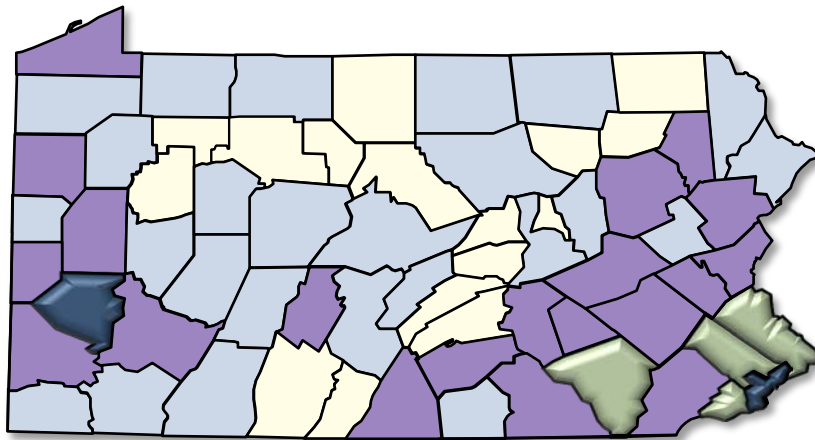
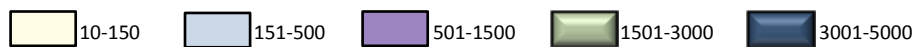


Pennsylvania Autism Census Update 2014



Number of Individuals with Autism Receiving Services by County in 2011



Pennsylvania Department of Public Welfare
Office of Developmental Programs
Bureau of Autism Services

Lindsay Shea, MS, DrPH
Autism Services, Education, Resources & Training Collaborative (ASERT)
A. J. Drexel Autism Institute

The 2014 Pennsylvania Autism Census Update was funded by the Bureau of Autism Services, Pennsylvania Department of Public Welfare. The project was led by Dr. Lindsay Shea, Director of the ASERT Collaborative Eastern Region, with additional support from Paul Turcotte, MPH, Lauren Tucker, MPA, Kaitlin Koffer Miller, MPH, Dr. Craig Newschaffer, and Mary Mathew, MPH.

Suggested Citation:

Shea, L. (2014). *Pennsylvania Autism Census Update*. Study funded by the Bureau of Autism Services, Pennsylvania Department of Public Welfare. Retrieved from www.paautism.org/census.

For more information on the 2014 Pennsylvania Autism Census Update and a clickable map by county, visit www.PAautism.org/census. For detail on methods, requests for presentations, or additional custom analyses not available on the website, please contact Lindsay Shea at ljl42@drexel.edu or info@paautism.org.

Dear Readers:

We are pleased to present the 2014 Pennsylvania Autism Census Update. This report is an important update to the original Pennsylvania Autism Census Project that was released in 2009. The original census study was undertaken to determine the prevalence of autism spectrum disorder or “autism” in Pennsylvania. With the support of the Autism Services, Education, Resources and Training Collaborative (ASERT), the Department of Public Welfare (DPW) embarked on an effort to gather this information, and the result was the first and largest study of its kind in the nation.

The 2014 Pennsylvania Autism Census Update gathered data about how many children, adolescents, and adults with autism were receiving services in Pennsylvania in 2011, where in the state these individuals were living, and other demographic information. The newly released report includes comparisons with the autism population identified in the original Pennsylvania Autism Census Project, which used data from 2005 and estimations of how this population will continue to grow. The information collected can help individuals with autism, families, and others in our communities understand the landscape of autism in the commonwealth.

The study found that the number of individuals with autism receiving services in all age groups has increased tremendously since the original census study was released. It also found that adults with autism receiving services were the fastest growing group in Pennsylvania. This dramatic upward trend is expected to continue.

As more individuals with autism age into adulthood, it becomes imperative for community leaders and decision-makers to learn more about this complex disorder. It is important to understand that autism is a lifelong condition that an individual is born with. Autism is not acquired, and individuals do not “outgrow” autism. It is found in every ethnic group and every socio-economic group.

Each person with autism is different, and their needs change over time. Individuals living with autism often have challenges with social interactions, communication, and behavioral development. Understanding that individuals on the spectrum may express themselves differently can influence personal interactions so that these interactions can be both positive and effective.

Many members of the community, including medical professionals, first responders, educational professionals, college administrators, spiritual leaders and business leaders, can benefit from the information in the PA Autism Census Update.

We encourage you to learn more about this study and share it with friends, colleagues and associates.

Sincerely,



Stephen H. Suroviec
Deputy Secretary, Office of Developmental Programs
Pennsylvania Department of Public Welfare



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

PA Autism Census Update 2014

EXECUTIVE SUMMARY

In 2005, the Pennsylvania Bureau of Autism Services (BAS), within the Department of Public Welfare (DPW), commissioned the Pennsylvania Autism Census Project, a study to estimate the number of Pennsylvanians living with autism spectrum disorder (referred to as “autism” throughout this report) who were receiving services. The purpose of the study was to reveal the scope and need for autism-specific services and programs, as well as to inform policy development and the design and delivery of effective interventions and services. The Pennsylvania Autism Census Project was published in 2009.

The 2014 Pennsylvania Autism Census Update includes more recent data as well as data from additional sources. This update now reflects data from the Pennsylvania Departments of Public Welfare, Education, and Corrections, as well as data from the Office of Vocational Rehabilitation (OVR) and the Pennsylvania Commission on Crime and Delinquency. However, the data reflects only individuals receiving services through one or more of these systems. Therefore, the estimates outlined in this report likely exclude many people with autism, particularly adults, who are not receiving any kind of services, or who are misdiagnosed or not formally diagnosed.

Since the initial study released in 2009, the number of Pennsylvanians with autism receiving services has nearly tripled. The 2014 Pennsylvania Autism Census Update revealed that the number of Pennsylvanians with autism receiving services has reached over **55,000 individuals**. Based upon the 2014 CDC prevalence rate of 1 in 68 children being diagnosed with autism,¹ there could be more than **130,000** additional Pennsylvanians living with autism who are not included in this total.

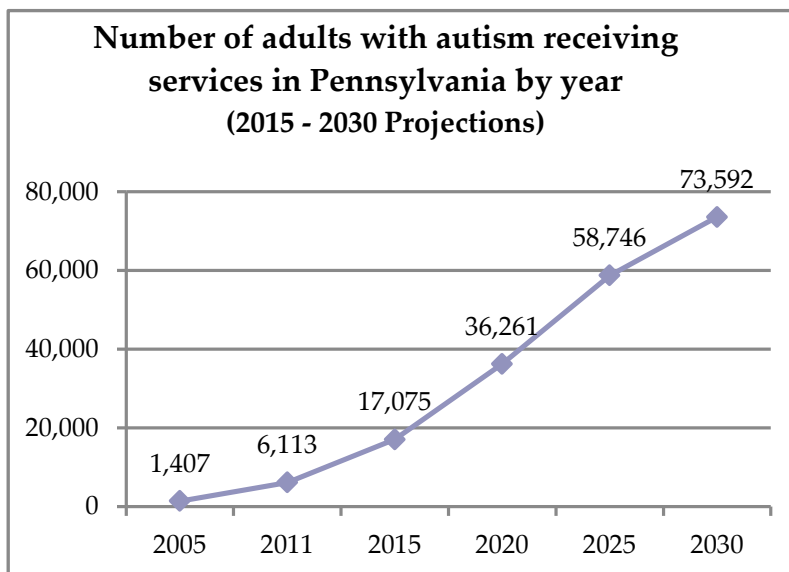
Of particular concern is the growing number of adults with autism receiving services, which reflects an increase of 334% since the original count in 2005. This demographic is estimated to rise to over 36,000 adults with autism living in the Commonwealth of Pennsylvania by 2020, and this dramatic growth is expected to continue as more children transition to adulthood and more adults are diagnosed. Most of these individuals will require services across the lifespan. Previous research has documented that the social and communication deficits that serve as the hallmark criteria for an autism diagnosis persist

¹ Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. MMWR Surveillance Summaries, March 28, 2014/63(SS02); 1-21. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w.

into adulthood and in some cases, may exacerbate, or worsen.² Recent research indicates that adults with autism have higher rates of both medical and psychiatric comorbidities than adults without autism, and issues a call for services and supports to be delivered across the lifespan.³ Otherwise, the risk increases for homelessness, law enforcement intersections, expensive hospitalizations, and poor quality of life. However, in adulthood, the services that have supported children with autism, through the education system and behavioral health services, come to an end.

The information provided by this study has significant implications for the Commonwealth of Pennsylvania, regional and county government, service providers, and community resources. The implications include:

- The need to plan for the thousands of children with autism who are already transitioning into adulthood. While Pennsylvania has developed nation-leading programs to meet the needs of adults with autism including the Adult Autism Waiver and the Adult Community Autism Program (ACAP), the current funding level will serve only a fraction of the adults with autism who currently and will, in the future, require support.
- The need to provide access to appropriate employment and transition services for adults with autism. Adults with autism need services such as supported employment, vocational training and career counseling to obtain and maintain employment.
- The necessity to plan for the housing needs of this growing population. There is a wide range of skills and needs among adults with autism and their housing needs change over time as they and their families move through different life stages.
- The need for cross-systems coordination in order to provide efficient, effective services. Individuals with autism have diverse needs and may receive services from multiple systems; however, differences in the funding streams and foci of those systems often do not allow for or



² Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. 2007 Shattuck PT, Seltzer MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, Lounds J, Lord C. Journal of Autism and Developmental Disorders, 37(9): 1735-47.

³ Psychiatric and Medical Conditions among Adults with ASD. Croen L, Zerbo O, Qian Y, Massolo ML. Kaiser Permanente Northern California. 2014 International Meeting for Autism Research.

maximize collaboration or coordination. The Bureau of Autism Services provides technical assistance and clinical guidance to state offices and departments that support individuals with autism, but integration of evidence-based care for people with autism across systems is needed.

- The need to provide appropriate services that meet the complex needs of children and adults with autism. This is especially critical because the [PA Autism Needs Assessment](#) found that 85% of individuals with autism also have another diagnosis such as an intellectual disability, physical health challenge, or mental health diagnosis.
- The continued need to increase the capacity of professionals to evaluate, diagnose, educate, support, and provide services to people living with autism.

Individuals with autism are valued members of the Commonwealth, and it is vital to ensure they are provided the opportunity to live as independently as possible, engage actively with their communities, and experience enriched quality of life.

BACKGROUND

Pennsylvania Autism Census

The number of individuals with autism spectrum disorder (referred to as “autism” throughout this report) in Pennsylvania has grown rapidly in the past decade and is expected to continue to grow in the coming years. The 2009 Pennsylvania Autism Census Project identified 19,862 individuals with autism receiving services in Pennsylvania. Data sources included Pennsylvania’s public health insurance (Medical Assistance or Medicaid) and educational systems. As noted throughout the original report, this count was an underestimate since only individuals receiving services associated with a diagnosis or classification of autism were counted. The data did not account for children and adults with autism who were not receiving services through these two systems, or who were misdiagnosed or not diagnosed.

The goal of the 2014 Pennsylvania Autism Census Update was to collect information from additional data sources in order to identify a more accurate number of individuals with autism receiving services in Pennsylvania, determine the growth of this population, and identify where individuals with autism are receiving services.

The 2014 Pennsylvania Autism Census Update is an effort of the [Autism Services, Education, Resources and Training Collaborative \(ASERT\)](#) funded by the Bureau of Autism Services within the Pennsylvania Department of Public Welfare. The effort was led by Dr. Lindsay Shea, Director of the ASERT Collaborative Eastern Region, which is housed at the [A.J. Drexel Autism Institute](#). The mission of the ASERT Collaborative is to enhance the lives of Pennsylvanians living with autism, of all ages and abilities, by improving regional access to quality services and interventions, providing information and support to families, training professionals in best practices and facilitating collaboration among providers of services throughout the Commonwealth.

Autism Spectrum Disorder

Autism spectrum disorder, commonly referred to as autism, is a developmental disability that can cause significant social, communication and behavioral challenges.⁴ The causes of autism are unknown but likely include few, specific genetic and environmental factors, and there is no cure. With early identification and intervention, however, individuals with autism can achieve better developmental outcomes and live more independent lives with a lower cost to society over the long term.

⁴ Centers for Disease Control and Prevention. Autism Spectrum Disorder, April 28, 2014. Available at: <http://www.cdc.gov/ncbddd/autism/index.html>

Epidemiological estimates indicate that approximately 1 in 68 children have an autism spectrum disorder diagnosis,⁵ having increased from 1 in 88 in 2012, 1 in 110 in 2009, and 1 in 150 in 2002. Furthermore, it is estimated that nationwide almost 50,000 individuals with an autism diagnosis turn 18 each year.⁶ As children with autism become adults, research has found that the need for services and supports does not diminish, and may even increase.⁷ National research efforts have found that the social and communication symptoms of an autism diagnosis persist into adulthood, and adults with autism have recently been found to have higher rates of both medical and psychiatric comorbidities than other adults without autism.⁸ However, the services that support children with autism, delivered through the education and behavioral health systems are no longer available after ages 21 or 22, depending on the system.

METHODS

To complete the 2014 Pennsylvania Autism Census Update, data from multiple Pennsylvania sources were collected and summarized. Below (and as illustrated in Figure 1) is a list of sources of data for the 2014 Pennsylvania Autism Census Update, which includes a description of each source. All data was collected for calendar year 2011.

- The **Department of Education (PDE)** administers public education in Pennsylvania.
- The **Office of Vocational Rehabilitation (OVR)**, under the Department of Labor and Industry, provides employment related supports for individuals with disabilities including: job placement assistance, assistive technology, and a variety of training programs.
- The **Department of Public Welfare (DPW)** houses the Offices of Medical Assistance Programs (OMAP), Children, Youth and Families (OCYF), Developmental Programs (ODP) and Mental Health and Substance Abuse Services (OMHSAS). OMAP administers joint state and federal Medicaid programs. OCYF is Pennsylvania's child welfare system. ODP provides supports and services to individuals with developmental disabilities, including waivers for individuals with

⁵ Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. MMWR Surveillance Summaries, March 28, 2014/63(SS02); 1-21. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w.

⁶ Shattuck P, Carter Narendorf S, Cooper B, Sterzing P, Wagner M, Lounds Taylor J. Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder. *Pediatrics*. 2012; 129 (6): 1-8.

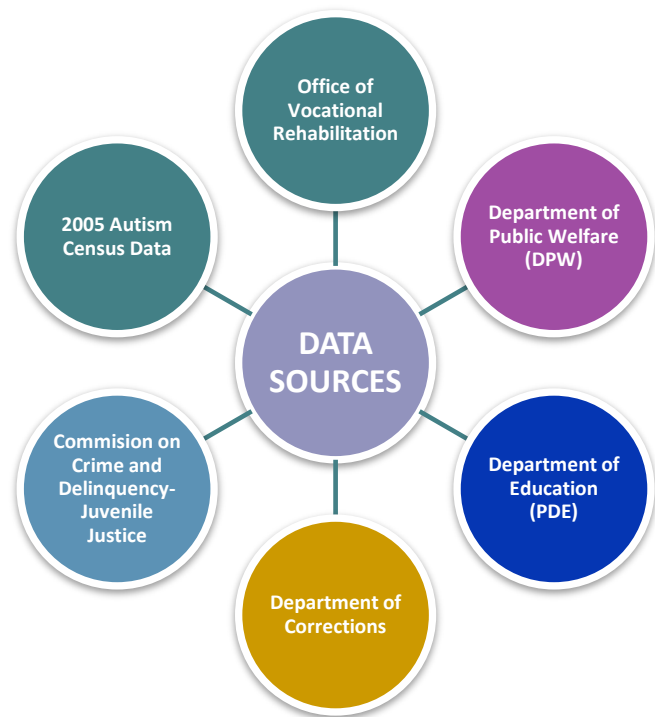
⁷ Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. 2007 Shattuck PT, Seltzer MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, Lounds J, Lord C. *Journal of Autism and Developmental Disorders*, 37(9): 1735-47.

⁸ Psychiatric and Medical Conditions among Adults with ASD. Croen L, Zerbo O, Qian Y, Massolo ML. Kaiser Permanente Northern California. 2014 International Meeting for Autism Research.

intellectual disabilities. The Bureau of Autism Services (BAS) within ODP administers autism-specific services to adults. OMHSAS provides children’s behavioral health services and services to individuals with substance abuse and mental health disorder diagnoses.

- The **Department of Corrections** and the **Pennsylvania Commission on Crime and Delinquency** coordinate the courts, law enforcement, the jail and prison system, and probation in Pennsylvania.

Figure 1. 2014 Pennsylvania Autism Census Project Update Data Sources



As an individual with autism ages, their interaction with these systems and the services and supports offered changes. For example, the DPW and PDE Office of Child Development and Early Learning and the Department of Education provide services to children and adolescents under age 21, and the adult programs administered through BAS are only available to individuals 21 years of age or older, with program capacity limited by available resources.

ANALYSES

Data from each agency were merged to provide an unduplicated count of individuals with autism who received services. The Department of Public Welfare considered a person to have autism if an autism diagnosis was associated with any Medicaid claim for that individual in calendar year 2011. The Department of Education 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 in calendar year 2011. Within the Department of Education, individuals may be enrolled in one or two categories.

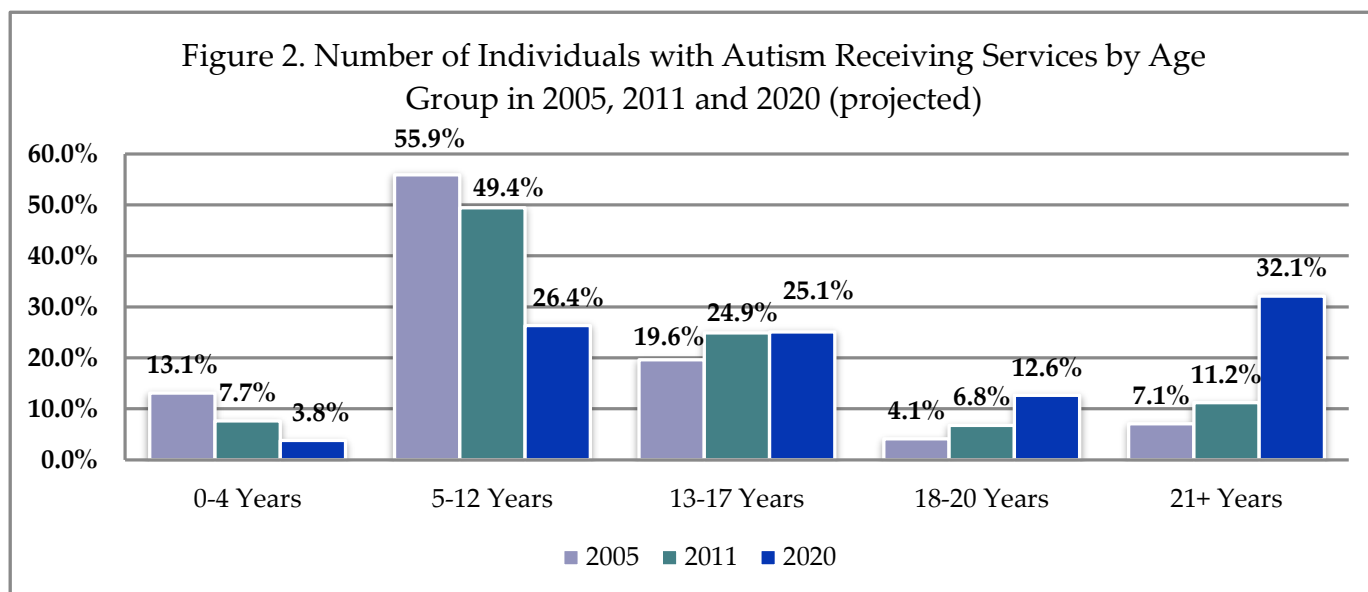
Data first were merged across Department of Public Welfare (DPW) agencies using a combination of name, date of birth, social security number and Client Information System (CIS) number. This unduplicated dataset was then given to the Pennsylvania Department of Education (PDE). PDE

matched individuals in the DPW dataset to individuals in their dataset using a combination of first name, last name, and date of birth. The Office of Vocational Rehabilitation (OVR) within the Department of Labor and Industry provided de-identified aggregate information so individual matching was not possible. Both the Department of Corrections and the Pennsylvania Commission on Crime and Delinquency matched individuals using the same method as PDE. Individuals from the 2009 Pennsylvania Autism Census Project were also added and matched on first name, last name and date of birth.

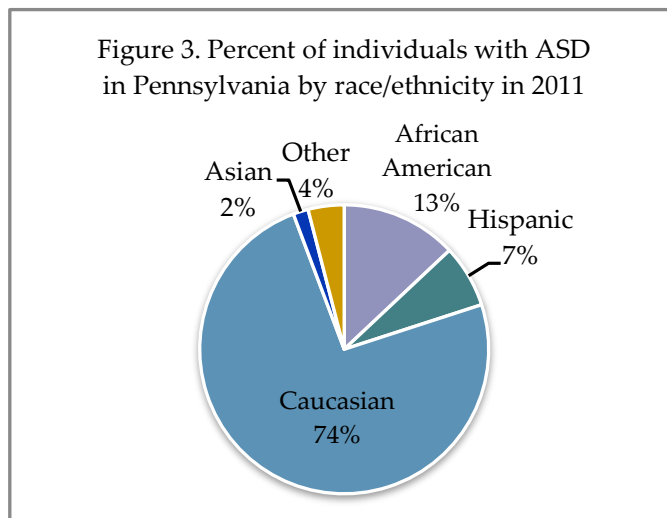
Frequencies and cross tabulations were used to calculate the proportions of individuals with autism served in each system and in each combination of systems. Demographic characteristics of individuals served in each combination of systems also were determined.

FINDINGS

In total, 55,830 individuals with autism receiving services were identified in Pennsylvania in 2011, which is almost triple the number of individuals with autism identified in 2005 (19,862). Figure 2 depicts the projected number of individuals with autism in Pennsylvania by age group through 2020, not adjusted for mortality rate. In calendar year 2011, most individuals (49.4%) were between the ages of 5 to 12 and about one in four (24.9%) were between the ages of 13 to 17. Although adults over the age of 21 represented 11.2% of all individuals in 2011, this age group is projected to continue to experience the largest growth. Through 2020, the proportion of adolescents transitioning into adulthood and adults with autism in Pennsylvania who will likely be in need of continued services is expected to continue to grow rapidly, from 7.1% in 2005 to 32.1% in 2020.



The gender of Pennsylvanians with autism receiving services aligned exactly with national epidemiologic studies of autism with 80% male and 20% female. This also duplicates the gender distribution from the 2009 Pennsylvania Autism Census Project. Figure 3 displays the race/ethnicity of individuals with autism in Pennsylvania. These numbers generally align with Pennsylvania data from the U.S. Census Bureau. The percent of individuals from a Hispanic ethnicity may be underreported since in state systems individuals may not be able to check Hispanic ethnicity in addition to a race.



Appendix A and Appendix B include maps of the number of individuals with autism receiving services in each county in Pennsylvania and the prevalence rate per capita of individuals with autism receiving services in each county as well. The three counties in the Commonwealth with the highest number of individuals with autism were Allegheny (4,895), Philadelphia (4,617) and Montgomery (1,691). These counties also represent the most populous counties in Pennsylvania and had the highest number of individuals with autism receiving services in the 2009 Pennsylvania Autism Census Project as well. The counties with the highest prevalence of individuals with autism receiving services per 10,000 county residents were Clearfield (57.1), Warren (54.8) and Mercer (52.1). These counties were also among the highest prevalence of individuals with autism receiving services per 10,000 county residents in the 2009 Autism Census Project.

Individuals with autism in Pennsylvania most often received services through both the Departments of Public Welfare and Education. Specifically, 64% or about 36,000 individuals received services through the Department of Public Welfare and 70% or 39,000 individuals received services through the Department of Education. Across these groups, two out of three individuals (or a total of about 25,000 individuals) were identified as having autism and were receiving services from both Departments. Since the most common age groups of individuals with autism in Pennsylvania were 5-12 and 13-17, the high enrollment for services in both the Departments of Education and Public Welfare is not surprising. Services through the Department of Education are not available for the vast majority of individuals over age 21, or age 22 in some cases.

Pennsylvania Department of Public Welfare

Several programs in the Pennsylvania Department of Public Welfare serve individuals with autism. Behavioral Health Rehabilitation Services (BHRS) are one-to-one support services that children with autism who are eligible for Medical Assistance can access until their 21st birthday. Since the majority (86%) of Pennsylvanians with autism receiving services in the Department of Public Welfare in 2011 were under the age of 21, most children with autism are likely accessing BHRS. Children who are eligible for Medical Assistance due to their families' income may also be accessing Medical Assistance for other health care needs including primary care and other health services. The Pennsylvania Department of Public Welfare also serves over 6,000 adults with autism and this age group was the fastest growing. The Pennsylvania Department of Public Welfare houses waivers, which are special exceptions to normal Medical Assistance eligibility rules. Currently operating waivers include the Infant, Toddlers, and Families waiver, the Consolidated Waiver for Individuals with Intellectual Disability, the OBRA Waiver and the Person/Families Directed Support Waiver. The Bureau of Autism Services operates the only two programs that are specifically intended to provide services to adults with autism in Pennsylvania. At the time this report was released, the Adult Autism Waiver (AAW) had the capacity to support 518 adults and the Adult Community Autism Program (ACAP) had the capacity to support 146 adults, and both programs were at capacity.

Pennsylvania Department of Education (PDE)

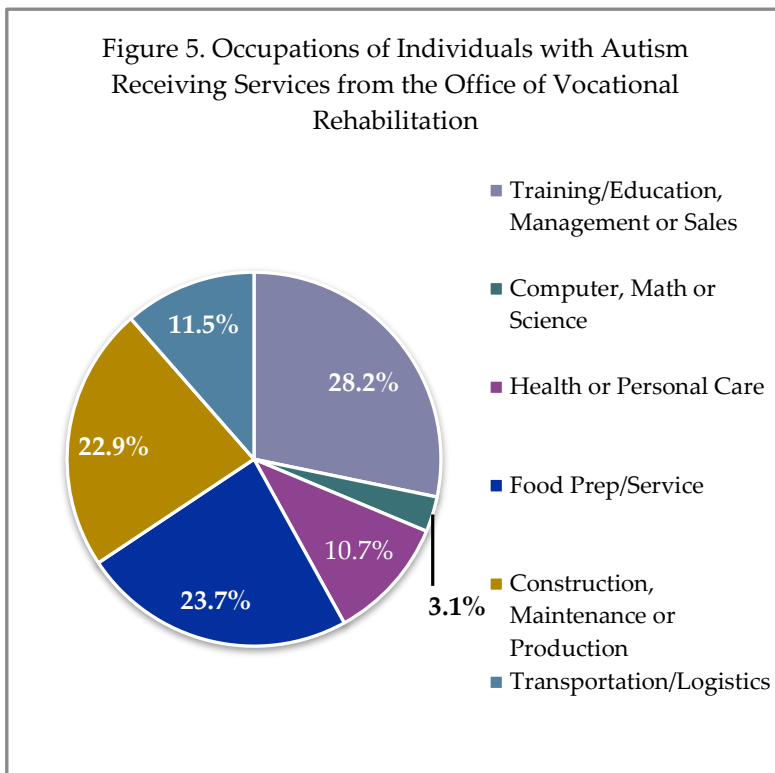
Among the children and adolescents with autism served by the Department of Education, about two in five (39%) had a primary or secondary classification of Autism and almost one in four (23%) had a primary or secondary classification of Speech or Language Impairment. About 60% of children or adolescents with autism served by the Department of Education were included in their classroom 80% or more of the day. As shown in Figure 4, most children and adolescents with autism served by the Department of Education in 2011 received Learning, Autistic, Emotional or Life Skills Support. Speech/Language, Multiple Disabilities and Other support totaled less than 7% of the support delivered to this group.

Figure 4. Type of Support

Learning	37%
Autistic	36%
Emotional	10%
Life Skills	10%
Speech/Language	4%
Multiple Disabilities	2%
Other	< 1%

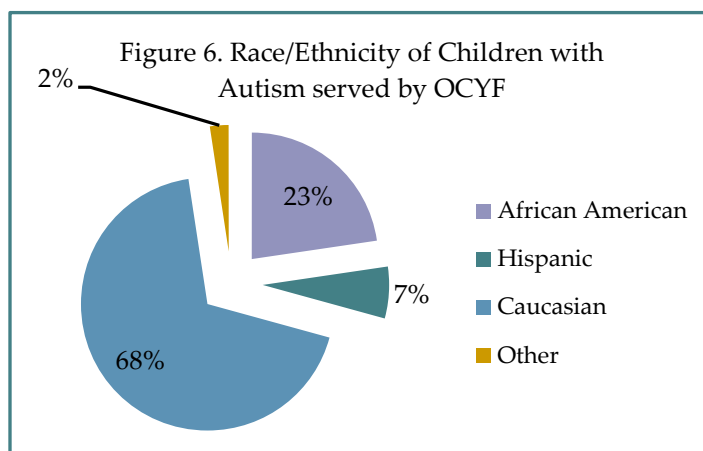
Pennsylvania Office of Vocational Rehabilitation (OVR)

The Pennsylvania Office of Vocational Rehabilitation (OVR) reported serving 1,705 individuals with autism in 2011 with about 8% of those individuals gaining employment. As shown in Figure 5, more than one quarter (28.2%) of individuals with autism who gained employment through OVR were working in training, education, management or sales. About one in five individuals who gained employment through OVR were working in food preparation or services or were working in construction, maintenance, or production. The average age of individuals with autism being served by OVR in 2011 was 22 years old.



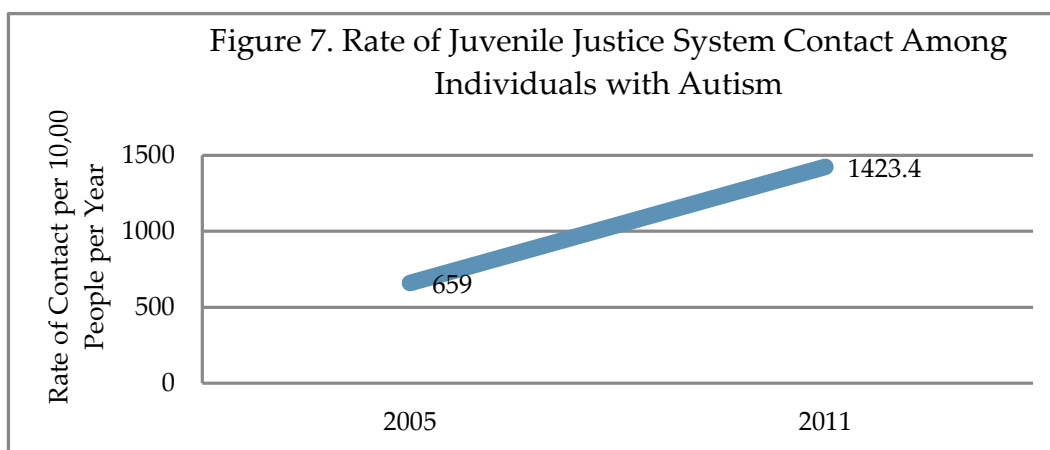
Pennsylvania Office of Children, Youth and Families

Within the Pennsylvania Department of Public Welfare, the Office of Children, Youth and Families (OCYF) served about 1,500 children with autism in 2011. Fewer than half of these children were flagged in the OCYF system as having a disability of any kind. Children with autism served by OCYF were more likely to be from a minority community than children served in other systems (Figure 6). Several counties had especially high rates per capita of children with autism in the OCYF system including Cameron, Warren, Crawford, Juniata and Tioga counties.



Over 500 individuals with autism in Pennsylvania who were receiving services from Medicaid had contact with the juvenile or criminal justice systems in 2011. Property offenses and physical contact crimes were the most common charge types. As shown in Figure 7, the rate of contact with the justice system among juveniles with autism receiving services through the Medicaid system increased over time. The rates of juvenile justice system contact for the general population of the same ages (including both individuals receiving services from the Medicaid system and those not receiving services through this system) were lower than the rates of contact among juveniles with autism receiving Medicaid services in both 2005

and 2011, and decreased over that same period. This relative overrepresentation of individuals with autism in the juvenile justice system and the increasing contact rate over time for



this group warrants additional investigation, especially in understanding how it might translate to adults with autism as this group continues to grow. The observed increasing rate of justice system contact over time for juveniles with autism should not be taken to suggest that this group is becoming more dangerous. It does, however, underscore the need for community supports to help individuals with autism avoid crises as well as motivate the development of tools and trainings within the justice and first responder systems on the diverse presentation of autism and appropriate strategies for most effectively interacting with individuals with autism.

CONCLUSIONS

The number of individuals with autism receiving services in Pennsylvania is growing rapidly. The estimated 55,830 individuals with autism receiving services in the Commonwealth is a significant undercount because it only captures individuals diagnosed with autism receiving services through public systems in Pennsylvania. Adults with autism are likely among the most undercounted in an administrative census since there is a lack of services to support them, or they may be misdiagnosed or undiagnosed.

The data also reflects the wide diversity of autism across racial, ethnic, and socio-economic groups. From 2005 to 2011, the proportion of individuals with autism representing minority groups rose. This indicates a need for focused efforts to engage individuals from minority communities around autism awareness and support them through the navigation of service pathways. In addition, the data captures Pennsylvania's diverse geographic composition of rural, urban and suburban regions. Some of the counties with the highest per capita prevalence rates of individuals with autism receiving services were rural and further efforts to understand these variations are needed. In counties with fewer total residents, a small number of additional individuals with autism receiving services from one or a few providers could result in a large increase in the prevalence rate.

Another key finding of the 2014 Pennsylvania Autism Census Update is specific to individuals with autism who are particularly at risk. Children with autism being served in the Office of Children, Youth, and Families in the Department of Public Welfare warrant particular attention given the overrepresentation of children in this system from traditionally underserved and underrepresented communities. Individuals with autism who have contact or multiple contacts with the justice system are another at risk group both because contact with the justice system can be traumatic and misunderstood, and because the short- and long-term costs to the system for crisis events are generally disproportionate when compared to the cost of the services that might prevent such events.

Finally, the majority of individuals with autism receiving services in Pennsylvania at this time are children and are served by the Pennsylvania Department of Education. However, as children with autism continue to age into adulthood and more adults with autism are diagnosed, increases in the number of individuals with autism served by other systems, including the Department of Public Welfare and the Office of Vocational Rehabilitation, will likely continue to rise.

LIMITATIONS

Several limitations of the 2014 Pennsylvania Autism Census Update should be noted. As is described throughout this report, only individuals receiving services through Pennsylvania's public service

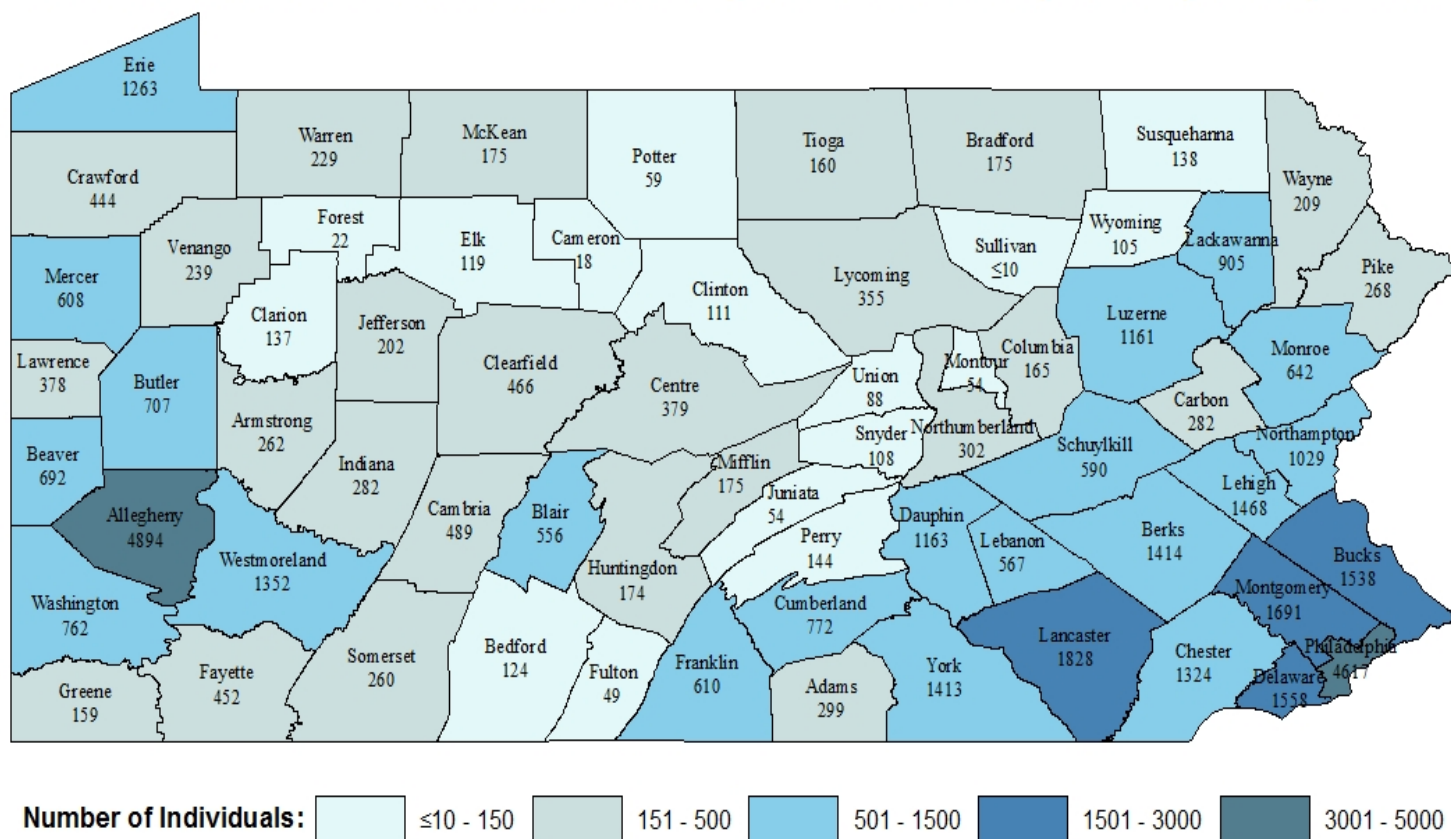
systems were included in this count. An autism diagnosis has not been validated among these individuals although research indicates the strategies used to identify individuals with autism yield a high specificity of an autism diagnosis in the community. Individuals who have autism but are receiving services due to another diagnosis may not be counted if the services they receive are not associated with their autism diagnosis. Individuals who may have moved or changed names during calendar year 2011 due to marriage or adoption, or whose names might be different across systems may have been counted twice. Finally, the Department of Education data includes public and charter schools but not parochial or private schools.

APPENDICES

- 1) Appendix A Number of individuals with autism receiving services per county
- 2) Appendix B Prevalence rate of individuals with autism receiving services per county

APPENDIX A

Number of Individuals with Autism Receiving Services in Pennsylvania by County in 2011



APPENDIX B

Prevalence Rate of Individuals with Autism Receiving Services in Pennsylvania, per 10,000 County Residents in 2011

(Total Number of Individuals with Autism Receiving Services in Parentheses)

