



PENNSYLVANIA AUTISM CENSUS PROJECT: FINAL REPORT

OCTOBER 2009

**Pennsylvania Department of Public Welfare,
Bureau of Autism Services**

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Dear Readers:

We are pleased to present the Pennsylvania Autism Census Project Final Report, the first study to estimate the number of individuals living with autism spectrum disorders (ASD) in the Commonwealth. Pennsylvania's 2004 Autism Task Force Report noted that the prevalence of ASD in Pennsylvania was unknown due to a lack of a comprehensive approach to track persons with this disorder. An understanding of the number of Pennsylvanians with ASD and their demographic characteristics is vital in order to effectively plan for the future.

How many people with ASD live in Pennsylvania? Where do they live and how old are they? Until this study, we did not even have an educated guess. Educated guesses are not meaningful for systems planning. They do not inform the magnitude of the need for better services and new programs, and they surely do not make the case for allocating more resources now or in the future to support individuals with ASD. So we set out to uncover, as best we could, the prevalence of ASD in the Commonwealth. We sought answers. We got an alarming reality.

In 2005, we estimate that there were close to 20,000 Pennsylvanians living with autism, a number that we know is extremely conservative. Given the trend, that number will rise to at least 25,000 by 2010. And as the prevalence of ASD continues to increase nationwide, more and more children with autism will grow into adults with autism, and many, if not most, will require some type of support. By next year, we project that there will be about 3,800 adults with ASD, a number which is expected to increase to 10,000 within five years.

It is our sincere hope that the evidence provided in this report will serve as an eye-opener for policy makers, legislators, service providers, and concerned family members. As you read the findings included in this report, we urge you to keep in mind the implications that these numbers will have on a service system wholly unprepared to meet the rapidly increasing population of children and adults with ASD.

Now that we know what the future holds, a more informed discussion of realistic, practical, and creative solutions for meeting the challenges can begin.

Sincerely,

A handwritten signature in black ink that reads "Estelle B. Richman".

Hon. Estelle B. Richman
Secretary of Public Welfare
Pennsylvania Department of Public Welfare

A handwritten signature in black ink that reads "Nina Wall-Cote".

Nina Wall-Cote, MSS, LSW
Director, Bureau of Autism Services
Pennsylvania Department of Public Welfare

2005 AUTISM CENSUS PROJECT FINAL REPORT

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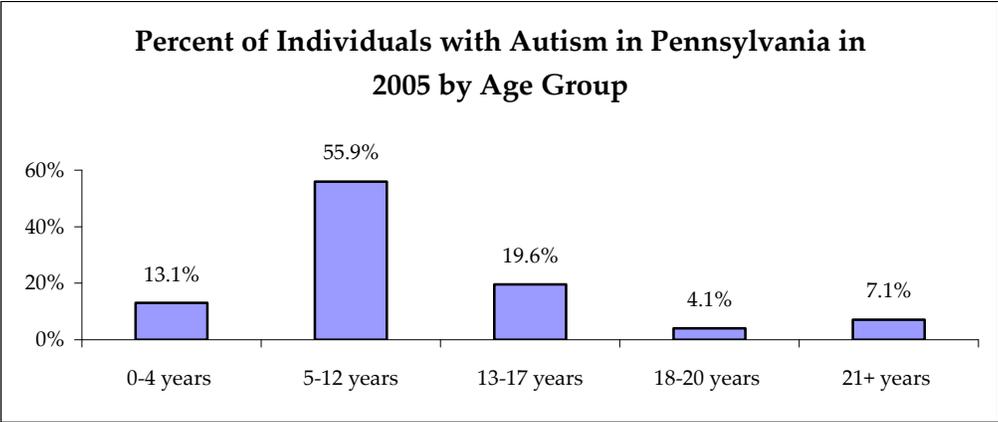
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EXECUTIVE SUMMARY

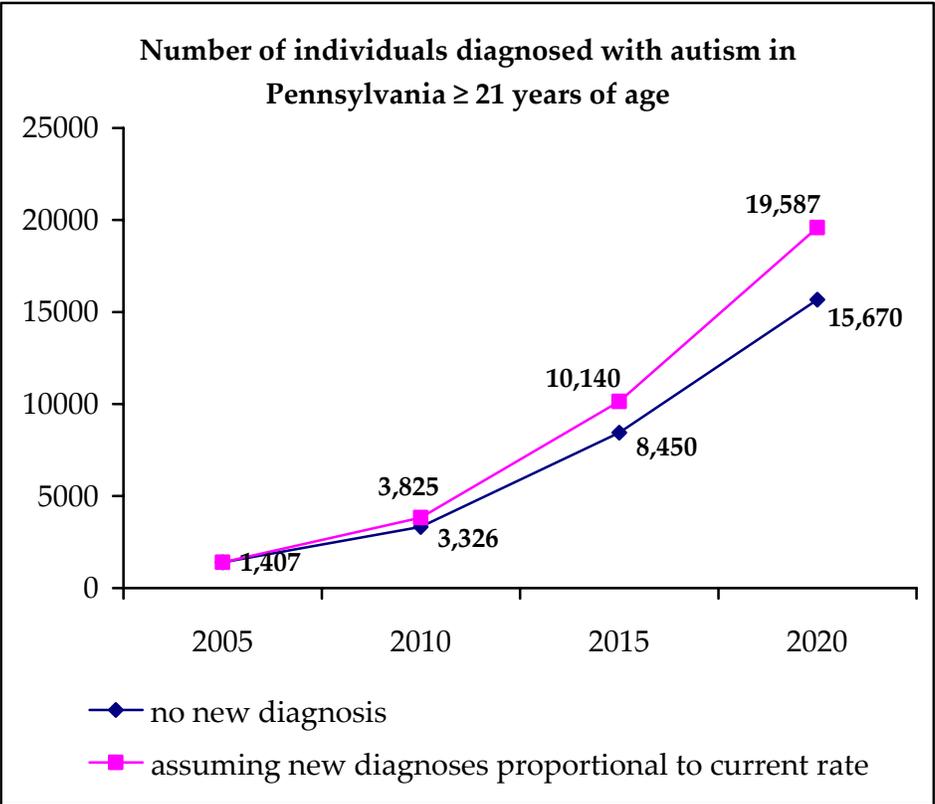
In 2005, the Pennsylvania Department of Public Welfare (DPW) commissioned Dr. David Mandell and his team of researchers at the University of Pennsylvania School of Medicine's Center for Mental Health Policy and Services Research to conduct a census of the number of individuals diagnosed with autism spectrum disorders (ASD) living in Pennsylvania. The purpose of this study was to obtain an estimate of the number of individuals living with ASD in Pennsylvania as well as to learn about demographic characteristics of that population in order to reveal the scope of need for autism-specific services and programs and to inform policy development and the design of effective services.

Data for this study was gathered from the Pennsylvania Departments of Public Welfare and Education, county Mental Health/Mental Retardation (MH/MR) and human services programs, children and youth offices, early intervention programs, HealthChoices, county behavioral health agencies, and the United States Department of Education's Rehabilitation Services Administration. Individuals with ASD not receiving services through one or more of these program offices, and/or those who are misdiagnosed or were never formally diagnosed, were unable to be counted. Due to these limitations, as well as other factors which are discussed in subsequent sections, the estimate is likely a dramatic undercount of the number of Pennsylvanians with ASD, particularly adults. Nevertheless, the census yields important information about the ASD population in the Commonwealth.

Results of the census show that in 2005 there were a total of 19,862 individuals diagnosed with ASD living in the Commonwealth and that by 2010 that number will increase to at least 25,000. Estimates of the prevalence of ASD in the U.S. have increased dramatically in recent years. In 2007, the Centers for Disease Control and Prevention (CDC) estimated the prevalence rate of ASD among 8 year old children to be about 1 in 150 based on 2002 data. More recently, in October 2009, the CDC released the results of a 2007 national survey which found the prevalence of parent-reported diagnosis of ASD to be roughly 1 in 91 among U.S. children aged 3 to 17 years. While the CDC findings are not directly comparable to the findings of the Pennsylvania Autism Census Project due to differences in the way that data was gathered and in study design, they serve to illustrate the dramatic rise in ASD across the nation.



Pennsylvania will see a dramatic increase in the number of adults with autism in the near future. In 2005, we counted 1,421 adults with ASD who were 21 years of age or older, just 7.1% of the total ASD population in Pennsylvania. We estimate that this number will increase by 179% to 3,825 in 2010 and by 621% to 10,140 by 2015. By 2020, the adult ASD population will be roughly equal to the Pennsylvania's entire ASD population, children and adults, in 2005.



The three counties in the Commonwealth with the highest number of individuals with autism were Allegheny (2,235), Philadelphia (2,142) and Montgomery (1,109). These counties are also the most populous in the state. Census results further indicate that certain counties within the Commonwealth may have a higher prevalence of individuals with ASD than others. ***Warren, Pike, Clearfield, Mercer, and Monroe counties have the highest prevalence,*** while Juniata, Sullivan, Union, and Adams counties show the lowest prevalence. The differences in prevalence may be due to factors such as regional diagnostic expertise (the presence or lack of clinicians who have been trained to diagnose autism can contribute to these results) and/or inconsistent classification methods between serving systems as well as the low population numbers in some of the very rural counties where one or two people can change the percentage drastically. At this time, there is no reason to believe that there are other underlying factors causing this difference in prevalence rates across counties

About 51% of the individuals counted in the study receive services from both the Pennsylvania Department of Education (PDE) and the Department of Public Welfare (DPW). An additional 29% receive services only through DPW and about 20% receive services only through PDE. This statistic illustrates the need for coordination within and across the multiple systems that provide care for people living with autism.

The information provided by this study has implications for Commonwealth policies which impact the design and funding of services as well as the continued need for cross-systems collaboration and coordination. Key policy implications include:

- **The need for high-level planning for the thousands of children with autism who will transition into adulthood in the near future.** These adults will likely require some level of support throughout their lives. Although the Bureau of Autism Services has developed programs to meet the needs of adults with ASD, the current funding level will serve only a fraction of the adults who will require support over the next five years.
- **The need for planning for the housing needs of the growing population of adults with ASD.** There is a very wide range of skills and needs among adults with ASD and their housing needs change over time as they and their families move through different life stages. Is Pennsylvania prepared for the increased numbers as well as for the unique needs of this population?

- **The need for cross systems coordination** in order to provide efficient, effective services. It makes sense that all systems serving individuals with ASD need to collaborate and coordinate. Without such an approach, gaps and overlaps may occur, opportunities for consistency of treatment across settings are missed and resources are not used efficiently.
- **Consistent data collection methods must be implemented between and across state and county systems serving all individuals with ASD.** This is vital to an accurate census, as this data will serve to inform program development and the allocation of increasingly limited resources.
- **The continued need to increase the capacity of professionals to evaluate, diagnose, educate and provide services** to people living with autism. The numbers of professionals who have received autism-specific training have increased significantly since the 2004 Autism Task Force Report. Given the current numbers of individuals with ASD, particularly those who will transition into adulthood, training and education efforts must continue at all levels.

FINAL REPORT

Background

The number of individuals diagnosed with autism spectrum disorders (used interchangeably in this report with 'autism') is increasing dramatically in the United States. A survey of epidemiologic studies from 1966 to 2001 documented a rise in prevalence from approximately two per 10,000 in the 1960s to 30 per 10,000 in the 1990s (Fombonne, 2003). There is much debate with regard to the cause of this increase. Potential explanations include modifications in the diagnostic criteria (Byrd, 2003), more efficient differential diagnosis practices (Croen, Grether, Hoogstrate, & Selvin, 2002), younger age at diagnosis (Wing & Potter, 2002) and increased knowledge of the disorder in the general public (Mandell, Thompson, Weintraub, DeStephano, & Blank, 2005).

Autism comprises a group of developmental disorders with common core symptoms manifesting as varying levels of deficit in social abilities and communication skills, and the presence of restricted or repetitive behaviors, interests and activities (American Psychiatric Association, 2000). The presentation of autism can vary widely among affected individuals and within an individual over the lifespan (Volkmar & Pauls, 2003; Wing, 1997). Treatment of autism and its frequently co-occurring conditions, such as mental retardation and seizure disorders, is expensive (Byrd, 2003). One report (SAGE Crossing Foundation, 2009) projected that costs of care for adults with autism in the US will reach \$10 billion by 2019. Lifetime societal costs that include care and lost productivity are estimated at \$3.2 million per person (Ganz, 2007).

Currently, the Center for Disease Control and Prevention (CDC, 2007) estimates that in the US, 500,000 individuals from birth to 21 years of age have an autism spectrum disorder. This finding is based on records reviewed at 14 sites around the country. The most recent study estimated that 673,000 US children have autism, based on parent report (Kogan et al., 2009). Some groups, including Easter Seals and the Autism Society of America, have conducted state-specific censuses. Most state-level efforts to evaluate the prevalence of autism have relied exclusively on education data and are limited to individuals between the ages of 3-21 years. Other states, including New Jersey, have developed registries to track the number of individuals with autism.

Using special education data alone may result in undercounting, since many children with autism may be diagnosed solely through the health system. In addition, no education data are available on individuals older than 22 years of age. Registry strategies that rely on physician reporting also may result in undercounting because they rely on already overburdened physicians and families to report in a timely and accurate manner.

The purpose of the current project is to provide an unduplicated count of the number of individuals residing in Pennsylvania who are diagnosed with autism in any publicly-funded system, thereby broadening the traditional administrative census strategies.

Methods

The goal of the 2005 Pennsylvania Autism Census Project was twofold: to determine the administrative prevalence of autism and to describe demographic characteristics of individuals diagnosed with autism in the Commonwealth of Pennsylvania. Data were collected from a number of Commonwealth-level sources (see below). Similar data were collected directly from four southeastern counties and compared with the data provided from Commonwealth offices. A comparison of state and county total number of individuals with autism showed no consistent pattern in difference. In some counties the state records showed more persons served than did county records, while in other counties the county data showed more persons served than state data records. Counties also varied in their ability or willingness to provide necessary data. Therefore only data provided by Commonwealth offices were used for these analyses.

Statewide data for all individuals labeled with an autism spectrum disorder (ASD) in the Pennsylvania Departments of Education (PDE) and Public Welfare (DPW) administrative records in calendar year 2005 were collected. Within DPW, data were collected from:

- 1) The Office of Mental Health and Substance Abuse Services (OMHSAS) including OMHSAS Fee for Service (non-managed care) and OMHSAS HealthChoices, a mandatory managed care program for Medical Assistance recipients;

- 2) The Office of Developmental Programs (ODP) including a list generated by ODP from the PROMISe (Provider Reimbursement and Operations Management Information System) List, the new HIPAA-compliant claims processing and management information system implemented by DPW in March 2004, which processes some claims for the Departments of Aging and Education as well as claims for individuals receiving medical assistance, mental health, mental retardation and other services from DPW;
- 3) The Office of Social Programs (OSP), which included persons with an autism diagnosis receiving services in 2005 from the OBRA/Amended OBRA Waiver;
- 4) The Office of Medical Assistance Programs (OMAP) including all individuals receiving Medical Assistance services in 2005.

Analyses

Data from different agencies were merged to provide an unduplicated count of individuals with autism. The Department of Public Welfare considered a person to have autism if a diagnosis of any autism spectrum disorder (ICD-10 code 299.xx) was included in any part of their record. The Department of Education (PDE) counted individuals as having autism if their primary or secondary disability category (“exceptionality”) was autism, or when they received “autistic” services without the autism disability category. Within PDE, individuals may be enrolled in one or two categories.

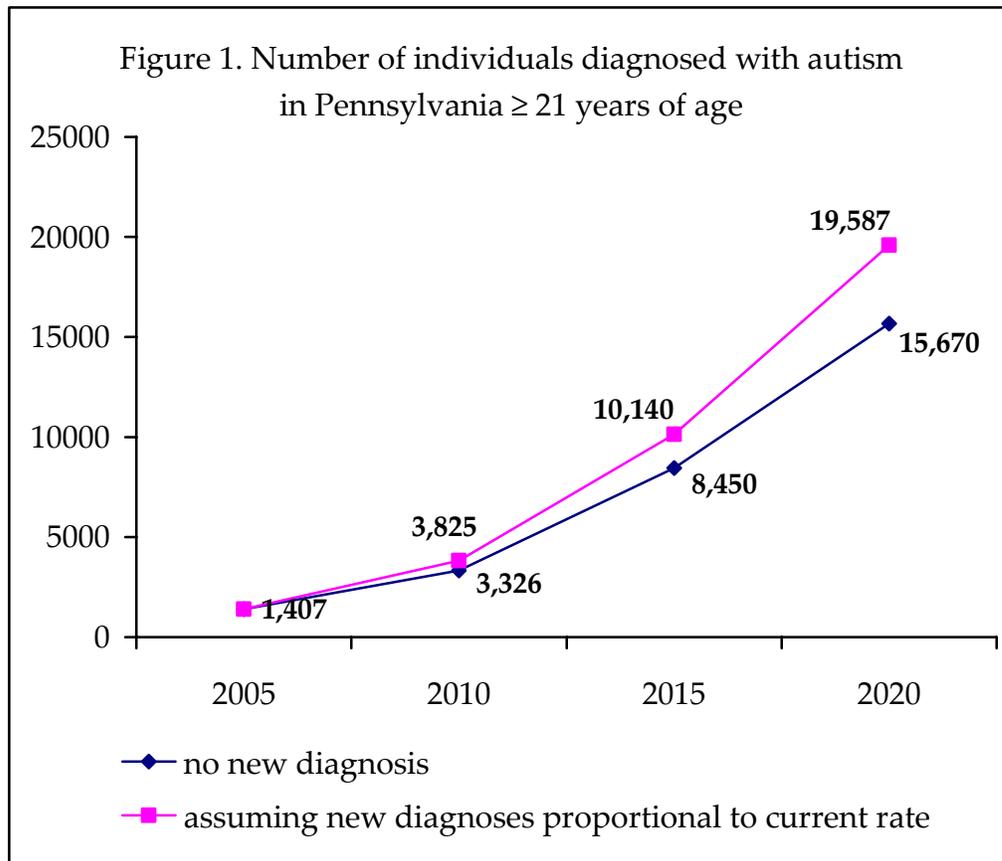
Data first were merged across Department of Public Welfare (DPW) agencies using a combination of name, date of birth, social security number and Client Information System (CIS) number. This unduplicated dataset was then given to PDE. PDE matched individuals in the DPW dataset to individuals in their dataset using a combination of first name, last name, date of birth and social security number. In cases in which an individual received services in multiple counties because of relocation or because he or she crossed county borders for services, the chronologically first county listed was used.

Frequencies and cross tabulations were used to calculate the proportions of individuals with autism served in each system and in each combination of systems.

Demographic characteristics of individuals served in each combination of systems also were determined.

Summary of Findings

In total, 19,862 individuals with autism were identified in Pennsylvania in 2005. Based on this number, the total number of individuals with autism in Pennsylvania will reach 25,000 in 2010 when not considering mortality or new diagnosis rates. Figure 1 illustrates the projected number of individuals with autism in Pennsylvania age 21 and older through 2020. This figure is also not adjusted for mortality rate. Two sets of figures are presented. The first presents the number of adults with autism in 2005, 2010, 2015 and 2020 without considering new diagnoses. That is, it presents the number of the 19,862 individuals now diagnosed with autism who will be more than 21 years of age in each year. The second, higher line includes a projection of individuals newly diagnosed between 2005 and 2020 who will be more than 21 years of age. The number of newly diagnosed individuals was calculated by applying the proportion of currently diagnosed individuals in each age group to future cohorts.



The average age of individuals diagnosed with autism in Pennsylvania in 2005 was 11.13 years. Statewide, the percent of individuals with autism in Pennsylvania in 2005 who were under the age of 21 is shown in Appendix 2. Consistent with epidemiologic studies, 80.3% was male. Figure 2 shows the percent of individuals with autism in Pennsylvania by age group.

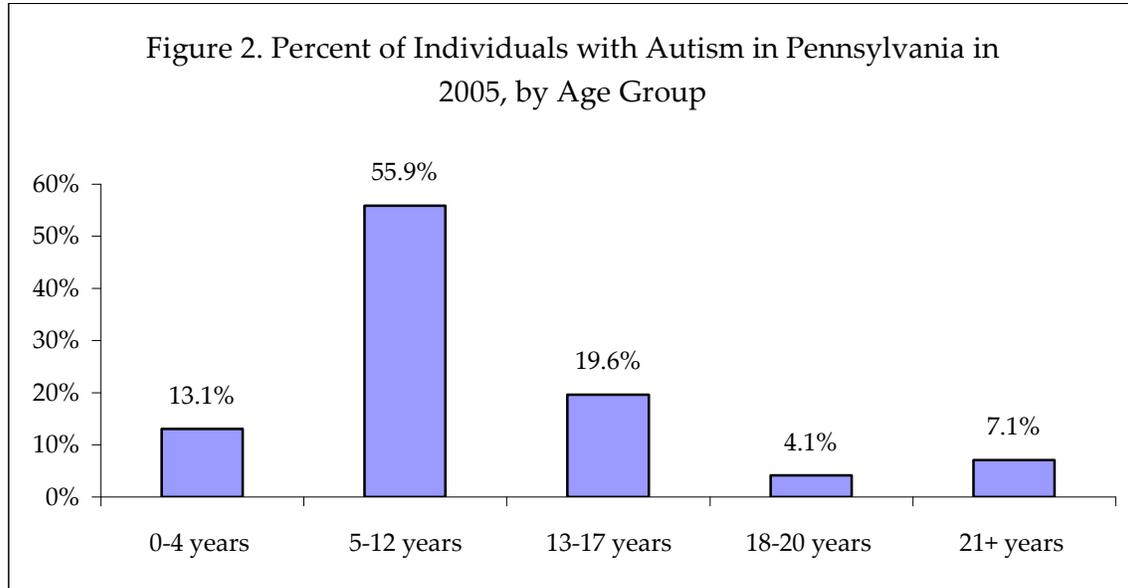
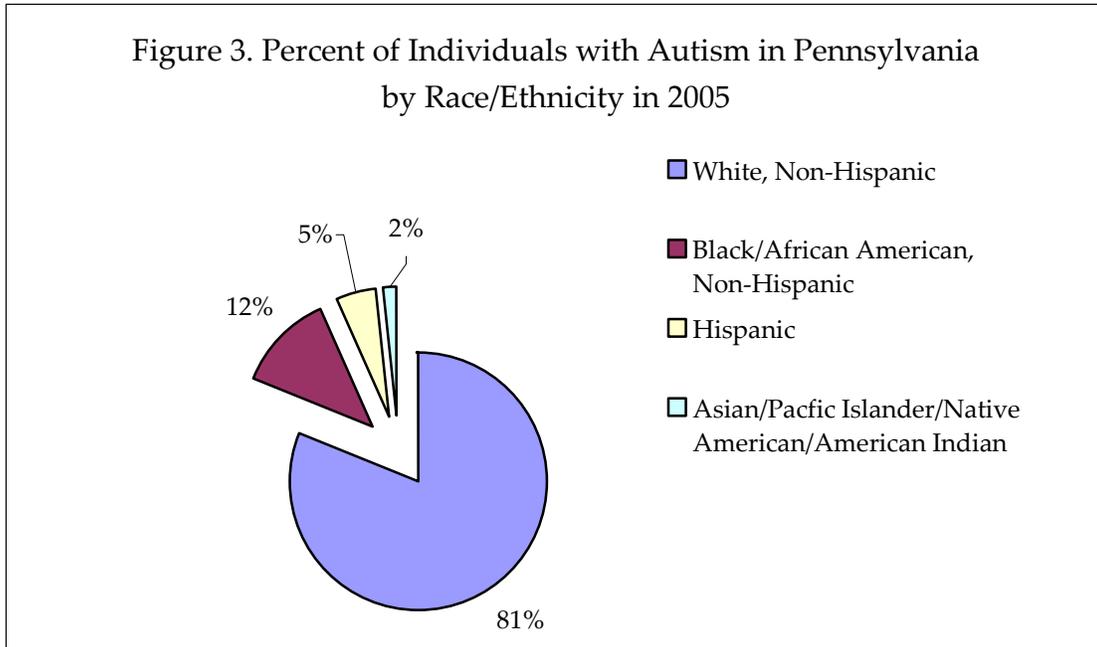
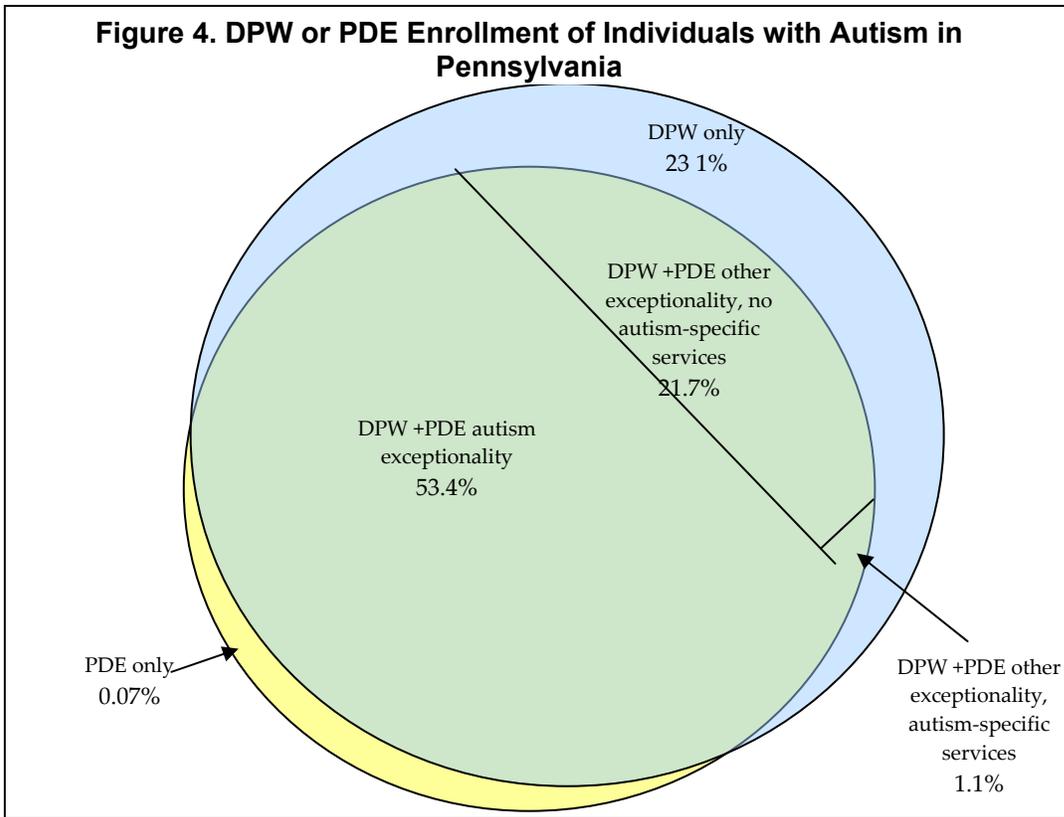


Figure 3 illustrates the race/ethnicity of individuals with autism in Pennsylvania. These numbers almost exactly match the 2005 race/ethnicity estimates for Pennsylvania from the U.S. Census Bureau, suggesting no disparity in diagnosed autism prevalence across race or ethnicity. Hispanic numbers may be under reported, however, since combining race/ethnicity categories across datasets resulted in mutually exclusive race and ethnicity categories (individuals could not check Hispanic ethnicity in addition to a race).

Figure 3. Percent of Individuals with Autism in Pennsylvania by Race/Ethnicity in 2005



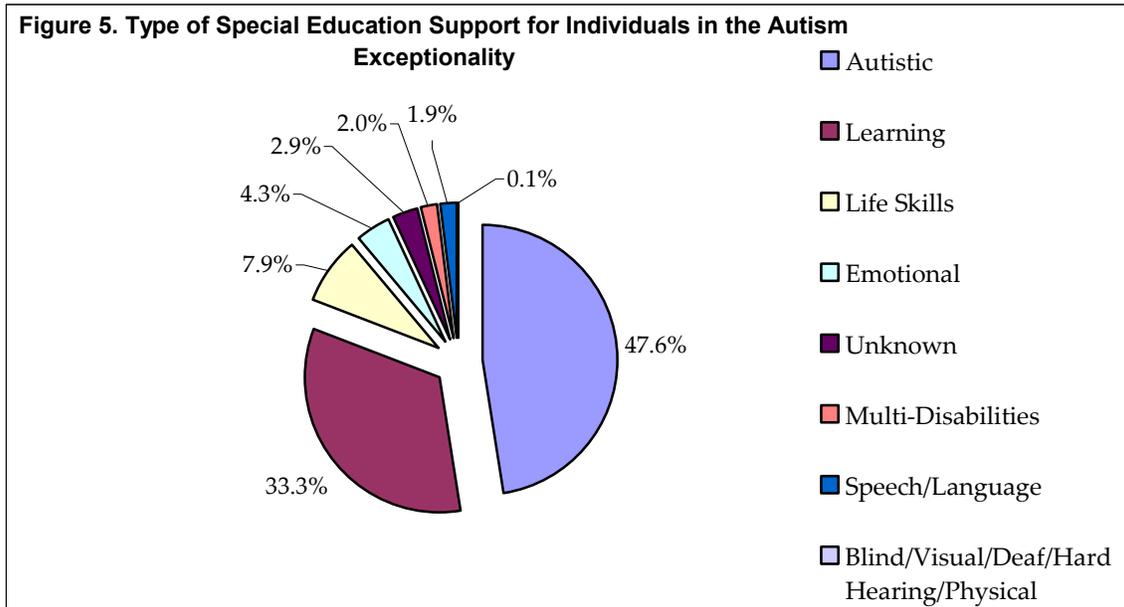
Individuals with autism in Pennsylvania most often received services through both DPW and PDE. Figure 4 shows the percent of individuals with autism enrolled in programs through DPW or PDE in 2005. Further analysis of individuals with autism enrolled in programs through specific offices within DPW was limited as only certain characteristics of individuals with autism were available and program enrollment is nuanced. For example, 1,200 individuals with autism identified by the PROMISE list could not be matched to enrollment through a specific DPW office and matching across multiple Departments was both time and resource intensive to uncover information on relatively few individuals. Historical investigation of program enrollment by offices within DPW was also difficult since policies for eligibility and enrollment in previous years are often unavailable and some offices changed structure or no longer exist.



For this figure, only individuals between the ages of 3 and 21 years, who therefore would be eligible for services in PDE were counted. “DPW” in Figure 4 denotes enrollment in programs through the Department of Public Welfare that is associated with an autism diagnosis. PDE is shown in Figure 4 as either enrollment for services through the autism exceptionality (PDE) or through a different exceptionality that does not include autism (PDE other exceptionality). If an individual was enrolled for services through PDE through an exceptionality that did not include autism, the delivery of autism-specific services is denoted. DPW and PDE use the diagnosis of autism for program enrollment in most cases (53.4%) in which individuals are enrolled through both. However, individuals with autism are often enrolled for programs through only DPW (23.1%) or are enrolled through DPW with an autism diagnosis and PDE through non-autism exceptionality(ies) and do not receive autism-specific services.

Figure 5 shows the type of special education support for individuals in the autism exceptionality classification in PDE. Most individuals with autism enrolled for services through the Department of Education (PDE) received autistic special education support

in 2005.



The three counties in the Commonwealth of Pennsylvania with the highest number of individuals with autism were Allegheny (2,235), Philadelphia (2,142) and Montgomery (1,109). US Census data for Pennsylvania indicate these three counties are also the most populous in the state. The counties with the highest proportion (as opposed to absolute number) were Warren (0.32%), Pike (0.24%), Clearfield, Mercer, and Monroe (0.23% in each), Dauphin (0.22%), and Jefferson and Wyoming (0.21% in each). Consistently, Warren County had the highest prevalence of individuals with autism across age groups and program enrollment (DPW or PDE). The counties with the lowest prevalence were Adams, Sullivan and Union (0.09% in each), Juniata and Lycoming (0.10% in each), Clinton and Montour (0.11% in each), Bedford, Bradford, Bucks, Centre and Tioga (0.12% in each) and Armstrong, Cambria, Clarion, Columbia and Perry (0.13% in each). County profiles including total number of individuals with autism, rate per 10,000 and demographic information for all of Pennsylvania in 2005 can be found in Appendix 3.

Conclusions

Statewide, Pennsylvania's autism population is consistent with national estimates of prevalence and demographic distribution. However, the estimate of 19,862 individuals with autism in Pennsylvania is likely a dramatic under-count of the total number of individuals with autism in Pennsylvania. The limitations section of this report further discusses potential gaps in the administrative data used to determine the autism count. Throughout work on this project, it has become clear that adults with autism are likely not included in most administrative datasets and may be diagnosed with other disorders or not at all. Anecdotal information provided by clinicians throughout Pennsylvania indicates a dearth of professionals with experience diagnosing and treating adults with autism. Other research funded by the Bureau of Autism Services at DPW suggests significant under-diagnosis of autism at state psychiatric hospitals and centers. Specifically, a research team led by Dr. David Mandell at the University of Pennsylvania, has found that prevalence of autism within one state hospital is likely closer to 5-7% than the 0.5% prevalence indicated by initial review of 2005 administrative data. Other initial screening efforts to examine prevalence led by Dr. Larry Sutton of the PA Bureau of Autism Services indicate that between 15-40% of individuals at one state center may qualify for an autism diagnosis. A higher prevalence of autism at Pennsylvania state centers than at state hospitals is expected, since state centers are intended to serve individuals with developmental disorders while state hospitals serve individuals with psychiatric disorders.

Reports in Pennsylvania news sources have used Department of Education data to estimate that the number of individuals diagnosed with autism in Allegheny County is higher than the number of individuals in Philadelphia County (Kurutz, 2009). Administrative data reviewed for this project from PDE and DPW validate this finding, although neither Allegheny nor Philadelphia counties has the highest autism prevalence in any age category. Low population density in many Pennsylvania counties (48 of 67 counties are considered "rural" by the US Census Bureau) means that a small number of cases can result in high autism prevalence. It may be that having only a few clinicians specializing in autism can contribute to a significant increase in autism diagnoses. Further investigation into the high prevalence in specific counties is warranted, to determine factors associated with greater diagnosis.

Several specific gaps in understanding the population of individuals with autism in Pennsylvania were highlighted through the efforts of this census report. First, consistent data collection requirements across systems at state and county levels should be established and disseminated. If individuals were assigned a unique ID across systems especially those Departments in Pennsylvania who provide services such as PDE and DPW, service usage and coordination would more easily be tracked for clinical treatment and research purposes. Evaluations of programs serving the autism (and other) population(s) in Pennsylvania would more easily be completed and require less time and resources. Although differences between county and state level data are clear through analytical comparison, inconsistencies across variables within datasets create barriers to effective cross-system tracking, communication and interpretation.

Second, efforts to further qualitatively and quantitatively describe people with autism in Pennsylvania, especially those focusing on adults, should be completed. Such efforts should utilize methods other than administrative data and validate an autism diagnosis. Some systems, such as the criminal justice system, and individuals covered by private health insurance, warrant particular foci of investigation. Efforts to identify and describe the characteristics of adults with autism in Pennsylvania would also contribute to the national gap in understanding the needs of adults with autism.

Finally, reasons for differences in county versus state program enrollment should be investigated. Particularly for a Commonwealth, relatively autonomous county systems may be setting disparate eligibility criteria within state guidelines that impact service delivery. Examining eligibility criteria for specific county profiles that drives prevalence rates or even outcomes could establish specific county-based policy recommendations.

Limitations

A number of study limitations should be mentioned. First among them is that the presented counts include only individuals who were identified with autism in at least one system. There has been no validation of these diagnoses or their relationship to the community prevalence of autism. Several studies suggest the high specificity of a community diagnosis of autism (Fombonne et al., 2004; Yeargin-Allsopp, 2003). Therefore, it is likely that the vast majority of individuals identified with autism would meet research criteria for the diagnosis, but that many individuals with autism in the community were likely missed. This is most likely especially true of adults with autism. A

second limitation is that there are no means to account for individuals whose name changed during 2005 due to marriage or adoption, or who use different names within or between each system. These individuals may have been counted twice. A third limitation is that Pennsylvania Department of Education data includes public and charter schools, but not parochial or private schools.

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