USABILITY AND UTILITY OF BEHAVIORAL HEALTH PROVIDER AND STATE AGENCY DATABASES FOR QUANTIFYING AND CLASSIFYING AUTISM SPECTRUM DISORDERS: AN EXAMPLE FROM SOUTHWESTERN PENNSYLVANIA

by

Amy DeStefano

Bachelor of Science, University of Pittsburgh, 2006

Submitted to the Graduate Faculty of

Epidemiology

Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Public Health

University of Pittsburgh

2014

UNIVERSITY OF PITTSBURGH

GRADUATE SCHOOL OF PUBLIC HEALTH

This essay is submitted

by

Amy DeStefano

on

March 29, 2014

and approved by

Essay Advisor:
Evelyn O. Talbott, MPH, Dr.PH
Professor
Department of Epidemiology
Graduate School of Public Health
University of Pittsburgh

_____

Essay Reader:
Vincent C. Arena, PhD
Associate Professor
Department of Biostatistics
Graduate School of Public Health
University of Pittsburgh

_____

Evelyn O. Talbott, MPH, Dr.PH

USABILITY AND UTILITY OF BEHAVIORAL HEALTH PROVIDER AND STATE AGENCY DATABASES FOR QUANTIFYING AND CLASSIFYING AUTISM SPECTRUM DISORDERS: AN EXAMPLE FROM SOUTHWESTERN PENNSYLVANIA

Amy DeStefano, MPH

University of Pittsburgh, 2014

ABSTRACT

According to the CDC, the most recent estimate of the prevalence of autism spectrum disorders is 1 in 68. The continuing increase in prevalence over the last several years has professionals across disciplines searching for the true etiology of the disorder and for effective treatments to address this public health problem. An important caveat to acknowledge is that the CDC's prevalence estimates for autism are based upon a sentinel surveillance system that experiences great variability between sites. In order for a more population-based surveillance system to be implemented, a standardized set of data would need to be collected across the entire population. This paper will examine what kind of data would be available from the electronic health records of behavioral health treatment agencies using data from an autism treatment agency in Southwestern Pennsylvania and reviews Pennsylvania's current efforts to estimate the burden of autism throughout the state. This paper focuses on the public health problem of accurate assessment of disease burden to allow for adequate resource allocation at a state policy level to care for affected residents.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS

ADDM…………………………… …………Autism and Developmental Disabilities Network

ASDs……………………………….…...………………… Autism Spectrum Disorders

ASERT……………………..Autism Services, Education, Resources, and Training Collaborative

BHRS…………………………………………Behavioral Health Rehabilitation Services

CDC …………………………………………Centers for Disease Control and Prevention

DPW…………………………………………………..Department of Public Welfare

DSM…………………………………………………Diagnostic and Statistical Manual

EMR…………………………………………………Electronic Medical Record

FERPA…………………………………………Family Education Rights and Privacy Act

HIPAA…………………………………..Health Insurance Portability and Accountability Act

ICD-10……………………………………International Classification of Disease (10th version)

ODP………………………………………………..Office of Developmental Programs

OMAP……………………………………………....Office of Medical Assistance Programs

OMHSAS………………………….Office of Mental Health and Substance Abuse Services

OSP………………………………………………………Office of Social Programs

OVR………………………………………………..Office of Vocational Rehabilitation

PDD-NOS…………………………Pervasive Developmental Disorder, Not Otherwise Specified

PDE……………………………………………Pennsylvania Department of Education

1.0   INTRODUCTION

Data from surveillance systems inform several aspects of public health activities. Surveillance is defined as "the ongoing and systematic collection, analysis, and interpretation of health data in the process of describing and monitoring a health event."[1] For infectious diseases, surveillance is an incredibly valuable tool for detecting epidemics, testing hypotheses about the source of infection, and evaluating control measures that are put into place.[2] Surveillance systems are also a useful tool in the management of chronic conditions and developmental disabilities such as Autism Spectrum Disorder. In these cases, surveillance systems can help public health professionals estimate the prevalence of the problem, detect increases or decreases in prevalence over time, and document the distribution of the cases in various locations.[2] Using this information, policy makers can make informed decisions about resource distribution for prevention and treatment and researchers can cross-reference this information with other data sets to conduct research into etiology and intervention effectiveness.[2] There are a variety of methods utilized to capture health data for surveillance activities such as active surveillance, where staff of the entity managing the surveillance system reach out to health care providers or the general population to obtain health data, or passive surveillance where health care providers are responsible for providing information for surveillance activities, often through electronic reporting.[3] A case that is included in the surveillance system can be based on a diagnosis made by a health care practitioner or in the case of syndromic surveillance, based on evidence of a cluster of symptoms consistent with the disease being monitored.[3]

The Centers for Disease Control and Prevention (CDC) currently conduct surveillance for Autism Spectrum Disorders (ASDs) using an active, syndromic surveillance system. The data from this system indicates that the prevalence of (ASDs) has been increasing since 2002.[4] The designated population for CDC surveillance for ASDs is based on the Autism and Developmental Disabilities Monitoring Network (ADDM), which contains programs within fourteen communities that are funded by the CDC for active record review.[5] Trained reviewers look at historical comprehensive professional evaluations in records for evidence of behaviors consistent with the ASD diagnosis according to the DSM-IV-TR criteria.[6] In 2008, the record review revealed a prevalence of 1 in 88 or 11.3 per 1,000 children for children who were eight years of age within the review year.[4] Currently, the CDC is reviewing records from 2010 to abstract an updated prevalence estimate of autism.[5] Children are not required to have a diagnosis of autism to be considered as a case in this surveillance system, and in 2008, only 79% of cases had a documented diagnosis of autism.[7] While this system picks up diagnoses that wouldn't be reported if the CDC relied on only diagnosed cases of ASDs, one study estimated that the CDC tracking system is missing 12 out of every 177 cases of autism.[8]

ASDs are a group of developmental disabilities that are marked by a group of social impairments that have a significant impact on an individual's day-to-day functioning.[6] To be included as a case in CDC's current surveillance system, the individual must have documented symptoms that are consistent with one of the three types of Autism Spectrum Disorder based on the criteria defined in the current Diagnostic and Statistical Manual (DSM-IV-TR).[7] The first diagnosis that is included is Autistic Disorder, which is characterized by impairments in social interaction and communication that is also accompanied by restricted interests and stereotyped patterns of behavior.[6] To be considered a case of Autistic Disorder, symptoms must appear prior

2

to age three.[6] Asperger's Disorder is also included in ASD cases, and is characterized by a similar social impairment and restricted interests with repetitive behavior, but individuals with Asperger's do not have the delay in language seen in Autistic Disorder.[6] The third diagnosis included is Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) for individuals that have an impairment in social interaction and either communication skills deficits or restricted interests.[6] The CDC also includes Atypical Autism in the PDD-NOS category for individuals that meet the criteria for Autistic Disorder but don't have symptom onset prior to the age of three.[6]

There is some evidence that a portion of the recent increase in the prevalence of autism is related to factors such as increased screening and changes in diagnostic criteria. One study did a record review of children who were evaluated for autism in the 1980s using the DSM-IV-TR case definition and found that 59% of the cases that were considered "not autistic" using the DSM-III criteria met the case definition using the DSM-IV-TR definition.[9] The case definition for ASDs in clinical settings will soon change again. In May 2013, the American Psychiatric Association released an update to the Diagnostic and Statistical Manual of Mental Disorders with the DSM-5.[10] Instead of having three separate diagnoses, the DSM 5 contains a single Autism Spectrum Disorder diagnosis that requires that symptoms appear in early childhood and rates on a scale of one to three based on the level of support needed.[11-12] Preliminary studies indicate that the change in diagnostic criteria may result in a decrease in the number of individuals diagnosed with ASD. A recent study by Huerta, et al. concluded that 91% of children with a PDD-NOS diagnosis would maintain the Autistic Disorder diagnosis with the DSM-5 and that the new criteria will provide greater specificity for true cases of Autistic Disorder.[13] The CDC has not yet

published if they will adopt a new case definition based on the DSM 5, so the impact of this change on prevalence estimates is currently unknown.

Since the CDC's current surveillance activities only focus on a limited portion of the United States' population, the prevalence numbers that are published cannot be generalized to the entire population. Prevalence of autism varied drastically from site to site in the 2008 review; the lowest prevalence was in Alabama with a prevalence of 4.8 per 1,000 while the prevalence in Utah was the highest at 21.2 per 1,000.[7] A portion of this variation was accounted for by the type of records the reviewers were able to access. Overall, prevalence was higher in ADDM sites that had access to educational and health records.[7] While accuracy of numbers is very important for determining the true burden of disease in society, the wide variation of prevalence by location makes it difficult to estimate what prevalence looks like in areas that do not have ADDM sites. To expand the current surveillance system to a wider geographic area would increase the expense of surveillance, but it would provide some important data for public health professionals. There is some evidence that environmental exposure to hazardous air pollution or the prescription drugs thalidomide and valproic acid during pregnancy or early childhood could affect the prevalence of autism.[14-15] A population based surveillance system could allow for cross-referencing of autism prevalence with presence of environmental exposures to further test these hypotheses or to create new ones. Public Health professionals could also use this data to help support the deployment of resources for early intervention and treatment. Since prevention is not possible for this disorder because of the unknown etiology, resources for early intervention are important for affecting outcomes for children with autism. Moving to a population-based surveillance system would likely result in an underestimation of the true burden of ASDs, but it would capture the important variability of case distribution across the nation and provide local

and state governments with information to help distribute resources and address the needs of the population they serve.

1.1   AUTISM IN PENNSYLVANIA

The commonwealth of Pennsylvania has shown an interest in quantifying the burden of ASDs in the population. While the CDC has an ADDM site in Philadelphia County that estimated that 13.3 per 1,000 were living with autism,[16] the commonwealth created an initiative to gain a more comprehensive picture. The Pennsylvania Department of Public Welfare (DPW) sponsored a study to determine an unduplicated count of individuals in Pennsylvania living with ASD who were accessing any publicly funded system.[17] The census report used administrative records from the Pennsylvania Department of Education (PDE) and the Department of Public Welfare (DPW) in calendar year 2005.[17] Data were collected from multiple offices in DPW including the Office of Mental Health and Substance Abuse Services (OMHSAS), Office of Developmental Programs (ODP), Office of Social Programs (OSP), and the Office of Medical Assistance Programs (OMAP).[17] DPW used ICD-10 codes for autism (299.xx) to identify cases and then merged data across all offices using name, date of birth, social security number, and Client Information System number to attain an unduplicated count.[17] PDE used primary and secondary disability categories of autism or receipt of "autistic services" to identify cases and then matched their data to DPWs data using first name, last name, date of birth, and social security number to obtain a final unduplicated count.[17]

The final census report showed that there are a higher number of cases in Allegheny County (2,235) than in Philadelphia (2,142), where the CDC has their ADDM site for the national surveillance.[17] This could be an indication that prevalence of autism is actually higher in Allegheny County or that more individuals with autism are accessing services in the home,

school, or community. The report also indicated that the highest prevalence was noted in Warren, Pike, Clearfield, Mercer, and Monroe counties but note that diagnostic expertise and low population numbers in some rural counties could account for this difference.[17] The report determined that the average age of individuals being served with autism in 2005 was 11.3 years with 80.3% of individuals being male.[17] Race classification was consistent with expected numbers based on Pennsylvania census data, with 81% of individuals with autism being white, 12% were black, 5% were Hispanic, and 2% were Asian/Pacific Islander.[17]

From a fiscal perspective, the number of individuals with autism in a given area is valuable information when budgeting for their health care and educational needs. According to the CDC, individuals with autism's health care costs are 4.1-6.2 higher than those without ASD with the additional need of intensive behavioral interventions for children that cost $40,000-60,000 per year.[4] In Allegheny County, a non-profit agency called Allegheny Health Choices, Inc. provides demographic and cost reports for behavioral health claims processed in Allegheny County for individuals enrolled in the Medicaid managed care plan. In 2012, 18% of all children who used behavioral health services were treated for autism spectrum disorders.[18] The average cost of treatment per user was $9,254 as compared to an average cost of $3,815 for treatment of ADHD, the most common diagnosis for children treated in Allegheny County in 2012.[18]

2.0   AUTISM IN AGENCY A

In order for a passive surveillance system to be successful, professionals who are diagnosing autism must use a standard case definition and collect and report data in a standardized fashion. To determine what information could be captured from individual provider agencies, the author was granted access to a behavioral health agency's (Agency A) electronic medical record system. The agency collected a variety of demographic information from individuals with autism, parents of children with autism, or other professionals, such as case managers, that worked with the individuals when they called to express their interest in receiving services. The individual's diagnosis would be obtained and entered into the medical record prior to the start of services.

The data below represents individuals with a diagnosis of autism who either contacted Agency A between April 2010 and March 2013 or had someone contact Agency A on their behalf expressing an interest in services. At this point of contact, individuals and their demographic information is entered into the agency health record. Data that is presented by year is based on the date of contact with Agency A. These individuals may or may not have received health care treatment with Agency A.

Agency A has three office locations that are primarily designated to serve children with autism. The red circles on Figure 1 indicate each of these office locations and the concentration of individuals contacting the agency about services. The finding that the highest number of cases is concentrated around the office locations is most likely explained by the need for individuals

served to come to the office locations to receive services or have staff from those offices willing to travel to serve these individuals in their homes. It is not likely a true picture of the prevalence of autism in each of those zip codes.
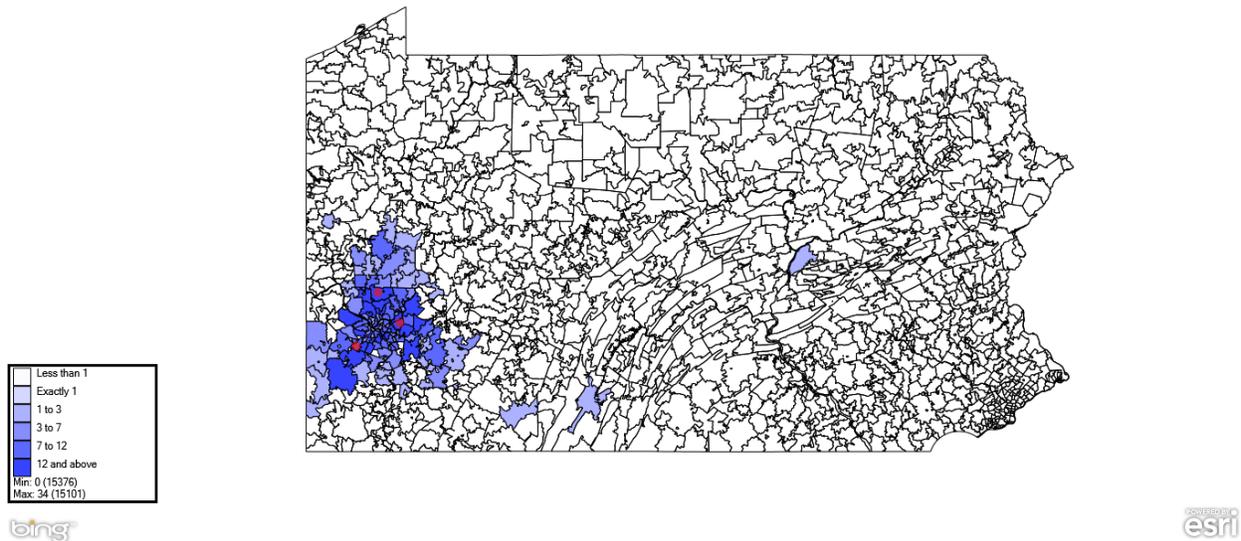

Figure 1. Agency A ASD Cases by Zip Code

There were 392 new electronic records created for individuals with Autism created between April 2010 and March 2011. The number of individuals entered into the health record database fell drastically in the following years to 225 and 229 in 2011 and 2012 respectively (Figure 2). Some of this variation might be explained by the transition of Agency A to an EMR in April of 2010. There was a need to have all individuals currently being treated electronically imported into the new EMR so that clinicians could document their work. The majority of individuals were successfully imported into the system on March 17, 2010. These 740 individuals were removed from the analysis since their contact with the agency was prior to the timeframes included in this analysis. However, some individuals being served were not included in the initial import were manually entered into the new EMR. Manual entry occurred on all different dates so these individuals could not be reliably removed from the analysis.
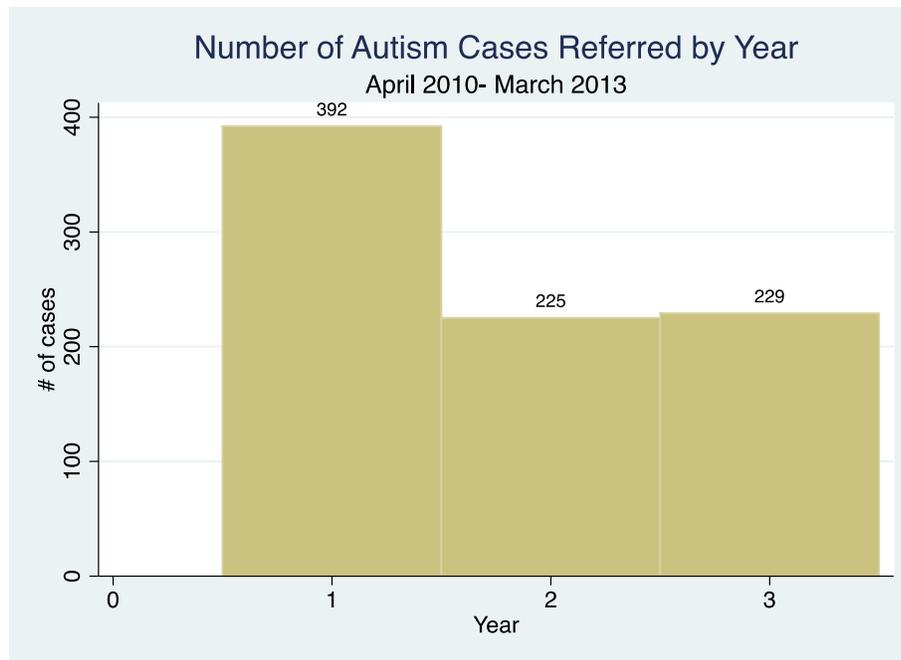
9

Figure 2. Number of ASD Cases Referred to Agency A by Year

The majority of individuals received a diagnosis of Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). This diagnosis accounted for 81.6% of total new individuals entered into the health record in 2010 (Figure 3). Overall, PDD-NOS accounted for 81% of all of the new individuals entered into the health record (Figure 4). Since a diagnosis of PDD-NOS does not require a child to display the deficits in communication and the restricted interests that are a part of the Autistic Disorder diagnostic criteria, it is a diagnosis that would apply to a larger number of children. Another potential reason for high number of PDD-NOS diagnoses seen here could be attributed to the services provided by Agency A. One of the most highly attended treatment programs is a social skills group that requires that attendees have some proficiency in their communication skills and limited stereotypical behavior in order to receive the full benefit of the program. Based on the diagnostic criteria for Autistic Disorder, it is expected that this program would attract individuals with a diagnosis of PDD-NOS or Asperger's Disorder instead.

10

Subtypes of autism diagnosis by year

	Aspergers Disorder	Autistic Disorder Current/Active State	Other Pervasive Developmental Disorder	Rett's Disorder
2010-2011	8	61	320	2
2011-2012	0	42	183	0
2012-2013	0	48	181	0
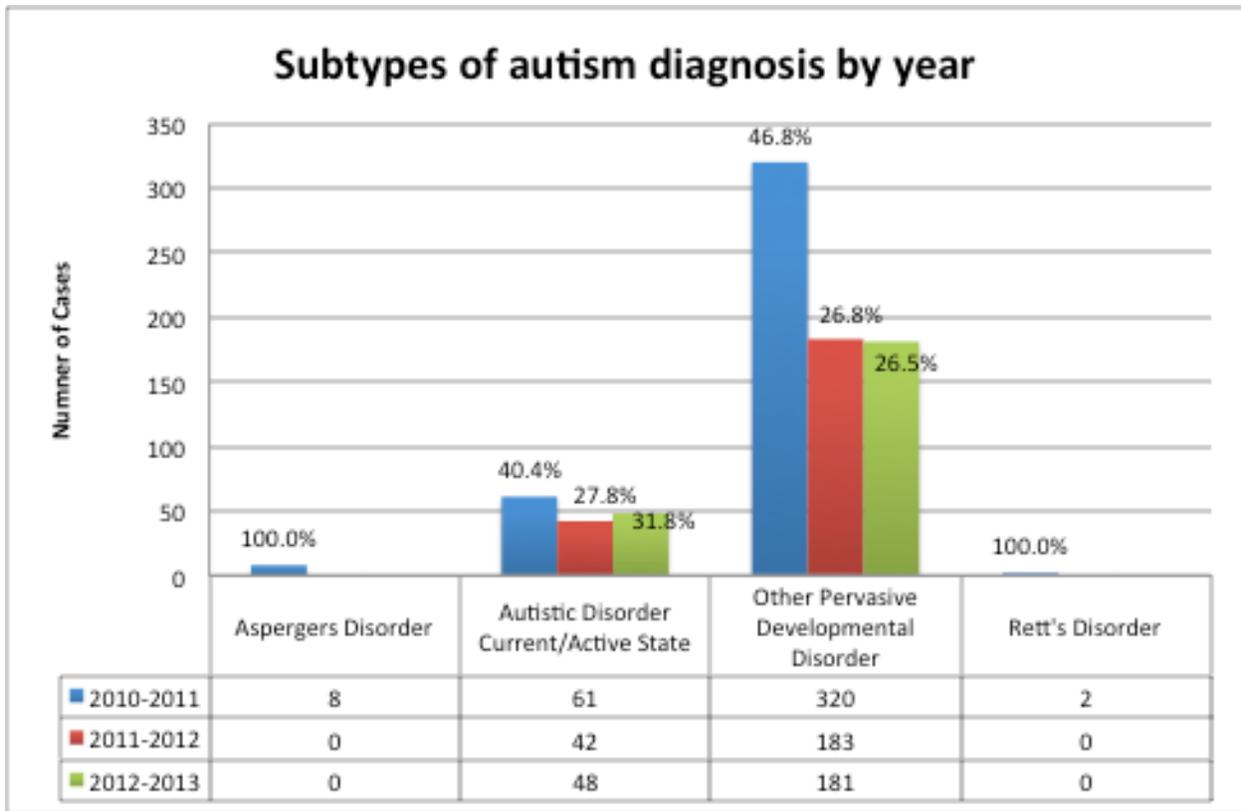
Figure 3. Subtypes of ASD Diagnosis by Year

ASD Diagnoses Sub-Types

	PDD	ASPERGERS	RETT'S	AUTISM
Series1	684	8	2	151
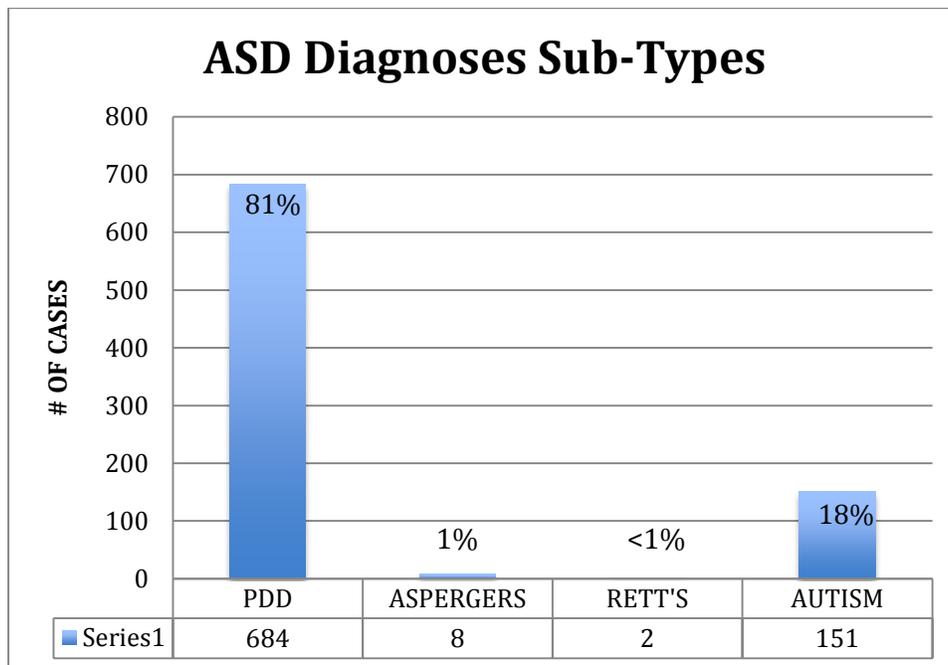
Figure 4. Subtypes of ASD Diagnosis

11

Consistent with CDC statistics for nationwide gender distribution of autism, 81% of individuals who contacted Agency A who had autism were for males (Figure 5).

Gender of Individuals with Autism Referred to Agency from April 2014 to March 2013

Female 19%

Male 81%
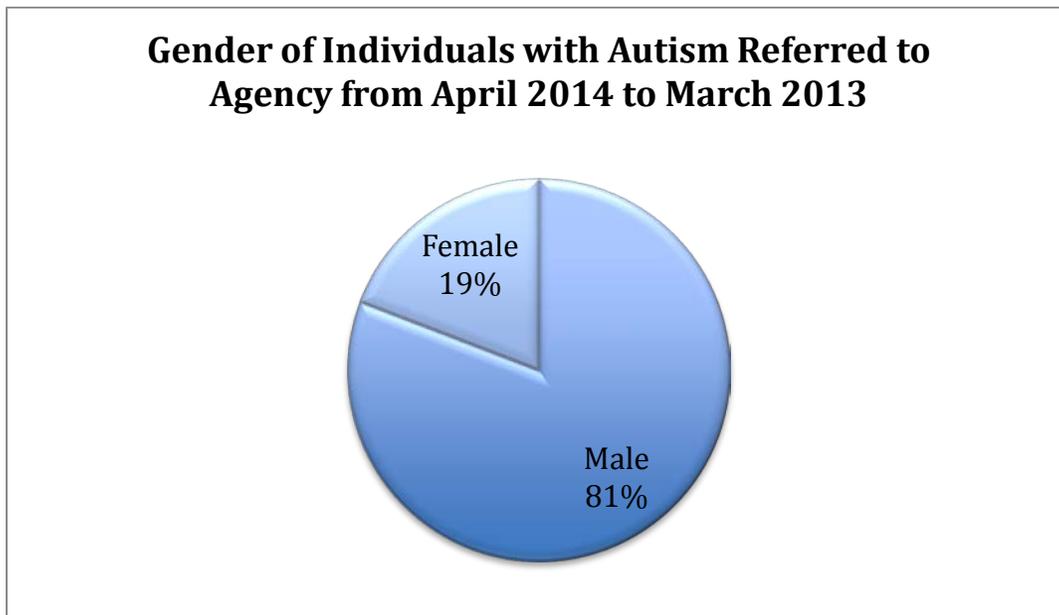
Figure 5. Gender Distribution for Individuals with ASD

The average age of children when their parent or case manager contacted Agency A for services was 11.1 years of age and the median age was also 11 years old. As seen in Figure 6, there are also a large number of eight year olds referred for services which is consistent with studies that show most children with developmental disabilities have been diagnosed and identified for services by age eight.[5]
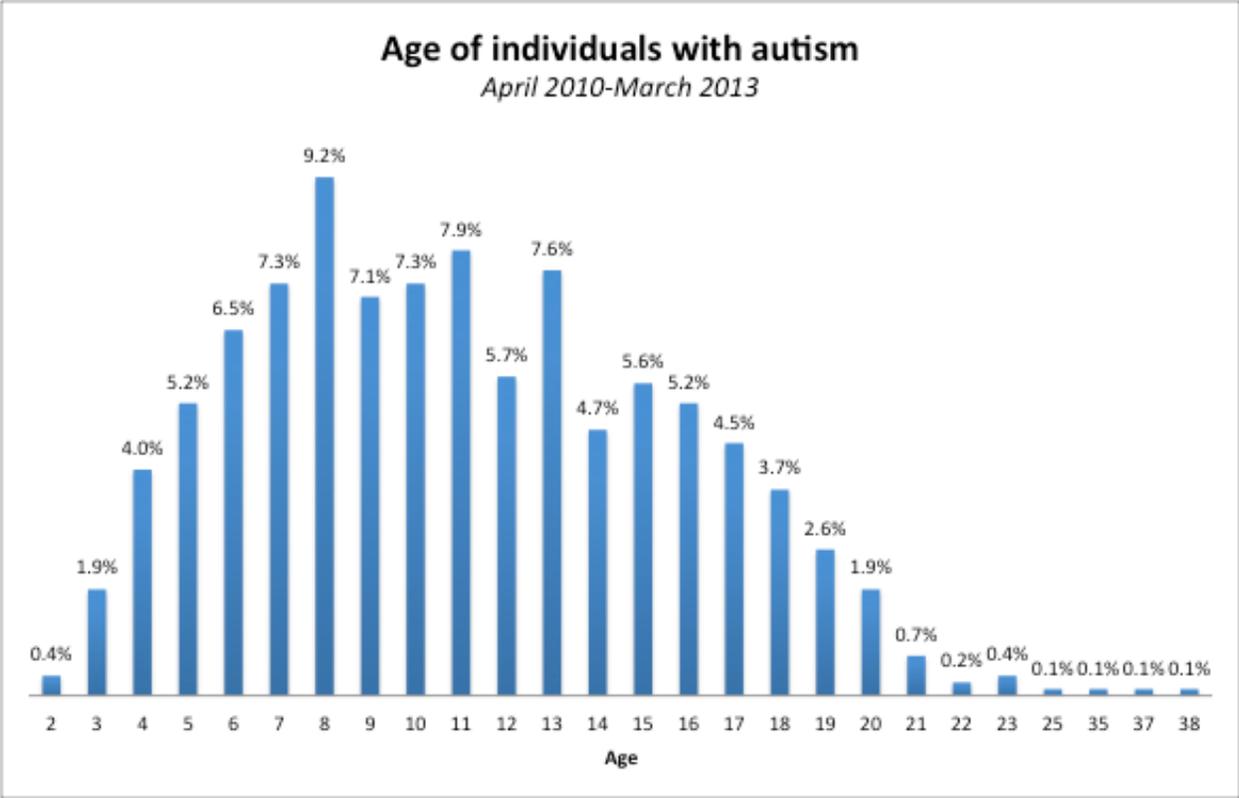
Figure 6. Ages of Individuals with ASD in Agency A

Interestingly, the children's age at the time Agency A was contacted for services illustrates a trend of referral for service at a younger age (Figure 7). The trend potentially could represent an increased awareness in the community of the benefits of identifying autism and obtaining treatment as early as possible to maximize the benefits to treatment. Agency A also started offering diagnostic evaluations in May of 2012. This most likely accounted for the large increase seen in the percentage of 2-4 year olds that contacted Agency A for services because the symptoms of autism begin to become apparent around 2 years of age.[6]

Age of individuals with ASD
April 2010-March 2011

Age Group	Percentage
2 to 4	0.3%
5 to 7	15.1%
8 to 10	24.5%
11 to 13	24.5%
14 to 16	17.1%
17 to 19	14.0%
20-25	4.3%
26-30	0.0%
30+	0.3%

Age of individuals with ASD
April 2011- March 2012

Age Group	Percentage
2 to 4	6.3%
5 to 7	21.4%
8 to 10	28.1%
11 to 13	21.0%
14 to 16	15.6%
17 to 19	4.5%
20-25	3.1%
26-30	0.0%
30+	0.4%

Age of individuals with ASD
April 2012- March 2013

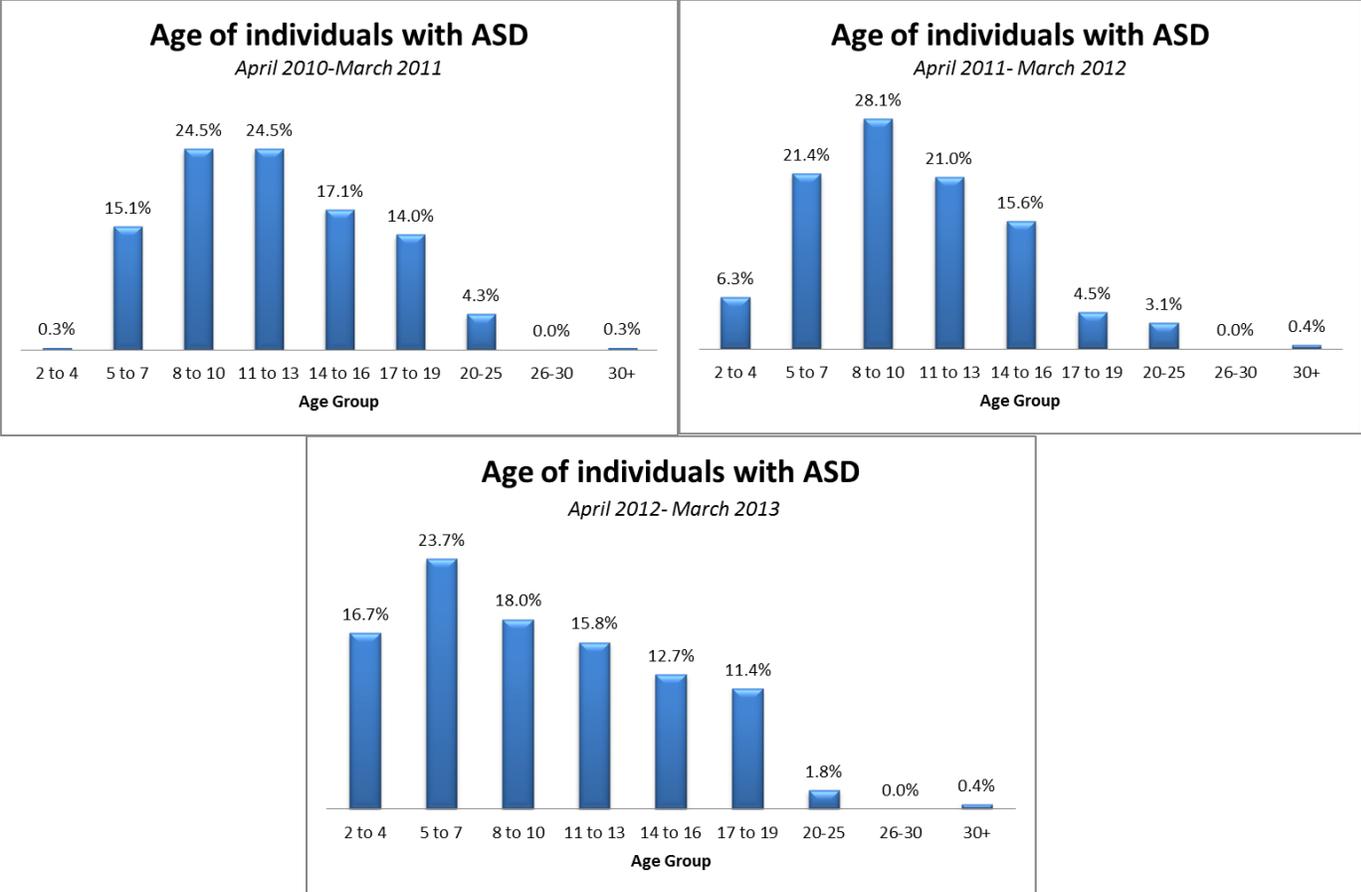| Age Group	Percentage
2 to 4	16.7%
5 to 7	23.7%
8 to 10	18.0%
11 to 13	15.8%
14 to 16	12.7%
17 to 19	11.4%
20-25	1.8%
26-30	0.0%
30+	0.4%

Figure 7. Ages of Individuals with ASD in Agency A by Year

Consistent with the Pennsylvania Autism Census report, the majority of individuals with autism who contacted Agency A between 2010 and 2013 identified themselves as White/Caucasian (Figure 8). Some of this data is incomplete as indicated by the 'missing' and 'not known at this time' categories. Both of these categories represent missing information, and the differing classifications represent a process change that made the race field a required field when entering a new individual into the system. The missing category represents when the field was blank.

Race classification of autsm cases in Agency A

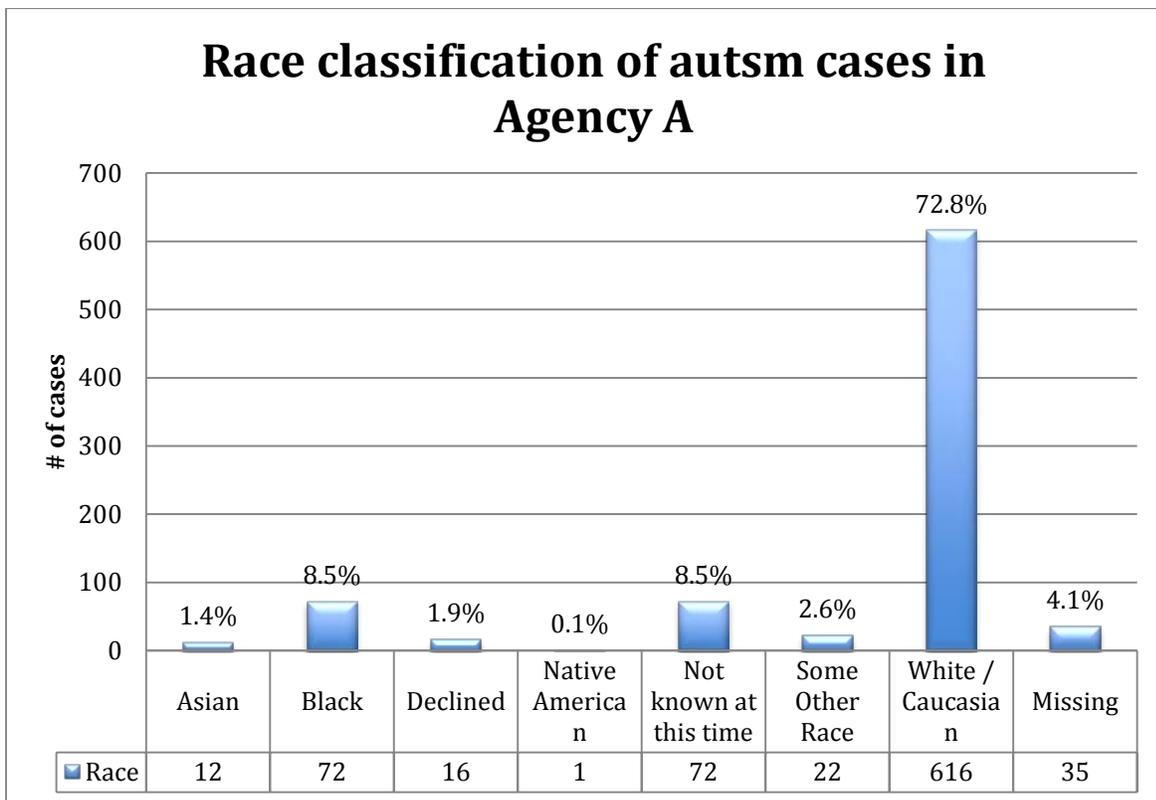|	Asian	Black	Declined	Native American	Not known at this time	Some Other Race	White / Caucasian	Missing
	1.4%	8.5%	1.9%	0.1%	8.5%	2.6%	72.8%	4.1%
Race	12	72	16	1	72	22	616	35

Figure 8. Race of Individuals with ASD in Agency A

The following table illustrates the county-specific demographic information based on the PA Autism Census Report and the demographic information from Agency A. There were 22 observations from Agency A that were missing the county designation and are placed at the bottom of the table. The number of cases identified in Agency A accounts for a fairly substantial percentage of all of the cases identified through the PA Autism Census Report, ranging from 11% of all cases in Westmoreland County to 28% of all cases in Allegheny County. The race and age distributions follow the same patterns, indicating that using treatment agency data could be a viable source for a surveillance system.

Table 1. Comparison of Agency A ASD Cases and Demographics to Surrounding Counties Data from the PA Autism Census Report

County/ Agency	# of Cases	Rate	Race		Age		Gender (% male)
Allegheny	2,234[15]	18.08 per 10,000[15]	White Black Asian/NA/PI Hispanic Missing	77.6% 15.1% 1.2% 0.5% 5.6% [15]	0-4 yrs.: 5-12 yrs.: 13-17 yrs.: 18-20 yrs.: 21+ yrs.:	15.9% 54.5% 17.5% 4.4% 7.7%[15]	80.3%[15]
Agency A (Allegheny)	624	N/A	White Black Asian/NA Declined/Other Missing	71.2% 10.9% 1.6% 4.8% 11.5%	0-4 yrs.: 5-12 yrs.: 13-17 yrs.: 18-20 yrs.: 21+ yrs.:	6.6% 57.2% 26.4% 8.5% 1.3%	81.3%
Butler	317[15]	17.41 per 10,000[15]	White Black Asian/ NA/PI Hispanic Missing	97.5% 0.9% 0.6% 0.3% 0.6%[15]	0-4 yrs.: 5-12 yrs.: 13-17 yrs.: 18-20 yrs.: 21+ yrs.:	12.6% 60.3% 15.8% 3.8% 7.6%[15]	83.6%[15]
Agency A (Butler)	53	N/A	White Declined Missing	85% 1.9% 13.2%	0-4 yrs.: 5-12 yrs.: 13-17 yrs.: 18-20 yrs.: 21+ yrs.:	1.9% 66.0% 26.4% 5.7% 0%	77.4%
Washington	308[15]	14.92 per 10,000[15]	White Black Asian/NA/PI Hispanic Missing	92.5% 4.9% 0.6% 0.3% 1.6%[15]	0-4 yrs.: 5-12 yrs.: 13-17 yrs.: 18-20 yrs.: 21+ yrs.:	18.6% 52.6% 18.3% 3.3% 7.2%[15]	79.2%[15]
Agency A (Washington)	68	N/A	White Black Declined/ Other Missing	75.0% 2.9% 4.4% 16.2%	0-4 yrs.: 5- 12 yrs.: 13-17 yrs.: 18-20 yrs.:	7.4% 51.5% 32.4% 5.9%	83.8%

Table 1 Continued

					21+ yrs.:	2.9%	
Westmoreland	658[15]	17.90 per 10,000[15]	White	93.6%	0-4 yrs.:	15.7%	80.2%[15]
			Black	3.6%	5-12 yrs.:	56.7%	
			Asian/ NA/ PI	0.2%	13-17 yrs.:	15.9%	
			Missing	2.6%[15]	18-20 yrs.:	4.0%	
					21+ yrs.:	7.8%[15]	
Agency A (Westmoreland)	73	N/A	White	76.7%	0-4 yrs.:	4.1%	75.3%
			Asian	1.8%	5-12 yrs.:	46.6%	
			Declined	1.8%	13-17 yrs.:	34.2%	
			Missing	20.5%	18-20 yrs.:	11.0%	
					21+ yrs.:	4.1%	
Agency A (county information missing)	22	N/A	White	68.2%	0-4 yrs.:	13.6%	86.4%
			Black	9.1%	5-12 yrs.:	50.0%	
			Asian	4.5%	13-17 yrs.:	27.3%	
			Other	13.6%	18-20 yrs.:	0.0%	
			Missing	4.5%	21+ yrs.:	9.1%	

A major limitation of the data presented in this paper is that it is not representative of the entire population of individuals with ASDs, only individuals referred to Agency A. Agency A provides treatment to individuals with autism in Southwestern Pennsylvania. The data from this agency cannot be generalized to the larger population because the agency only provides treatment to children and adolescents ages 2-21 and only began to provide services to adults in January of 2012.

2.1   DISCUSSION

The ability of autism treatment agencies to collect the type of information presented above could be the basis for a population based, passive surveillance system. While it would be more costly to implement this type of surveillance, the variances seen in the county-level data could be incredibly valuable for further research and evaluation in this highly prevalent and expensive public health issue. The mandatory use of Electronic Medical Records and the requirements put forth for meaningful use could help to ensure that a standardized set of data is captured and reported by all treatment agencies. Additionally, Electronic Medical Records usually have the capability to provide an export of defined fields that could be used for public health activities such as surveillance. Using a similar model for other reportable diseases, the provider could report identified cases for all children with an ASD diagnosis that turned 8 years of age within a given year to a local health department.

However, a major drawback to implementing a surveillance system based on treatment agency data would be that children with autism often obtain multiple services at a time and often use different agencies to obtain these services. For example, a common prescription for a child with autism would be to obtain speech therapy, Behavioral Health Rehabilitation Services (BHRS) which is a community based therapeutic service, and a social skills group. A child could receive speech therapy from the Children's Institute, BHRS from Family Behavioral Resources, and attend a social skills group from Wesley Spectrum Services. Because of the large number of autism treatment providers in Pennsylvania, obtaining an unduplicated count of individuals with autism could become fairly complicated using individual treatment provider data. With the Department of Public Welfare providing oversight of all of these treatment agencies, the department will have information on all of these children unless their families self-pay for

18

services or use only commercial insurance. Self-pay and commercial-only funding is not a common situation because in Pennsylvania, almost all children with an autism diagnosis are eligible to receive Medicaid without having to consider parental income when determining benefit eligibility. For this reason, the methodology used for the PA Autism Census Report would provide an infrastructure for a surveillance system that would offer more simplicity than using data from individual treatment providers, with a minimal trade-off for the sensitivity of the system.

2.2   CONCLUSION

Pennsylvania is continuing to fund activities to enumerate the number of individuals living with autism in the state. In 2013, the Autism Services, Education, Resources, and Training Collaborative (ASERT), a statewide initiative that is funded by the Bureau of Autism Services which is part of DPW, began work to update the findings of the 2005 PA Autism Census Report.[19] Using data for individuals receiving services in 2011, ASERT provided an updated count of individuals with ASD receiving services from DPW and PDE, and added the additional sources of data from the Office of Vocational Rehabilitation (OVR) and Department of Corrections and the Pennsylvania Commission on Crime and Delinquency.[20]

To transition to a proper surveillance system, the state would need to establish a narrower case definition for autism. The case definition should include children residing in Pennsylvania that turned eight years of age within the given surveillance year and are accessing services through DPW, PDE, OVR, or the Department of Corrections with a ICD-10 diagnosis of autism or education disability category of autism in order to be able to compare the data with national

trends. Though the methods for collection are slightly different, the CDC chose eight year olds for their case definition because that is the age children are most likely to access services so discrepancies might be minimal.[5]

To obtain an unduplicated count of cases, ASERT could gather the data from PDE annually. The information collected by DPW is protected under the Health Insurance Portability and Accountability Act (HIPAA)[21] and the Family Education Rights and Privacy Act (FERPA) protects the information collected by PDE.[22] Since HIPAA allows for protected health information to be disclosed for public health activities and FERPA does not, DPW will need to continue to send information to PDE so they can use the name, social security number, and date of birth to identify and remove duplicates using the same process that was completed for the PA Autism Census Report. ASERT is already analyzing and reporting on the update to the PA Autism Census Report so they could also analyze and report on the prevalence numbers captured by the surveillance system. Due to the fact that autism is a life-long disability, and does not require immediate action that is needed with some infectious diseases, the passive, occasional reporting will be appropriate for this surveillance system.[3] Annual reporting will also support one of the surveillance system's main goals of assisting policy makers with distributing resources if the data were available for the annual state budgeting process.

Individuals who are not receiving services from any of these systems will not be included in this system so it will likely underestimate the true prevalence of autism. However, the main goal of the system is to monitor trends over time and uncover county-specific differences to distribute resources and conduct research. If under-reporting is fairly consistent across counties, the surveillance system will still be able to meet this goal. When reporting the surveillance data, it would be helpful to provide information on the availability of services in the various counties

since areas that are underserved could result in a greater underreporting of cases. A major concern for this type of surveillance system would be related to consistency in interpretation of the diagnostic criteria. In the current CDC surveillance system, reviewers are well trained on the diagnostic criteria and interpret behaviors that constitute a diagnosis of ASD in a consistent fashion. Since there is not a biomarker available to diagnose ASDs, there is a potential for diagnosticians to interpret the DSM differently throughout the state, leading to a potentially inaccurate case count. However, there is still a great benefit to public health if the state creates a system that allows for ongoing monitoring of disease burden via the amount of state resources dedicated to treatment, educational and employment assistance, and corrections.

By utilizing the existing state activities and the lack of laws governing surveillance for autism, a surveillance system could be created with the voluntary participation of these governmental departments. By moving from a system of occasional reporting to an ongoing surveillance system, state policy makers and public health professionals will be better able to quantify the need for services in Pennsylvania across age groups while also identifying trends in prevalence and geographic differences. This type of information would allow public health leaders in state and local governments to properly budget for autism treatment. The demographic information contained within these reports would allow treatment professionals to plan for appropriate program development. The combination of surveillance data with other data sources on local exposures could allow Epidemiologists to develop and test hypothesis about the etiology of autism. Finally, trending the number of individuals with autism that necessitate public assistance over time could help public health professionals evaluate the effect of interventions and treatments in various geographic areas.

BIBLIOGRAPHY

1. Klaucke, D.N. et al. (May 6, 1988). *Guidelines for evaluating surveillance systems* (Morbidity and Mortality Weekly Report Supplement May 6, 1998 / 37(S-5); 1-18). Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/00001769.htm

2. Thacker, S.B. & Stroup. D.F. (2006). *Applied epidemiology: Theory to practice.* New York, NY: Oxford University Press.

3. Jamison, D.T. et al. (2006). *Disease control priorities in developing countries.* Washington DC: World Bank.

4. Centers for Disease Control and Prevention. (June 27, 2013). *Autism spectrum disorders: Data and statistics.* Retrieved from http://www.cdc.gov/ncbddd/autism/data.html

5. Centers for Disease Control and Prevention. (March 29, 2012). *Autism spectrum disorders: Autism and developmental disabilities monitoring (ADDM) network.* Retrieved from http://www.cdc.gov/ncbddd/autism/addm.html

6. Centers for Disease Control and Prevention. (August 17, 2009). *Autism spectrum disorders: Diagnostic criteria.* Retrieved from http://www.cdc.gov/ncbddd/autism/hcp-dsm.html

7. Centers for Disease Control and Prevention. (2012). *Prevalence of autism spectrum disorders-Autism and developmental disabilities monitoring network, 14 sites, United States, 2008* (Morbidity and Mortality Weekly Report March 30, 2012 / 61(SS03); 1-19). Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w

8. Avchen R.N. et al. (2011). Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 41,* 227-236. Doi: 10.1007/s10803-010-1050-7

9. Miller J.S. et al. (2013). Autism spectrum disorder reclassified: A second look at the 1980s Utah/UCLA autism epidemiologic study. *Journal of Autism and Developmental Disorders, 43(1),* 200-210. Doi: 10.1007/s 10803-01201566-0

10. American Psychiatric Association. (2012). *DSM-5 implementation and support.* Retrieved from http://www.dsm5.org/Pages/Default.aspx

11. American Psychiatric Association. (2013). *Autism spectrum disorder fact sheet.* Retrieved from http://www.psych.org/practice/dsm/dsm5

12. Autism Speaks. (2013) *DSM-5 diagnostic criteria.* Retrieved from http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria

13. Huerta, M. et al. (2012). Application of DSM-5 criteria for autism spectrum disorder to three samples of children with DSM-IV diagnoses of Pervasive Developmental Disorder. *American Journal of Psychiatry, 169,* 1056-1064. Doi: 10.1176/appi.ajp.2012.12020276

14. Windham GC et al. (2006). Autism spectrum disorders in relation to distribution of hazardous air pollutants in the San Francisco Bay area. *Environmental Health Perspectives, 114(9),* 1438-1444.

15. Centers for Disease Control and Prevention (June 19, 2012). *Autism spectrum disorders: Research.* Retrieved from: http://www.cdc.gov/ncbddd/autism/research.html

16. Centers for Disease Control and Prevention (2012). *The Pennsylvania autism and developmental disabilities surveillance program.* Retrieved from http://www.cdc.gov/ncbddd/autism/states/addm-pennsylvania-fact-sheet.pdf

17. Lawer, L. (2009). Pennsylvania autism census project: Final report. Retrieved from: http://bastraining.tiu11.org/pluginfile.php/1775/mod_resource/content/0/PA_Autism_Census_Project.pdf

18. Allegheny Health Choices Inc. (2013). *The Allegheny County Health Choices program 2012 year in review.* Retrieved from http://www.ahci.org/Reports/QuarterReports/2012Q4%20Report.pdf

19. PA Bureau of Autism Services (2013). *Pennsylvania autism census.* Retrieved from http://www.paautism.org/en-us/inpa/pennsylvaniaautismcensus.aspx

20. PA Bureau of Autism Services (December 2013). Pennsylvania autism census report: Updated December 2013. Retrieved from: http://www.paautism.org/desktopmodules/asert-api/api/item/ItemDetailFileDownload/416/PA%20Autism%20Census%20Study%20Overview_updated%20DEC2013.pdf

21. Department of Public Welfare (2013). *Your privacy rights (HIPAA).* Retrieved from: http://www.dpw.state.pa.us/yourprivacyrightshipaa/

22. Pennsylvania Department of Education (2013). *PIMS postsecondary information.* Retrieved from: http://www.portal.state.pa.us/portal/server.pt/community/pims__postsecondary/8960