hospital services Physician Nonphysician Home health care Pharmacy Vision Equipment and supplies	\$3,020 (health care above typical) \$350 (therapies) \$3,370 total	2011	child	Lavelle et al. (2014)
\$2,092	Therapy Physician Dental Pharmacy CAM Therapy Hospital/Emergency Home Health and Supplies	\$1,510 (average of years 18+) (average amount above typical)	2003	adult	Ganz (2007)
\$6,129	In and Outpatient hospitalizations Physician Emergency Pharmacy Other associated healthcare expenses	\$13,700 (ASD) \$8,560 (typical) \$5,140 difference	2008	adult	Vohra et al. (2017)

(2007), and Liptak et al. (2006) all reported costs for inpatient and outpatient care, physician visits, hospitalizations, emergency medicine, and pharmacy costs. Leslie and Martin (2007) examined in and out-patient visits and pharmacy usage, however their reported costs are in total, not incremental to typically developing individuals. Other medical needs like medical supplies, therapy, laboratory and diagnostic services, facility fees, dental services, and other unspecified needs were included inconsistently across studies (detailed in Table 3).

Most studies reporting on the incremental cost of medical care for individuals with an ASD rely on surveys about private health insurance usage like the Medical Expenditure Panel Survey (MEPS), or surveys of health care providers, which include the National Ambulatory Medical Care Survey (NAMCS) and National Hospital Ambulatory Medical Care Survey (NHAMCS). Liptak et al. (2006) studied the MEPS, NAMCS and NHAMCS. Lavelle et al. (2014) and Ganz (2007) used the MEPS and National Health Interview Survey (NHIS), a survey of households. Shimabukuro et al. (2008) analyzed the MarketScan database of health insurance claims. Vohra et al. (2017) studied Medicaid claims.

Ganz (2007) provides a unique cost for each year of life, and when those are averaged by childhood (under 18) and adulthood (18 and older) the average is the highest reported. Ganz's estimate is also unique in reflecting the cost of medical need, as opposed to the cost of medical spending, or needs that have been met. Additionally, Ganz includes Early Intensive Behavioral Intervention (EIBI) in early childhood, while others do not.

There is some confusion between therapy and EIBI. Services that help you keep, learn, or improve skills and functioning for daily living, including speech-language pathology, physical, and occupational therapy, are called "habilitative services" (Healthcare.gov.,

2019) and are covered as an essential benefit under the Affordable Care Act (Centers for Medicare & Medicaid Services, 2019), however health insurance usually caps the number of therapy visits. Liptak et al. (2006), may have captured habilitative services under the category of “other” or non-physician services, Shimabukuro et al. (2008) included speech and occupational therapy in their estimate, Vohra et al. (2017) captured “all-cause” usage of insurance, and would have included habilitative services where covered, and Lavelle et al. (2014) provides an estimate for therapy as separate from health care, which we included in our analysis of direct medical costs for consistency. The childhood average calculated from Ganz's (2007) is an outlier, highlighting an important issue: the possibility of a treatment gap between costs that are being met, and the needs of individuals with ASD; and the difference between habilitative services which can include therapy, and EIBI, which is sometimes thought of as a therapy, and sometimes thought of as an educational approach. For this study, we exclude the Ganz (2007) childhood average estimate, but provide it as a reference in Table 3, maintaining the focus of this study on direct medical costs for the portion of needs that are being met, as opposed to unmet needs.

Future studies using similar approaches to those listed in Table 3 may reflect the higher EIBI costs due to changes that are now slowly unfolding in the insurance industry regarding coverage for ASD and EIBI. For example, the Blue Cross Blue Shield's standard benefit plan for Federal Employees covers, with pre-approval, Applied Behavioral Analysis (ABA), a form of EIBI, but denies coverage for ABA when offered as part of a school or educational program (Blue Cross Blue Shield, 2019). Another large health insurance provider, Cigna, covers ABA for autism, but denies coverage for other EIBIs, like Lovaas therapy (Cigna, 2019).

Early intensive behavioral interventions such as Lovaas Therapy, Discreet Trial Training, the Early Start Denver Model, and ABA, range in annual per-capita cost from \$20,000 when there is parent involvement (\$24,871 in 2019 dollars) (Chasson et al., 2007; Rogge & Janssen, 2019) to \$60,000 in 2003 dollars (\$83,119 in 2019 dollars) (Butter, Wynn, & Mulick, 2003; Rogge & Janssen, 2019). Though the cost of EIBI is high, studies show the costs are later offset with benefits in lower special education costs (Chasson et al., 2007; Rogge & Janssen, 2019). Further comprehensive studies similar to Jacobson et al. (1998), which measure how other later health, productivity, and care costs are impacted by EIBI could work toward incentivizing its coverage under health plans or the development of publicly available opportunities to make the treatment more accessible to children with an ASD.

To develop an incremental annual average per capita medical cost for this study, we took the adjusted 2019-dollar average of studies of children and multiplied by 15, assuming a diagnosis age of 3, and the average of adult studies and multiplied by 49, assuming a life expectancy of 67 years. Like Buescher et al. (2014), we apply life expectancy based on Shavelle and Strauss (1998) who projected that at the age of 5, ASD males would live, on average, another 62.0 years, and females another 62.5 years for an average life expectancy of 67 years. This means an adult will require another 49 years of medical care beyond the age of 18. Our review results indicate that for children with an ASD, an average of about \$6,142 more is spent on medical care each year, and for adults the annual incremental average is \$4,110.5. Across the individual's lifetime, this adds up to about \$293,545 added cost for medical care associated with ASD.

2.2.2. Direct non-medical costs (education)

In the United States, the current average per pupil spending to educate a K-12 student is \$12,201 for fiscal year 2017 (\$12,647 in 2019 dollars) (United States Census Bureau, 2019b). Under IDEA, children with disabilities are legally entitled to a free and appropriate public education in the least restrictive setting. This means that a child with an ASD qualifies for special education instruction, which can be provided in a typical classroom with typically developing peers, or other setting as needed to meet minimal education needs (National Council on Disability, 2018). These costs are in addition to the typical cost of education.

The cost of special education would naturally be higher if a student has greater need, for example in children with multiple disabilities, as can be the case with individuals with an ASD. Buescher et al. (2014) reported a figure for education costs for children with an ASD both with, and without, an intellectual disability (ID), splitting the population in a 40/60 ratio. The rate of 40 % of individuals with a co-occurring intellectual disability is further supported by Van Naarden Braun et al.'s (2015) study of data from Atlanta Georgia. Others, however, report a rate as low as 31 % (Baio et al., 2018). For this study, we include a 40/60 (ID / No ID) weighted average to replicate Buescher et al. (2014) and apply Baio et al.'s 31/69 (ID / No ID) as a sensitivity analysis. Table 4 summarizes the literature concerning the cost of special education for children with an ASD.

The cost of special education for children with an ASD is less well studied than the cost of medical care, with greater variability

Table 4
Direct Non-Medical Costs (Education).

Incremental annual average per capita cost (2019 dollars)	Calculated Expenses	Study dollars: Annual average per capita cost	Study dollar year	Adult / child	Author Reference
\$17,213	Special education cost in general	\$11,543	2000	child	Chambers et al. (2002)
\$11,031	Special Education cost	\$7,963 (child)	2003	child	Ganz (2007)
\$31,959 (child with ID) \$15,980 (child without ID) \$22,372 (weighted average 40/60) \$20,932.80 (weighted 31/69)	Special education cost	\$27,961 (child with ID 6–17) \$13,980 (child without ID 6–17)	2011	child	Buescher et al. (2014)
\$9,841	Additional total school cost	\$8,610	2011	child	Lavelle et al. (2014)

across the estimates of cost. For our estimate, we averaged across the available studies. We apply a 40/60 split between ID/No ID, and a 31/69 split as a sensitivity analysis for the estimate calculated from [Buescher et al. \(2014\)](#). In our final average across estimates, we use the more generally accepted 40/60 split producing an annual per-capita special education cost of \$15,114.25 per year. Across an assumed 13 years of special education need (K-12), the total estimated incremental per-capita education cost is \$196,485. Applying a 31/69 ID/No ID ratio for [Buescher et al. \(2014\)](#) decreases the overall lifetime figure slightly by about 2 %.

2.2.3. Indirect costs (loss of productivity of individual and family members)

Indirect costs can include the loss of productivity of individuals with an ASD from unemployment, and loss of productivity of family members through decreased hours worked, lower wages, and shifted household duties. [Ganz \(2007\)](#) provided an annual average per capita estimate of \$27,745 (\$38,436 in 2019 dollars) for the lost work productivity across the population of affected individuals, assuming 45 % would be employed. [Buescher et al. \(2014\)](#) provides an estimate of \$10,718 productivity loss of the individual with an ASD, however it is not reflective of only United States studies. More recent studies on rates of employment for the ASD population are 61.42 % ([Ohl et al., 2017](#)), 53.4 % ([Roux et al., 2013](#)), 55.1 % ([Shattuck, Nerendorf, Cooper, Sterzing, & Wagner, 2012](#)).

For lost productivity of caregivers due to lower household income, the lowest reported estimate of loss was based on a survey of children enrolled in afterschool programs collected as part of the National Household Education Survey of After School Programs and Activities in 2005 ([Montes & Halterman, 2008](#)). It is possible that the population of children with an ASD able to attend afterschool programs could be less severely affected overall, thus producing a lower estimate.

The highest estimate of lost productivity of family members is by [Ganz \(2007\)](#). The Ganz estimate is more complete and was developed based on the average income and benefits of the United States labor force, adjusted by age and sex, then applying assumptions regarding reduced employment dependent on level of disability, resulting in a metric that declines over time as the individual with an ASD ages. The estimate eventually turns to zero as the average work life expectancy of the parents is assumed to end when the individual with ASD reaches about 30 years old.

[Lavelle et al. \(2014\)](#) estimated the value of shifted household activities for parents of children with an ASD, however they did not estimate loss of family income, therefore we focused on other studies for a more complete estimate of indirect costs due to lost productivity. To assess the impact this may have on our final estimate, we performed a sensitivity analysis by adding Lavelle's value of shifted household activity to the two lost family income figures by [Montes and Halterman \(2008\)](#), and [Cidav, Marcus, and Mandell \(2012\)](#), then re-average the indirect costs for childhood years to estimate the impact the cost of shifted household activity has on the overall estimate of lifetime indirect costs. [Table 5](#) summarizes the literature concerning the loss of productivity associated with an ASD.

For this study, we averaged estimates 2019 inflated estimates from [Ganz \(2007\)](#); [Montes and Halterman \(2008\)](#), and [Cidav et al. \(2012\)](#) (\$28,668.67), and multiplied by 15 childhood years assuming diagnosis at age 3 for a childhood years family productivity loss of \$430,030. Like [Ganz \(2007\)](#), we assumed retirement by caregivers of adults after an additional 12 more work years during the affected individual's adulthood, each year bringing losses valued at \$31,042 for a total productivity loss for families of \$372,504 during the affected individuals adulthood. For the loss of productivity of affected individuals with ASD, we adopt Ganz's estimate of 34 years of lost employment by each valued, on average, at \$27,745 (\$38,436 in 2019 dollars) for a total of \$1,306,824 in 2019 dollars. Together, all these forms of lost productivity lead to an estimated total lifetime per capita indirect cost of \$2,109,358.

In our sensitivity analysis, if we add the cost of shift in household activity as reported by [Lavelle et al. \(2014\)](#), which is \$5089 (\$5,817 in 2019 dollars) to [Montes and Halterman \(2008\)](#) and [Cidav et al. \(2012\)](#) which focused on lost income only, then re-calculate average annual per capita figures across the studies for childhood years, the lifetime total increases by 3 % to \$2,167,528. The minimal effect on the overall figure indicates that shifts in household services are a minor factor in an overall large monetary loss due to lower wages, lost work hours, and lost employment for individuals with an ASD and their families. This does not mean, however, that this shift in household services has a minimal impact on the families for other, non-monetary reasons.

2.2.4. Direct non-medical costs (residential living supports: general care and accommodation)

In addition to the cost of medical care, individuals with an ASD and/or their families are faced with the cost of general care and accommodation for the individual with an ASD. In the United States, the Medicaid home and community-based services (HCBS) waiver program provides reimbursement for services to enable home-based care and accommodation when the individual would otherwise require institutional placement. HCBS waivers can fund supports such as home health, personal care, day care, habilitation, and respite care to enable family members to continue to provide in-home care for qualifying children and adults if the cost is less than institutional care ([Medicaid & CHIP Payment & Access Commission, 2019](#)).

In comparison to adults with other types of disabilities, a higher percentage of individuals with an ASD continue to live with a family member ([Anderson, Shattuck, Cooper, Rou, & Wagner, 2014](#); [Hewitt et al., 2017](#); [Newman et al., 2011](#)), and the percentage that live independently as young adults is as low as 17 % ([Newman et al., 2011](#)). In studies on the cost of ASD, [Buescher et al. \(2014\)](#) estimated that 1 % age five and below, 5 % under the age of 18, and 19 % of adults with an ASD are cared for in an intermediate care facility. [Ganz \(2007\)](#) and [Buescher et al. \(2014\)](#) based estimates for the cost of care on earlier studies that included Medicaid data, however more recent studies of the HCBS Waiver program enable an analysis of actual expenditures.

In the United States, as of 2009, there were 562,067 persons with a developmental and intellectual disability receiving HCBS waiver services ([Lakin, Larson, Salmi, & Webster, 2010](#)), and by 2017, HCBS 1915 (c) waiver spending for this population reached \$34 billion. For this study, we assume that all adults with ASD and combined ID will need and qualify for an HCBS waiver through Medicaid, and we adopt the most recently documented per capita cost for HCBS waivers for the developmentally and intellectually

Table 5
Loss of Productivity of individual and family members.

Incremental annual average per capita cost (2019 dollars)	Study dollars: Annual average per capita cost	Study year	Adult / child	Author Reference
\$38,436 (adults with ASD) \$56,640 (caregivers of children with ASD) \$31,042 (caregivers of adults with ASD)	Lost work productivity of the individual. Lost contribution to household services. Lost employment by care giver.	\$27,745 (adults with ASD) \$40,886 (caregivers of children with ASD) \$22,408 (caregivers of adults with ASD)	2003 Childhood and adult years	Ganz (2007)
\$8,184 \$21,182	Loss of household income from families with children in an afterschool program Lost employment and decreased wages.	\$6,200 \$17,763 (families of a single child with an ASD)	2005 Childhood years 2011 Childhood years	Montes and Halterman (2008) Cidav et al. (2012)

Table 6

HCBS Waiver Cost Per Enrollee With a Developmental and Intellectual Disability (Lakin et al., 2010; Musumeci et al., 2019).

State	HCBS spending per enrollee in 2009 dollars (Lakin et al. (2010))	HCBS spending per enrollee adjusted to 2019 dollars (Lakin et al. (2010))	HCBS spending per enrollee (2017 dollars) Musumeci et al. (2019)	HCBS spending per enrollee adjusted to 2019 dollars Musumeci et al. (2019)	Lifetime Per Capita Cost (2019 dollars)
AL	\$49,859	\$59,439	\$63,600	\$65,924	\$3,230,273
AK	\$64,017	\$76,318	\$78,700	\$81,576	\$3,997,209
AZ	\$26,805	\$31,956	no data	no data	no data
AR	\$34,469	\$41,092	\$48,300	\$50,065	\$2,453,179
CA	\$26,794	\$31,943	\$26,200	\$27,157	\$1,330,710
CO	\$41,472	\$49,441	\$36,600	\$37,937	\$1,858,931
CT	\$63,394	\$75,574	\$87,400	\$90,594	\$4,439,086
DE	\$107,453	\$128,099	\$110,800	\$114,849	\$5,627,583
DC	\$92,190	\$109,903	\$69,000	\$71,521	\$3,504,542
FL	\$29,215	\$34,828	\$28,400	\$29,438	\$1,442,449
GA	\$28,901	\$34,454	\$43,700	\$45,297	\$2,219,543
HI	\$41,441	\$49,403	\$40,600	\$42,084	\$2,062,093
ID	\$30,196	\$35,997	\$29,300	\$30,371	\$1,488,160
IL	\$32,264	\$38,463	\$3,100	\$3,213	\$157,450
IN	\$45,389	\$54,110	\$32,600	\$33,791	\$1,655,769
IA	\$23,147	\$27,595	\$35,300	\$36,590	\$1,792,903
KS	\$36,224	\$43,184	\$45,100	\$46,748	\$2,290,650
KY	\$48,831	\$58,214	\$43,700	\$45,297	\$2,219,543
LA	\$50,665	\$60,399	\$39,200	\$40,632	\$1,990,986
ME	\$72,821	\$86,813	\$68,900	\$71,418	\$3,499,463
MD	\$48,305	\$57,586	\$58,800	\$60,949	\$2,986,479
MA	\$56,241	\$67,048	\$82,300	\$85,307	\$4,180,055
MI	\$44,865	\$53,486	\$66,500	\$68,930	\$3,377,566
MN	\$66,158	\$78,869	\$69,600	\$72,143	\$3,535,016
MS	\$21,789	\$25,975	\$35,800	\$37,108	\$1,818,298
MO	\$48,765	\$58,135	\$60,600	\$62,814	\$3,077,902
MT	\$36,022	\$42,944	\$40,300	\$41,773	\$2,046,856
NE	\$44,304	\$52,817	\$35,400	\$36,694	\$1,797,982
NV	\$45,941	\$54,769	\$47,700	\$49,443	\$2,422,705
NH	\$40,370	\$48,126	\$44,400	\$46,022	\$2,255,096
NJ	\$54,142	\$64,545	\$56,500	\$58,565	\$2,869,661
NM	\$71,517	\$85,258	\$70,300	\$72,869	\$3,570,569
NY	\$69,752	\$83,155	\$70,300	\$72,869	\$3,570,569
NC	\$45,697	\$54,477	\$52,300	\$54,211	\$2,656,341
ND	\$22,467	\$26,784	\$38,200	\$39,596	\$1,940,196
OH	\$44,208	\$52,702	\$45,300	\$46,955	\$2,300,808
OK	\$52,099	\$62,109	\$55,200	\$57,217	\$2,803,633
OR	\$40,295	\$48,037	\$4,400	\$4,561	\$223,478
PA	\$44,062	\$52,528	\$44,900	\$46,541	\$2,280,492
RI	\$74,206	\$88,463	no data	no data	no data
SC	\$38,228	\$45,573	\$30,400	\$31,511	\$1,544,030
SD	\$31,297	\$37,311	\$31,800	\$32,962	\$1,615,137
TN	\$75,411	\$89,900	\$82,400	\$85,411	\$4,185,134
TX	\$39,125	\$46,643	\$37,700	\$39,078	\$1,914,800
UT	\$33,329	\$39,733	\$47,500	\$49,236	\$2,412,547
VT	\$54,151	\$64,556	no data	no data	no data
VA	\$57,570	\$68,632	\$67,000	\$69,448	\$3,402,961
WA	\$35,822	\$42,705	\$35,400	\$36,694	\$1,797,982
WV	\$60,839	\$72,529	\$66,400	\$68,826	\$3,372,487
WI	\$39,989	\$47,672	\$21,800	\$22,597	\$1,107,232
WY	\$46,002	\$54,840	\$47,600	\$49,339	\$2,417,626
National Average (2019)		\$56,767		\$51,337	\$2,515,503

disabled to reflect current spending associated with the current administration of the HCBS waiver program policies. We assume those with a combined ASD and ID will need care across their adult life, and apply the same 40/60 ID/No ID ratio, with a 31/69 ID/No ID ratio as a sensitivity analysis. Life expectancy is assumed to be an average of 67 years, meaning 49 total per-capita years of needed adult care for those with both an ASD and ID. Table 6 shows each state's average per person HCBS waiver cost for accommodation associated care in 2009 (Lakin et al., 2010) and 2017 (Musumeci, Chidambaram, & Watts, 2019). We calculated the per capita lifetime cost of care for individuals with both an ASD and intellectual disability by inflating the most recent data on the cost of HCBS waivers to 2019 dollars.

HCBS waiver cost varies from state to state due to differences in services provided and cost of living. In addition to inter-state variability in cost and services covered, HCBS waiver spending has changed over time. A detailed description of the variability in Medicaid coverage is beyond the scope of this study, however we provide two separate estimates of state-by-state HCBS waiver cost

for developmentally and intellectually disabled individuals (Lakin et al., 2010; Musumeci et al., 2019) to show that the HCBS waiver program changes over time. For more information about exactly what is offered in each state, a point-in-time description of each state's HCBS Medicaid waiver program can be accessed at <https://www.medicaid.gov/medicaid/ltrs/downloads/asd-state-of-the-states-report.pdf>.

To reflect the current state of HCBS service, our study applied the most recent data available on a state-by-state basis, and our final state-level calculations reflect the Lifetime Per Capita Cost in 2019 dollars shown in Table 6. On average nationally, a year of service under a Medicaid HCBS waiver for the developmentally and intellectually disabled costs \$51,337 in 2017, down by 11 % from 2009 when adjusted to 2019 dollars. Applying the 2019 adjusted national annual average from fiscal year 2017 to 49 years of adult care results in a lifetime per capita average cost for an HCBS waiver (general care and accommodation) of \$2,515,503. For the three states with no data in Musumeci et al. (2019), we applied Lakin et al. (2010) adjusted to 2019 dollars, which decreased the national average to \$2,418,732. Not all adults with an ASD living at home will qualify for an HCBS waiver, therefore we assume that 40 % will qualify based on a combined developmental (ASD) and intellectual disability (ID), decreasing the average lifetime per capita cost of care across the entire ASD population by 60 % to \$967,493. Under a scenario of only 31 % with a co-occurring ID requiring an HCBS waiver, the average national lifetime per capita cost of care could be as low as \$749,807. For state-level analysis, we weight by 40% and round to the nearest whole, or integer number.

3. Results

Using the previously described methods, the average per capita lifetime cost of ASD in the United States is \$3,566,881 in 2019 dollars. The total population level lifetime cost varies on a state-by-state basis, largely based on the size of the population and cost of Medicaid HCBS waivers, which vary in cost due to the amount and cost of services eligible for reimbursement under the State-defined programs. Applying what is known about the prevalence of ASD to the United States population of children since 1990, we estimate that there are approximately 2 million diagnoses 1990–2019, and the associated lifetime social costs of the disorder have reached more than \$7 trillion in 2019 dollars. Even if the future incidence of ASD remains the same as the current prevalence, that total is projected to increase to over 3 million affected, with associated lifetime social costs of \$11.5 trillion by 2029. If, however, the incidence of ASD increases at the same average rate per decade as the past increase in prevalence, or continues to increase at the United States Department of Education reported rate, we project that the number affected will increase to over 4 million individuals with an ASD, and a lifetime social cost of \$14.5 to \$14.9 trillion for cases of ASD 1990–2029. Table 7 provides the state-by-state results of our analysis for 1990–2019 and Table 8 provides the results of our three scenario analyses.

4. Discussion & implications

Our estimate of approximately \$3.6 million in lifetime social cost for an individual with an ASD is within the range of existing studies. Buescher et al. (2014) estimated the cost of ASD at \$1.4 million for individuals without, and \$2.4 million for individuals with a co-occurring ID (\$1.6 and \$2.7 million in 2019 dollars), and Ganz (2007) estimated \$3.2 million (\$4.4 million in 2019 dollars). To the best of our ability, we based our cost estimate on studies of actual expenditures, or productivity losses. Ganz's higher estimate includes EIBI, a need that is currently not met by any existing public programs and may be beyond the ability of most families to afford, naturally increasing his estimate substantially. Our estimate is higher than Buescher et al. (2014), however, their estimate of productivity loss for individuals with an ASD for adults is only \$10,718 (\$12,251 in 2019 dollars). We base our productivity loss estimate on Ganz (2007) which is \$27,745 (\$38,436 in 2019 dollars), who's estimate is more complete and includes the average earnings in the United States and earnings of those in supported employment. Fig. 4 provides a comparison of estimates of the lifetime per capita cost of ASD. Like Ganz (2007), we found the largest cost to society is from lost productivity and adult care for the affected individuals (Fig. 5).

On a state-by-state basis, the lifetime per capita cost of ASD varies considerably depending largely on the cost of an HCBS waiver, which depends on the cost of living and covered services. Fig. 6 shows the geographic distribution of the per capita lifetime cost, illustrating that there is no clear geographic pattern to the cost of ASD on a per-capita basis.

The analyses presented here represent an estimate of the lifetime social cost of ASD to states and to the country. To our knowledge, this is the first time the cost of ASD has been estimated at the level of the individual state. While we readily acknowledge that these are imperfect calculations and that there is uncertainty inherent in the estimates of population, existing prevalence, and future incidence of autism, and even incremental cost, we point out that the analyses have been conducted using well-accepted data from the most current studies on ASD rates and cost to produce a reasonable, baseline and projected future estimate of the cost of ASD to society.

Most importantly, our findings show that the largest proportion of cost rests with lost productivity for families and the individual, and the cost of care for affected adults. The lack of accessibility of EIBI points to an area where cost savings could be potentially gained with the development of publicly funded EIBI school programs. A maximum cost of \$83,119 in 2019 dollars for about four years (Butter et al., 2003; Rogge & Janssen, 2019), may result in cost savings that could span the remainder of the individual's life in the areas of special education, medical care, less productivity loss, and lower adult care costs, but more studies on the benefits of EIBI are needed to draw a definitive conclusion. EIBI typically takes place during the preschool years, which makes early diagnosis imperative. Even though the cost of ASD can decrease with early intervention (Jacobson et al., 1998), it can increase with delays in diagnosis (Horlin et al., 2014) and any lifetime social cost estimates of ASD would be affected if a portion of the population recovered from the disorder. For example, a survey of 673,000 children revealed that 40 % of parents with children age 3–17 stated that their

Table 7
State-by-State Results 1990–2019.

State	Estimated Population Level Lifetime Cost of Autism Per Decade in 2019 Dollars		
	1990-1999	2000-2009	2010-2019
AL	\$19,613,144,880	\$34,361,918,510	\$57,177,765,421
AK	\$3,283,048,704	\$6,339,390,720	\$13,757,737,344
AZ	\$18,070,992,060	\$34,206,366,150	\$79,334,215,070
AR	\$10,921,013,000	\$20,345,310,120	\$35,856,729,240
CA	\$128,877,697,816	\$227,155,828,520	\$471,557,774,744
CO	\$17,075,839,680	\$33,339,340,080	\$62,904,478,320
CT	\$16,327,582,104	\$26,753,259,530	\$50,444,003,660
DE	\$4,476,938,583	\$7,847,981,178	\$14,585,215,947
DC	\$1,976,595,270	\$3,385,019,430	\$6,449,942,460
FL	\$56,952,278,240	\$98,511,877,152	\$215,865,969,280
GA	\$37,096,886,790	\$69,395,379,500	\$138,135,164,460
HI	\$4,359,038,425	\$8,420,169,275	\$16,360,947,050
ID	\$5,641,755,432	\$11,178,087,348	\$19,742,949,360
IL	\$36,453,142,656	\$64,983,078,144	\$122,186,716,992
IN	\$22,994,956,800	\$41,280,024,576	\$73,143,532,800
IA	\$10,530,043,075	\$19,235,984,200	\$31,082,697,228
KS	\$10,761,398,528	\$20,650,916,352	\$34,650,226,688
KY	\$15,396,010,075	\$28,385,848,700	\$47,303,935,825
LA	\$16,350,690,330	\$30,348,103,734	\$53,782,395,316
ME	\$5,086,948,056	\$8,270,289,764	\$14,788,941,754
MD	\$22,642,472,640	\$39,958,197,360	\$86,677,267,080
MA	\$28,191,306,000	\$46,302,084,400	\$87,341,791,680
MI	\$42,478,801,742	\$70,202,807,194	\$135,676,968,830
MN	\$21,965,305,362	\$41,093,141,166	\$80,833,768,554
MS	\$10,944,866,030	\$19,956,915,293	\$32,515,234,218
MO	\$23,891,134,113	\$43,063,031,858	\$76,603,318,902
MT	\$3,322,422,360	\$6,063,762,620	\$10,145,009,840
NE	\$6,345,126,872	\$12,464,590,236	\$20,834,051,518
NV	\$9,920,346,600	\$19,041,355,920	\$44,406,040,680
NH	\$4,744,433,585	\$7,440,532,375	\$16,180,094,167
NJ	\$33,758,993,268	\$59,667,493,596	\$113,155,768,644
NM	\$8,925,197,056	\$16,718,634,016	\$27,790,550,400
NY	\$78,905,025,056	\$134,542,512,480	\$247,460,754,656
NC	\$35,919,812,516	\$66,863,070,316	\$133,535,720,584
ND	\$2,237,933,958	\$4,114,693,054	\$6,183,853,712
OH	\$42,757,449,228	\$74,441,887,650	\$130,767,822,783
OK	\$14,652,671,858	\$28,047,699,458	\$46,979,338,466
OR	\$10,163,584,620	\$18,383,182,023	\$37,460,069,028
PA	\$45,267,842,235	\$75,000,432,430	\$133,808,946,425
RI	\$3,940,536,064	\$6,121,711,104	\$12,510,210,560
SC	\$15,312,920,000	\$27,708,021,000	\$47,241,645,000
SD	\$2,752,135,664	\$5,380,944,494	\$8,717,259,898
TN	\$27,807,287,094	\$50,460,803,136	\$94,575,544,902
TX	\$96,294,923,112	\$186,899,110,396	\$377,998,125,176
UT	\$12,165,321,091	\$26,355,225,358	\$45,096,877,364
VT	\$1,669,633,560	\$2,517,576,390	\$4,888,141,020
VA	\$31,973,697,756	\$58,256,053,548	\$115,470,476,660
WA	\$22,709,049,783	\$41,551,952,701	\$80,153,686,893
WV	\$6,874,134,803	\$11,943,858,575	\$18,194,148,864
WI	\$17,922,077,371	\$31,852,682,070	\$57,651,224,950
WY	\$2,007,904,594	\$3,976,578,370	\$5,285,461,116
United States Total	\$1,157,998,515,441	\$2,082,772,970,329	\$4,008,267,903,678

child was once diagnosed with an ASD and no longer had the disorder at the time of the survey (Kogan et al., 2009). This contrasts with others that indicate for social cost analysis, the disorder results in lifelong impairment and social costs (Buescher et al., 2014; Ganz, 2007; Järbrink & Knapp, 2001; Knapp et al., 2009; Newschaffer & Curran, 2003).

This is a lifetime social cost analysis that does not incorporate the personal cost of ASD, and it in no way represents what families pay to treat the disorder. Individual family costs can be quite high and will vary depending on health insurance, symptom severity, and the presence of a variety of co-occurring disorders. Examples of personal costs not included in the social cost estimates are (1) uncovered medications; (2) supplements; (3) privately funded EIIBI, speech, occupational, physical, vision, and applied behavior analysis therapy; (4) dietary interventions; (5) transportation to and from medical appointments.

These calculations reflect the lifelong costs associated with ASD based on estimated cases of ASD. The social cost of a lifetime will be spread over 72 years, however due to the lack of a known cure for ASD, it is assumed that each new case will incur lifetime costs.

Table 8

Projected Cost of ASD Based on Three Scenarios of Future Incidence.

State	Projected Population Level Lifetime Cost of Autism Per Decade in 2019 Dollars		
	2020–2029 no increase in rate	2020–2029 consistent rate of increase	IDEA percent increase reported to congress compared to 2010–2019 estimates
AL	\$59,477,640,148	\$107,397,534,206	\$118,243,136,345
AK	\$15,050,805,120	\$27,179,612,928	\$27,897,517,440
AZ	\$95,976,350,140	\$173,299,194,310	\$151,848,054,270
AR	\$38,889,548,260	\$70,223,903,920	\$67,087,245,760
CA	\$480,072,790,912	\$866,853,072,944	\$825,696,639,520
CO	\$69,289,531,920	\$125,116,963,920	\$134,176,385,520
CT	\$49,223,372,522	\$88,878,571,930	\$81,616,035,410
DE	\$14,609,468,052	\$26,381,439,819	\$25,731,483,405
DC	\$5,745,730,380	\$10,375,124,565	\$14,736,438,015
FL	\$253,486,871,872	\$457,714,628,800	\$557,795,631,744
GA	\$155,212,007,345	\$280,263,178,645	\$228,889,674,585
HI	\$15,371,346,025	\$27,756,767,850	\$24,424,996,925
ID	\$21,298,744,884	\$38,457,220,776	\$32,262,790,548
IL	\$121,076,509,536	\$218,625,673,056	\$233,255,385,216
IN	\$76,525,911,552	\$138,178,489,344	\$113,813,620,224
IA	\$29,411,156,532	\$53,107,899,137	\$31,082,697,228
KS	\$34,073,660,416	\$61,523,840,000	\$62,511,737,088
KY	\$49,626,414,355	\$89,607,219,680	\$102,133,260,040
LA	\$54,135,556,644	\$97,747,584,870	\$103,476,269,104
ME	\$13,449,218,799	\$24,282,978,456	\$22,595,327,450
MD	\$90,782,353,440	\$163,926,493,860	\$125,679,381,480
MA	\$90,340,321,500	\$163,120,876,490	\$172,146,365,820
MI	\$130,012,075,154	\$234,761,252,778	\$218,983,299,262
MN	\$82,956,853,980	\$149,795,917,656	\$110,255,959,968
MS	\$32,335,592,040	\$58,387,034,557	\$92,865,025,905
MO	\$78,641,170,970	\$141,998,451,430	\$149,529,310,764
MT	\$9,563,927,740	\$17,268,392,760	\$15,429,438,820
NE	\$20,774,317,060	\$37,509,921,043	\$40,665,891,574
NV	\$54,522,653,130	\$98,454,087,300	\$90,853,246,200
NH	\$16,771,835,330	\$30,283,842,123	\$33,862,300,517
NJ	\$114,130,054,164	\$206,083,870,992	\$210,239,573,460
NM	\$25,152,461,920	\$45,415,398,016	\$64,369,358,912
NY	\$239,711,621,472	\$432,835,808,672	\$392,221,328,928
NC	\$158,293,988,748	\$285,827,815,896	\$233,953,000,512
ND	\$5,580,909,278	\$10,254,665,708	\$11,847,885,660
OH	\$127,174,197,852	\$229,636,504,773	\$240,878,461,707
OK	\$50,127,169,952	\$90,513,178,166	\$97,951,139,325
OR	\$41,770,181,765	\$75,422,939,729	\$46,900,372,097
PA	\$128,885,704,255	\$232,726,784,290	\$260,928,323,425
RI	\$11,879,292,160	\$21,447,620,352	\$24,180,398,336
SC	\$50,317,097,000	\$90,857,731,000	\$115,319,799,000
SD	\$8,704,278,126	\$15,717,680,449	\$13,896,986,926
TN	\$106,994,167,354	\$193,193,765,936	\$178,463,211,362
TX	\$426,465,290,992	\$770,056,507,176	\$785,859,993,544
UT	\$53,419,767,709	\$96,456,417,827	\$70,575,258,600
VT	\$4,654,497,330	\$8,403,297,210	\$4,888,141,020
VA	\$127,162,085,204	\$229,610,201,128	\$244,913,851,336
WA	\$90,119,385,636	\$162,726,619,335	\$134,979,963,594
WV	\$17,218,898,263	\$31,093,516,125	\$35,499,911,553
WI	\$55,807,602,664	\$100,769,473,563	\$100,656,909,166
WY	\$4,693,432,408	\$8,473,856,688	\$10,356,935,952
United States Total	\$4,234,343,935,336	\$7,645,819,196,990	\$7,288,425,350,562

The lifespan reported for ASD is shorter than the typical life span due to premature mortality from increased suicidality (Cassidy et al., 2014; Croen et al., 2015; Demirkaya, Tutkunkardas, & Mukaddes, 2016; Paquette-Smith, Weiss, & Lunsky, 2014), which is particularly true for high-functioning individuals (Hirvikoski et al., 2016), as well as shortened life expectancy due to epilepsy in low-functioning individuals (Hirvikoski et al., 2016; Pickett, Xiu, Tuchman, Dawson, & Lajonchere, 2011).

To keep the calculations simple and understandable, the costs applied in this analysis are based on studies conducted in the current decade. In some other studies, sometimes costs incurred over decades in the future are subjected to future-year discounting based on the idea that current generations value less the costs that must be paid by future generations. There is no evidence that current generations value less the cost of ASD to future generations, thus we did not apply a future year cost discount.

Such large numbers are not typically dealt with by most people. For perspective, the average household income in the United States is \$61,937 (United States Census Bureau, 2018). United States wage earners earned a total of \$10.4 trillion in 2017 (United

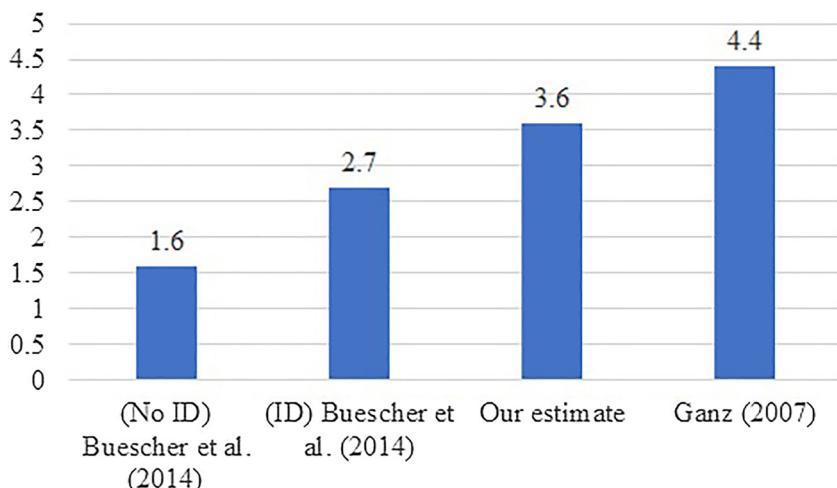


Fig. 4. Comparison of estimates of Lifetime per capita social costs associated with ASD in millions of 2019 dollars.

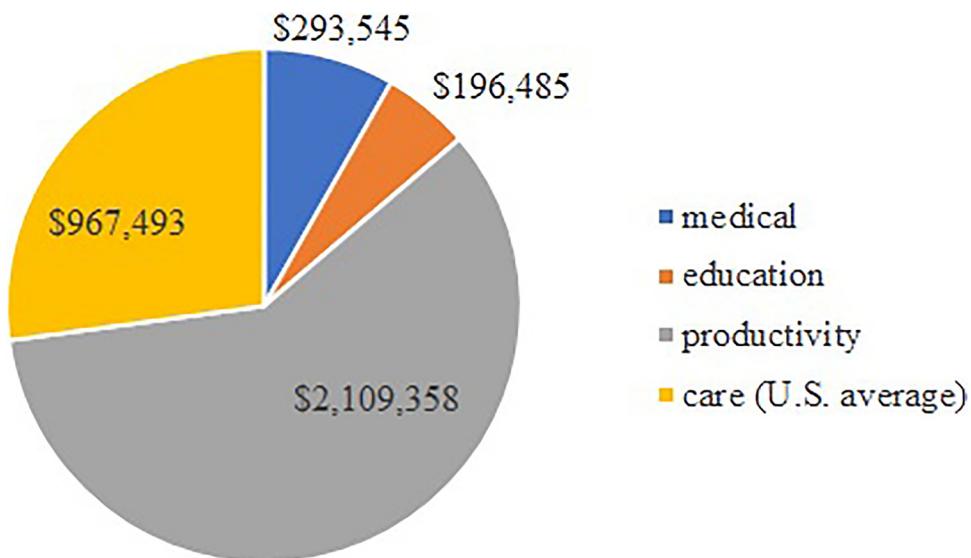


Fig. 5. Percentage distribution of the types of cost associated with an ASD in 2019 dollars.

States Bureau of Economic Analysis, 2019). The total annual revenue of the United States government is \$3.4 trillion (United States Department of the Treasury, 2018). Federal minimum wage is \$7.25 per hour (United States Department of Labor, 2019). If we use these data to translate the social cost of autism into something meaningful to everyday people, the total lifetime cost of ASD in the United States for the estimated cases to date (1990–2019) is the equivalent of 8 months of wages for all workers in the United States, or the total United States revenue from taxes and other sources for more than two years, or 1 trillion hours of minimum wage work.

Most of the funding for research in ASD comes from federal sources through agencies like the National Institute of Health (NIH), and in 2016, the United States spent about \$272 million (Interagency Autism Coordinating Committee, 2016), or one one-hundredth of a percent (0.01 %) of total annual federal revenue on research to understand the biology of individuals affected by ASD, what causes the disorder, and ways to prevent it.

5. Conclusion

For *all* of the individuals with ASD identified in the 3 decades from 1990–2019, the lifetime social cost for the US is estimated to be more than \$7 trillion in 2019 dollars. Even if one assumes that the rate of increase in prevalence of ASD is static for the next decade (2020–2029), the projected cost estimate for ASD in the US will increase to \$11.5 trillion in 2019 dollars. If, however, the prevalence of ASD continues at the current average rate of increase per decade, those costs are projected to reach nearly \$15 trillion by 2029 (accounting for an estimated 4 million affected individuals). These numbers serve to reinforce the conclusions of Leigh and Du (2015), who stated that the burden is significant and alarming, and the national policy response should be to focus the bulk of funding

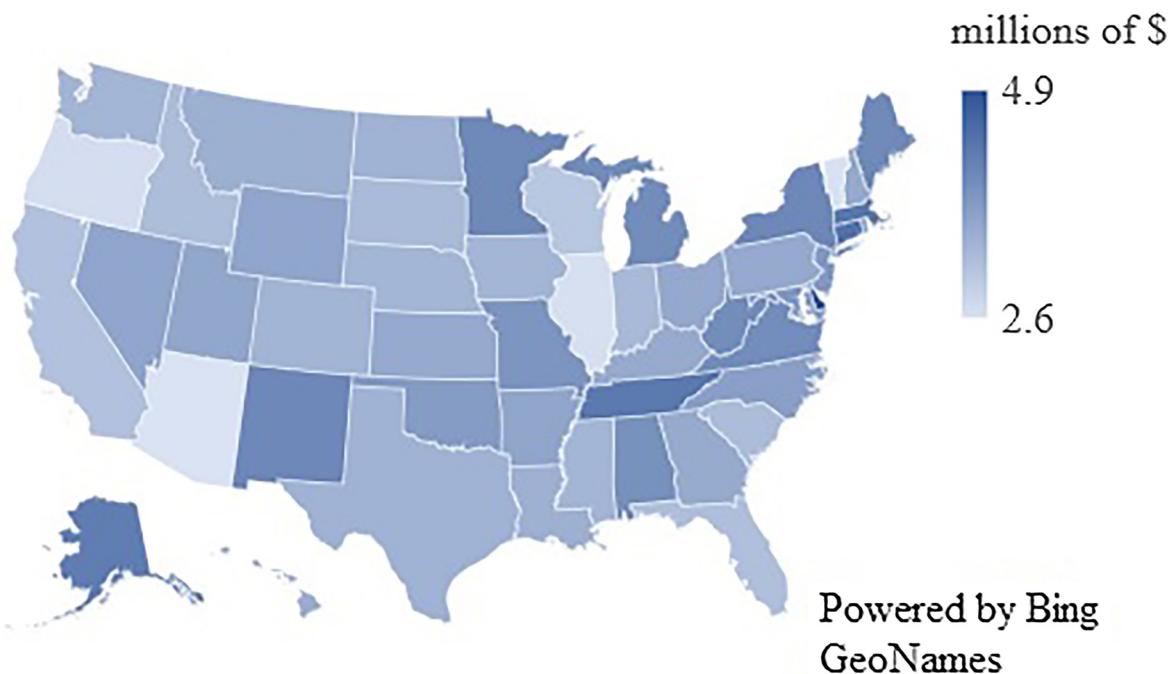


Fig. 6. Per Capita Lifetime Cost of ASD.

and resources on understanding the modifiable causes of ASD and then avoid those risk factors because prevention is far less expensive than treatment and management. A variety of approaches in the field of vulnerability assessment and risk management could be used to identify known modifiable risk factors that could potentially reduce rates, thereby reducing costs. Due to the high cost of care for affected adults, focusing on understanding risks associated with the severe forms of ASD, where there is co-occurring ID, holds the greatest potential benefit to society.

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Author A – Population and cost analysis.

Author B – Topic conceptualization, interpretation and discussion.

Author C – Topic conceptualization, interpretation and discussion.

Declaration of Competing Interest

Author A has a child with encephalopathy and features of autism.

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