

Implications of IDEA headcount data for estimating the current and future population of young adults with ASD

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While there are no hard numbers about the population of individuals with Autism Spectrum Disorder (ASD) in Massachusetts, there is a rich source of data that can be used to estimate the lower limit of numbers of current and future young adults with ASD. This is the headcount data states are required to report under the Individuals with Disabilities Education Act (IDEA). Headcount data state the numbers of individuals receiving special education via an Individualized Education Plan (IEP) due to type of disability. Autism is one of the categories used. Using these figures, it is possible to get a hard lower limit of adults 23-29 with ASD, and use a data-derived formula to estimate future numbers of young adults.

Data limitations and characteristics

IDEA data are restricted to individuals served on an IEP with public school funding. It does not include those who are diagnosed with ASD, but received modifications under a 504 plan; those who might have multiple disabilities and were encoded under a different heading in the headcount data; those who are not being educated with any public school dollars; and those not yet diagnosed. For these reasons, these data represent a *minimum* estimation of the population. Nonetheless, it can be assumed that, unless individuals die or move out of state, they are still present in the future and are still autistic. For this reason, they are a valuable figure for planning purposes; i.e. the state can assume it needs to expect at least this number will be present as adults.

All data were taken from the U.S. Department of Education State Level Data Files (<https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bcc>). From 2005-2011, childcount data included a breakdown for every year of age (for ages 3-21) by disability category. Beginning in 2012, through 2015 (the most recent data available), data were reported by age cohorts: 3-5, 6-11, 12-17, and 18-21. This change reduced the size of the data set on which to base specific age projections; however, as the data proved to be remarkably consistent in their rate of change over time, this does not seem to have been a significant limitation. While there are a full 11 years of cohort data, one difficulty with cohort data is that students continue to be diagnosed during adolescence, meaning that the number of 17 year olds with ASD captured in the data in 2010 is 20% larger than the number of 12 year olds listed in 2005. Nonetheless, the 6 year 12-17 cohort continues to represent a minimum number of individuals for whom to plan as adults.

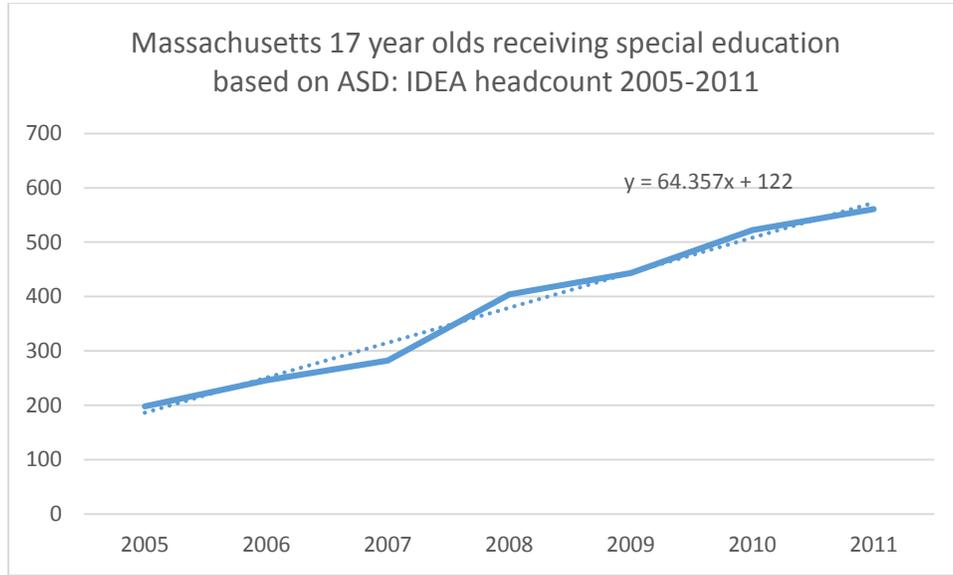
In general, the number of 17 year olds appears to be the most useful number for predicting the future number of adults. As indicated, younger students may not have been diagnosed yet – and indeed, with one exception, the data show an equal or greater number of 17 year olds than there were 16 year olds the year before. Beginning at 18, the number of students listed drops off each year, as students take diplomas and leave the system.¹ Data on students 6-11 are most useful in determining when patterns of steady increase in the numbers of 12-17 year olds might level off in the future, as indefinite growth is impossible.

Results

17 year olds:

Data are available for 17 year olds for a seven year period, from 2005-2011. The numbers grew every year. What was most startling about these data (and other discussed later) was the remarkable consistency in the rate of growth. This is indicated in the chart below by the goodness of fit between the trend line (dashed line) and actual data (solid line).

¹ Graduation alone, however, does not mean these individuals will necessarily be able to function without support, as, nationally, over 80% of adults with autism are not employed, and a similar figure continues to live with family throughout their 20s.

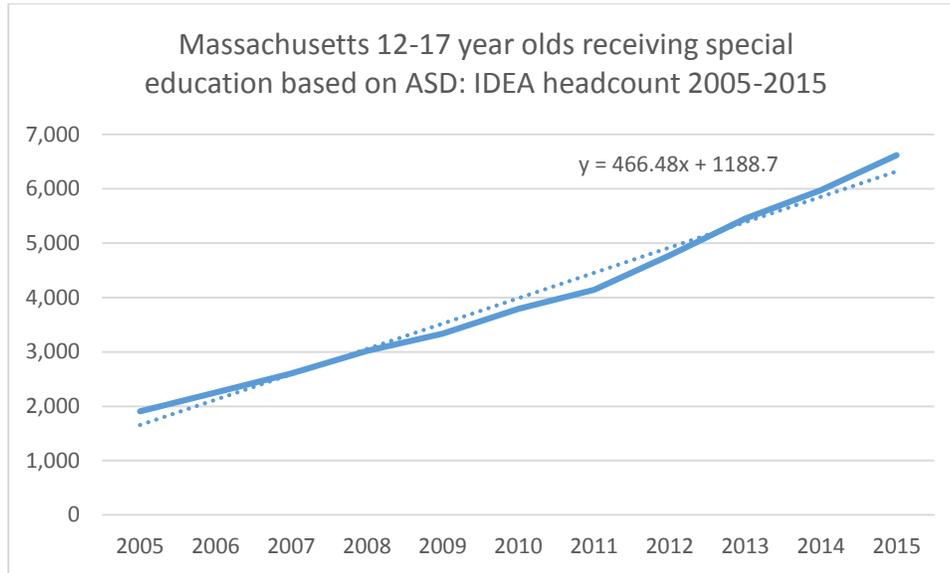


Extrapolating these data, using the trend line, it is possible to estimate future numbers of 17 year olds, as well as to establish a bottom estimate of the numbers of older individuals as the 17 year olds age. We know, for instance, that using numbers of actual 17 year olds from 2005-2011, that the current cohort of 23-29 year olds is likely to be at least 2,656. Additional data and projections are in Table 1.

Table 1: Actual and estimated numbers of Massachusetts 17 year olds receiving special education based on an autism diagnosis.				
	Year	Predicted	Actual	Age in 2025
2005	1	186	198	37
2006	2	251	246	36
2007	3	315	282	35
2008	4	379	404	34
2009	5	444	443	33
2010	6	508	522	32
2011	7	572	561	31
2012	8	637		30
2013	9	701		29
2014	10	766		28
2015	11	830		27
2016	12	894		26
2017	13	959		25
2018	14	1023		24
2019	15	1087		23
2020	16	1152		22
2021	17	1216		21
2022	18	1280		20
2023	19	1345		19
2024	20	1409		18
2025	21	1473		17

12-17 year olds:

Data are available for the 12-17 year old cohorts for an eleven year period, from 2005-2015. The numbers grew every year. Again, it is possible to fit a trend line closely to the actual data.

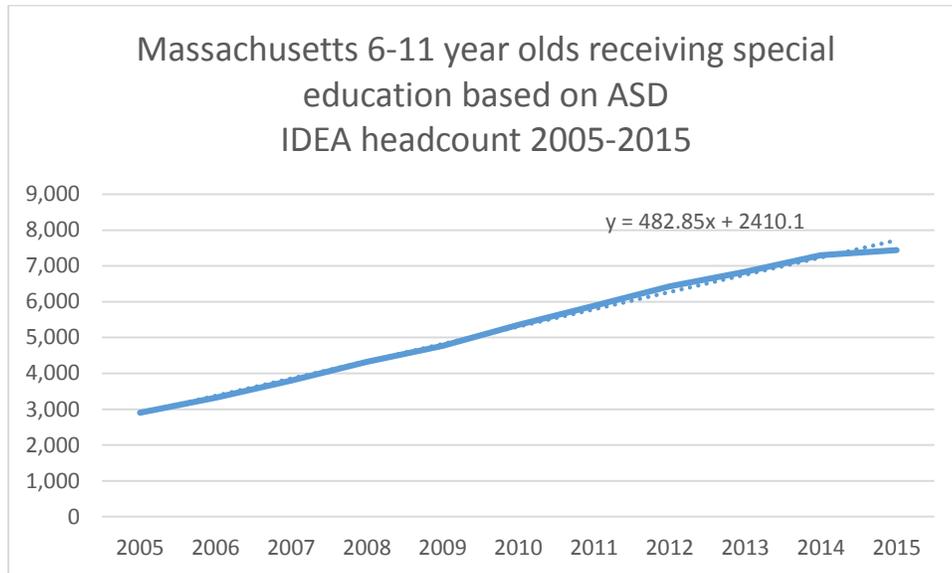


Using the trend line to extrapolate future cohorts provides the information found in Table 2.

	Year	Predicted	Actual	Year cohort becomes 17-22
2005	1	1655	1,904	2010
2006	2	2122	2,254	2011
2007	3	2588	2,604	2012
2008	4	3055	3,016	2013
2009	5	3521	3,336	2014
2010	6	3988	3,789	2015
2011	7	4454	4,143	2016
2012	8	4921	4,773	2017
2013	9	5387	5,454	2018
2014	10	5854	5,972	2019
2015	11	6320	6,618	2020
2016	12	6786		2021
2017	13	7253		2022
2018	14	7719		2023
2019	15	8186		2024
2020	16	8652		2025
2021	17	9119		2026
2022	18	9585		2027
2023	19	10052		2028
2024	20	10518		2029
2025	21	10985		2030

6-11 year olds:

Looking to the cohort of 6-11 year olds, no clear downturn in growth is in sight. Only one year, 2015, shows notably less steep growth than the year before, and additional data from later years will be needed to see if a trend is beginning.



If the incidence rate of autism in Massachusetts reflects national trends, then the rate of growth in numbers of individuals receiving special education on the basis of an ASD diagnosis should start to flatten out as 8 year olds served pass 1.5% - 2% of students (the percentage where the curve bends may be higher, however, as students with disabilities are more likely to be served with public school dollars). Extrapolating from the 2005-2011 data on 8 year olds (using the function $y=88.179x + 388.86$, where Year 1 = 2005), and examining total 3rd grade total student enrollment for 2015-2016 (available at <http://www.doe.mass.edu/infoservices/reports/enroll/default.html?yr=1516>), we may be on the cusp of this.

Discussion:

Looking at our actual numbers of 17 year olds (2005-2011) and our projected 17 year olds (2012-2025), we have a potential population of 18-37 year olds of 17,428 in 2025. In that same year, there are a projected 10,985 individuals ages 12-17 in the pipeline. Combining these, we get 28,413 potential 12-37 year olds.

We can check the reasonableness of this estimation by looking at some additional numbers. Nationally, the Centers for Disease Control (CDC) estimates that the incidence of autism is 1 in 68 children. If a similar ratio holds true in Massachusetts, we would get a number of about 100,000 Massachusetts residents with ASD. Our 12-37 year olds represent a 25 year age span. Multiplying our 25 year span by 3.2 (to estimate a life expectancy of 80), we get 90,922 individuals with ASD, not too distant from the ceiling of 100,000. Given that our IDEA numbers represent a *minimum* expected population for the reasons discussed above, these numbers appear to present a reasonable estimation for planning purposes.

If Massachusetts experiences a leveling off when 8 year olds with ASD receiving special education approach 1.5% - 2% of all 3rd grade students, there may be a leveling off of growth in adults turning 22 in about 2030. Future data will need to be monitored to see if this is occurring.