

**Prevalence of Comorbidities in Middle-Aged and Older Adults Diagnosed with Autism Spectrum Disorder: A De-Identified Retrospective Review of Medical Records with Peer-Matched Comparison & Qualitative Review of Barriers Associated with Autism spectrum disorders in Adults**

by

**Cary Lee Zik**

Bachelor of Arts in Sociology, University of Pittsburgh, 1998

Submitted to the Graduate Faculty of the  
School of Public Health in partial fulfillment  
of the requirements for the degree of  
Master of Public Health

University of Pittsburgh

2022

UNIVERSITY OF PITTSBURGH

SCHOOL OF PUBLIC HEALTH

This thesis was presented

by

**Cary Lee Zik**

It was defended on

February 4, 2022

and approved by

Committee Member

Benjamin L. Handen, Ph D, M Ed

Professor

Department of Psychiatry

School of Medicine

University of Pittsburgh

Committee Member

Todd M. Bear, Ph D, MPH

Assistant Professor

Department of Behavioral & Community Health Science

Graduate School of Public Health

University of Pittsburgh

Thesis Director

Steven M. Albert, Ph D, MS

Professor

Department of Behavioral & Community Health Science

Graduate School of Public Health

University of Pittsburgh

Copyright © by Cary Lee Zik

2022

**Prevalence of Comorbidities in Middle-Aged and Older Adults Diagnosed with Autism Spectrum Disorder: A De-Identified Retrospective Review of Medical Records with Peer-Matched Comparison & Qualitative Review of Barriers Associated with Autism spectrum disorders in Adults**

Cary Lee Zik, MPH

University of Pittsburgh, 2022

Autism Spectrum Disorder (ASD) is a condition that has been recognized by the medical community for decades. However, the evolution of the diagnosis and lack of research regarding how ASD affects aging has created gaps in our understanding of ASD across the person's lifespan. In addition, the complexities and variations of ASD present challenges to the application of outcomes of research. This study examined electronic health records (EHR) of community-dwelling residents aged forty and over who sought care at UPMC facilities from January 1st, 2011, to December 31st, 2019. This study seeks to determine the prevalence of certain medical and neuropsychiatric disorders in patients with an ASD diagnosis and those without. Literature reviews have shown that this approach has been used in research prior to this study. While there is some agreement about certain health conditions being more prevalent in those with ASD, there are also conflicting results regarding others (such as whether substance abuse disorders disproportionately affect those with ASD). In our research, 1,995 controls were age and gender matched for comparison, with similar years for medical follow-up, using inverse probability weighting to achieve balance between the groups. The key findings from our EHR analysis were that while the control group was more likely to experience many of the physiological and cognitive disorders, there were statistically significant results that found those with ASD are more likely to develop anxiety, schizophrenia, and Alzheimer's disease. Our findings also suggest there is no significant difference in rates of mortality between the ASD and control populations. We also

completed two qualitative interviews with a support group leader and an individual with ASD to discuss barriers to care for those with ASD. The common themes of those interviews were the importance of utilizing technology to make interacting with medical providers more accessible and the need to increase the number of providers who are knowledgeable in providing care specifically tailored to the needs of individuals on the spectrum.

## Table of Contents

<b>Preface.....</b>	<b>ix</b>
<b>1.0 Introduction.....</b>	<b>1</b>
<b>1.1 Background.....</b>	<b>1</b>
<b>1.2 History of Autism .....</b>	<b>2</b>
<b>1.3 Brief Review of Current Knowledge.....</b>	<b>3</b>
<b>1.4 Gaps in knowledge.....</b>	<b>4</b>
<b>1.5 Literature Review.....</b>	<b>6</b>
<b>1.6 Methods .....</b>	<b>11</b>
<b>2.0 Results .....</b>	<b>15</b>
<b>3.0 Discussion.....</b>	<b>19</b>
<b>3.1 The Link Between ASD and Schizophrenia.....</b>	<b>22</b>
<b>3.2 The Link Between ASD and Alzheimer’s Disease .....</b>	<b>24</b>
<b>3.3 Qualitative Results Discussion.....</b>	<b>27</b>
<b>3.4 Limitations .....</b>	<b>34</b>
<b>3.5 Future Directions.....</b>	<b>35</b>
<b>Bibliography .....</b>	<b>36</b>

## List of Tables

<b>Table 1. Literature Review Table.....</b>	<b>7</b>
<b>Table 2. ASD Diagnoses Received by Cases in EHR Review .....</b>	<b>12</b>
<b>Table 3. ICD-9 and ICD-10 Codes Used in Analysis .....</b>	<b>13</b>
<b>Table 4. Matched Data Analysis .....</b>	<b>16</b>
<b>Table 5. Prevalence of Medical and Psychiatric Disorders Among Controls and Cases .....</b>	<b>16</b>

## List of Figures

<b>Figure 1. Raw and Matched BirthYears Balance Plot .....</b>	<b>17</b>
<b>Figure 2. Raw and Matched Birth Years Balance Plot .....</b>	<b>18</b>



## Preface

This thesis is the result of a process that would not have been possible without the assistance, input, and support of so many people. Many thanks to my committee members, Dr. Todd Bear, Dr. Benjamin Handen, and Dr. Steven Albert. Their insights and suggestions lead to a better final draft. Dr. Handen also graciously allowed me to interview him for an earlier project which provided direction for my thesis work. Dr. Albert, the Chair for this committee, has been invaluable as my professor, advisor, and collaborator throughout this process. This would not have been possible without him.

My deep appreciation is for the individuals who completed interviews for the qualitative section of this work. These people shared their experiences with me so freely and their candor and perspectives contributed to a better understanding of ASD in adulthood for me. This thesis benefitted from their thoughtful input.

I would also like to acknowledge the support from my colleagues at the University of Pittsburgh's Alzheimer's Disease Research Center. The encouragement and flexibility extended during this process kept me going towards the goal.

Finally, it takes a village, and I am forever grateful for my family for believing in me, even when I had difficulty believing in myself. Thank you all for allowing me to take the time to complete my master's degree and the support shown every day. I hope my sons have learned that anything is possible for them to achieve, and I hope they always reach for their dreams. I cannot repay my parents for all they have done over the years to help me reach this culmination, but the debt of gratitude I owe them will be paid forward to my own children. This is for you.

## **1.0 Introduction**

### **1.1 Background**

Autism spectrum disorder (ASD) is a complicated neurological condition that can range widely in severity but is commonly characterized by differences in social expression, highly developed interests, and greater adherence to routines and rituals. Although ASD is not a new disorder, there have been diagnostic criteria changes over time that seem to have impacted how ASD is classified. For example, ASD was thought to be a form of schizophrenia and was not separated from this condition until 1980. More recently, in the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV published in 1994, autism disorders had separate codes for Autistic Disorder, Asperger's, and Childhood Disintegrative Disorder. This changed in 2013 when DSM-5 included all three disorders under the umbrella of the autism spectrum disorder code (Herman, 2019). These changes may have led to increasing numbers of people, particularly children, being diagnosed than previous generations. By way of comparison, in the 1980s prevalence was reported as 4 in 10,000 while the Centers for Disease Control (CDC) now estimates 1 in 44 have an ASD diagnosis (Maenner et al, 2021; <https://www.cdc.gov/media/releases/2021/p1202-autism.html>). Given the lack of consistent diagnostic criteria over time, it makes it challenging to assess how ASD affects the aging process from a longitudinal perspective. Variations in symptoms and severity of ASD increase complexities in researching those on the spectrum. Some people who have ASD may be non-verbal or too impaired to participate in some research studies leading to non-coverage of those with severe ASD and a bias in research findings.

Some people who have ASD may be non-verbal or too impaired to participate in some research studies leading to non-coverage of those with severe ASD and a bias in research findings.

## **1.2 History of Autism**

At the onset, autism was initially linked to schizophrenia in the early 1900s by Dr. Eugene Bleuler. The first case of autism was documented in 1938 by Dr. Leo Kanner, in which a five-year-old boy named Donald Triplett was observed to have difficulty responding to others in his environment, decreased communication skills, and an intense focus on a few interests. The term “early infantile autism” was coined by Dr. Kanner in a 1943 article, “Autistic Disturbances of Affective Contact.” Around the same time, Dr. Hans Asperger was studying groups of children with profiles similar to those assessed by Dr. Kanner, but his focus was on children who were functioning at a higher level. (Baron-Cohen, 2015). Around the mid-1900s, autism was thought to be the result of poor parenting, particularly mothers not paying adequate attention to their children. This was contested in the 1960s by a psychologist named Bernard Rimland, who also was the father of a child with autism. It was not until the 1980s that autism and Asperger’s became more commonly known to the public. DSM-III, published in 1980, was the first edition DSM to include autism spectrum disorder (calling it “Infantile Autism”) (Ianelli, 2020).

The end of the century has led to the development of screening tools, particularly geared to the early diagnosis of children, and changes in diagnostic codes that evolved from separate codes to one inclusive code that encompasses all autism spectrum disorders. Although screening and diagnostic tools have been developed for adults and children, there is not a medical test that can definitively diagnose ASD. A commonly used screening tool for adults are the Autism Quotient

(AQ), developed in 2001 by Simon Baron-Cohen (Baron-Cohen,2001; Lundqvist, 2017). However, this is a self-diagnostic tool that is available to all online and might be used to facilitate discussion with medical providers. Another tool that can be used to diagnose ASD in adults is the Social Responsiveness Scale, Second Edition (SRS-2), developed by John M. Constantino in 2003. This tool is available for purchase to health care providers and can be used with individuals throughout the lifespan.

### **1.3 Brief Review of Current Knowledge**

There has been recent research that explores the prevalence of increased medical and psychiatric disorders in those with ASD. In 2019, Lauren Bishop-Fitzpatrick and Eric Rubenstein published an article, “The Physical and Mental Health of Middle-Aged and Older Adults on the Autism Spectrum and the Impact of Intellectual Disability”, which reviewed the de-identified claims of 143 Medicaid beneficiaries aged 40-88 with a diagnosis of ASD. This study compared the presence of various medical and psychiatric diagnoses in two groups. The two groups used for comparison were those with intellectual disability and those without intellectual disability. This study examined the presence of more conditions than our study, but there were conditions we studied as well, including hypertension, diabetes, cardiovascular disease, anxiety, dementia, depression, and schizophrenia. The authors concluded those with ASD were at risk for concurrent medical conditions, including “immune conditions, cardiovascular disease and its risk factors, sleep disorders, gastrointestinal disorders, neurologic conditions, and psychiatric disorders.” Furthermore, there was higher correlation between ASD and intellectual disability and epilepsy and higher correlation between ASD without intellectual disability and anxiety and depression.

Bishop-Fitzpatrick and Rubenstein noted “our findings suggest that people on the autism spectrum have a high prevalence of health conditions in midlife and old age, regardless of intellectual disability status” (Bishop-Fitzpatrick, 2019, p.40).

One of the common themes in the literature review was the assertion that those with ASD experience more anxiety and depression than the general population, along with other health problems, including Parkinson’s and schizophrenia. One of the most troubling statistics about those with ASD is the average life span. Studies have shown those with ASD have a life span about 16 years shorter than those in the general population. (“Premature mortality in autism spectrum disorder,” Hirvikoski, et al, 2018). This study found that although both men and women with ASD tended to experience higher mortality rates and at a younger age than the general population, there were differences along gender lines regarding causes. Males tended to succumb to “diseases of the nervous and circulatory systems” while females had higher rates of “endocrine diseases, congenital malformations, and suicide.”

#### **1.4 Gaps in knowledge**

Delay in diagnosis has multiple impacts that affect the well-being of adults with ASD, as well as impacting society. For example, cost of ASD care is expected to rise dramatically, from \$268 billion in 2015 to \$461 billion in 2025, according to Autism Speaks (<https://www.autismspeaks.org/sites/default/files/2018-09/autism-and-health-report.pdf>, 2017). Most of the cost of care will be used for services to adults rather than children. In the article “Brief Report: Forecasting the Economic Burden of Autism in 2015 and 2025 in the United States,” the authors state this figure was “calculated based on information on forecasted per-capita annual

growth in medical and non-medical expenditures, GDP, and population” (Leigh & Du, 2015). According to the Autism Society, if early diagnosis of autism occurs, two-thirds of costs associated with lifelong care can be reduced. It is estimated that only approximately 20% of adults with ASD are employed. Only about one-third of those with ASD will go to higher education after high school and of those a little over a third will graduate (<https://www.autism-society.org/what-is/facts-and-statistics/>). While there are school and community-based supports available for children with ASD, there remains limited formal support available for adults with ASD. This can become more challenging as those with ASD age because once reliable informal supports may no longer be available, for example, parental support will not always be present. In addition to the changes that aging brings, individuals with ASD will likely experience greater challenges than the general population (Perkins, 2012).

These challenges that affect adults on the autism spectrum are manifold and systemic. Yet despite these public health challenges that impact individuals with ASD, caregivers, and society at large, there is a dearth of research and research funding. Less than 2% of autism research funding is allocated for adult research. As the population ages, it will be critical to develop strategies and supports as well as gain a better understanding of physiological and psychiatric differences to assist those aging with ASD, particularly since it is estimated there will be 700,000 people with ASD turning age of sixty-five within the next twenty years.

Since little is known about the effects of ASD and aging, this analysis of EHRs comparing various medical and psychiatric disorders will allow us to examine if there may be a correlation between ASD and poorer health outcomes than experienced by neurotypical peers as people get older. This study hypothesizes that due to the challenges outlined here, people with ASD may experience greater health challenges as age increases.

## **1.5 Literature Review**

Articles for the literature review were found via Ovid, University of Pittsburgh Health Sciences Library System, PubMed, and online search engines such as Google. The search terms used were autism spectrum disorders/ or autistic traits, asd or asperger\* or (pervasive adj1 development\*) aged sixty-five or older or middle age 40 64 or very old 85 yrs. older. The terms autism and aging were used as well. However, the results that were returned with less specific search terms about autism and aging tended to include results about “aging out” of supports for those with ASD when they reach the age of eighteen.

The literature review has yielded results that include recent studies that have used a similar study design as the one used here. There have been studies that examine the prevalence of comorbidities, and the findings generally share a consensus that those with ASD are at greater risk for multiple medical, psychiatric, and neurological conditions. The review also examined articles that discussed the experiences of receiving a diagnosis later in life and utilization of services among adults with ASD. Table 1 describes articles reviewed.

**Table 1. Literature Review Table**

<b>Article Title, Author, Year Published</b>	<b>Topic/ Focus Question</b>	<b>Sample</b>	<b>Methods</b>	<b>Results/Outcome</b>	<b>Future Research/Limitations</b>
“Psychiatric and Medical Profiles of Autistic Adults in the SPARK Cohort” (Fombonne, et al, 2020)	What are the rates of medical and psychiatric morbidities in adults with ASD as reported by caregiver	2917 dependent adults with formal ASD diagnosis in the SPARK cohort with twenty-one clinical sites in the United States	Quantitative study utilizing clinical sites that collected specimens and online questionnaires completed by caregivers	Those with ASD are more vulnerable than the general population for multiple health conditions, but there were also some differences noted along lines of gender and age. Females tended to have more psychiatric diagnoses than their male counterparts. Those older than thirty tended to have higher incidences of intellectual disability and language impairment than younger cases	No control group was used for comparison. It should be noted that these conditions were reported by caregivers of dependent adults with ASD. Also, most of the sample) included individuals aged 30 and younger (N=2630), while there was a limited number of responses for those 40 and over (N=70).
“The health status of adults on the autism spectrum” (Croen, et al; 2015)	What is the frequency of psychiatric and medical conditions among adults with ASD	1,507 adult cases and 15,070 adult controls enrolled in the Kaiser Permanente health system in Northern California	Quantitative retrospective case and control review of EHRs through Kaiser Permanente from 2008-2012	Their findings indicated that the ASD group was at higher risk of physiological and behavioral disorders than controls.	Over half of their sample was 18-24 with a mean age of twenty-nine. Additionally, one-fifth of the sample was also diagnosed with intellectual disability



**Table 1. Literature Review Table (continued)**

<p>“Living with Autism Without Knowing: Receiving a Diagnosis in Later Life” (Stagg &amp; Belcher, 2019)</p>	<p>What is the impact of receiving a diagnosis of ASD in adulthood?</p>	<p>Nine participants aged 52-54 who had received an ASD diagnosis within the past ten years through National Health Service in the United Kingdom</p>	<p>Qualitative study utilizing free-associative narrative interview technique</p>	<p>The article discusses the awareness of being different from peers, how it felt to receive a diagnosis as an adult, integration of the diagnosis into self-awareness, and lack of follow-up support for those individuals who received a diagnosis later in life and their acknowledgement of how therapy would have helped them with adjustment post-diagnosis</p>	<p>One of the suggestions made by the authors based on the participant’s responses was for health care providers to consider ASD as a diagnosis for older adults seeking out medical intervention for “anxiety, depression, and mental health issues along with failure to achieve in employment or lack of employment.”</p>
--	---	---	---	---	--

**Table 1. Literature Review Table (continued)**

<p>“Missed diagnoses and misdiagnoses of adults with autism spectrum disorder” (Fusar-Poli, et al, 2020)</p>	<p>Evaluation of the psychiatric history of those who received their first ASD diagnosis in adulthood</p>	<p>161 participants aged eighteen and older who had not received an ASD diagnosis and were referred to Italian university centers for evaluation</p>	<p>Retrospective analysis of 161 participants clinical charts through December 2019 followed by clinical assessment by psychiatrist utilizing ASD screening tools and standardized psychiatric assessment tools</p>	<p>Individuals with ASD had originally received a different mental health disorder diagnosis and experienced a median delay of 11 years before receiving an ASD diagnosis. This was even more prevalent in females than males and thought to be due to the phenotype presenting differently in women than men and different coping techniques. The authors also found there was less anxiety in this sample (6.2%) than found in meta-analysis (20%)</p>	<p>Multiple factors, including provider unfamiliarity and symptom overlap, can lead to a differential diagnosis of a different psychiatric disorder</p>
<p>“Health Care Service Utilization and Cost Among Adults with Autism Spectrum Disorder in a U.S. Integrated</p>	<p>Do adults with ASD utilize health care services more frequently than adults with ADHD and adults in</p>	<p>ASD cases=1507 ADHD cases=9042 General population=15,070</p>	<p>Case/control study using database to determine health care utilization among cases with ASD, controls with ADHD, and general population</p>	<p>Those with ASD have “significantly higher utilization of primary care, mental health, and laboratory services” than either the ADHD or general population groups. The cost of healthcare was greater</p>	<p>There may have been confounding disabilities present in control population; results were not broken down among those with ASD and intellectual disability and those without intellectual disability, authors suggest future research</p>

**Table 1. Literature Review Table (continued)**

Health Care System (Zerbo, et al, 2019)	the general population?	18 years of age and older enrolled in Kaiser Permanente Northern California health system		for adults with ASD than either comparison group. However, females with ASD were less likely to receive gynecological care	
“Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults” (Hand, et al; 2019)	Are those with ASD at greater risk for physical and mental health conditions?	4,685 cases 46,850 controls	Cross-sectional retrospective cohort study of national Medicare recipients	Cases were found to have higher rates of almost all physical and mental health conditions than controls	The authors suggest future longitudinal studies to determine outcomes of medical and psychiatric conditions
“Anxiety and depression in adults with autism spectrum disorder: a systemic review and meta-analysis (Hollocks, et al; 2018)	Are adults with ASD at greater risk of developing anxiety and depression?	30 Studies measuring anxiety- n=26,070; 29 studies measuring depression- n=26,117 in adults with ASD	Systematic review and meta-analysis of studies published between January 2000 and September 2017	Pooled analysis demonstrated current anxiety disorder as 27%, lifetime prevalence was 42%; current rate of depression as 23%, lifetime prevalence was 37%	The authors suggest future studies examining prevalence of psychiatric disorders among those with ASD in non-clinical settings

## 1.6 Methods

The research design we employed was a retrospective case and control chart review. This method was chosen because this allowed us to compare a sample of adults who have a diagnosis of ASD to adults with the same criteria without an ASD diagnosis. De-identified medical records were obtained from the University of Pittsburgh Medical Center (UPMC) health care system. To maintain confidentiality of medical records, the data was extracted by Health Record Research Request (R3). R3 is an honest broker for the use of UPMC clinical data. Once the data had been extracted, an arbitrary number was assigned to the patient's records. The data was reviewed to compare medical diagnoses of patients aged forty and over who have received an ASD diagnosis with the diagnoses of age and gender matched peers from January 1st, 2011, to December 31st, 2019, in the UPMC system.

The medical records included individuals who have received a diagnosis of Autistic Disorder (299.00/299.0), Childhood Disintegrative Disorder (299.10/299.1) or Asperger's Disorder (299.80/299.8) based on DSM-IV; Autism Spectrum Disorder (299.0) based on DSM-V, Autistic Disorder (299.0) based on ICD-9, and Autistic Disorder (F84.0) based on ICD-10. Our n=402 and although there were 683 total ASD diagnoses in our sample, these are the first ASD diagnoses in the records. Almost 70% of our sample of cases was diagnosed with Autistic disorder, current or active state. Other specified pervasive developmental disorders comprised almost 30%. Three patients' first diagnostic code in the EHR was Childhood disintegrative disorder, current or active state. (Table 2). The non-ASD control group was obtained through a random pull of EHR records based on the R3 inclusion/exclusion criteria. There were 402 patients in our case cohort and 1608 for our control cohort. In our review of EHRs there were only 950 patients without any ASD diagnosis that were an exact match for our criteria, which was age, gender, and place of

service. The age imbalance was adjusted using propensity score matched analysis and related approaches with the “treatment effects” module in STATA. Results were then replicated in R. The main R packages used were "tableone" and "Matching."

**Table 2. ASD Diagnoses Received by Cases in EHR Review**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Autistic disorder, current or active state	281	69.9	69.9	69.9
	Childhood disintegrative disorder, current or active state	3	.7	.7	70.6
	Other specified pervasive developmental disorders, current or active state	118	29.4	29.4	100.0
	Total	402	100.0	100.0	

**Table 3. ICD-9 and ICD-10 Codes Used in Analysis**

Condition	ICD-9	ICD-10
Schizophrenia	V11.0, 295	F20*
Diabetes	V12.21, V18.0, V77.1, 250*, 253.5, 357.2, 588.1,648/648.04, 775.1	E08*, E09*, E10*, E11*, E13*, E23.2, N25.1, O24*, P70.0, P70.2, Z13.1, Z83.3, Z86.32
Hypertension	V81.1, 401, 401.0, 401.1, 401.9, 405, 405.0, 405.9, 405.91, 405.99, 416.0, 572.3, 642, 642.3, 997. 91	G93.2, H40.05, I10, I15*, I27/I27.29, I87.3/I87.399, I97.3, O10*, O11*, O12, O13*, O16*, P29.2, P29.30, R03.0
Heart Disease, Unspecified	429.9	I51.9
Stroke	429.9, 431, 433, 434/434.1, 437/437.4, 767.0, 851/851.8, V53.01	G46, G46.8, I67, I67.8/I67.9, I68, I68.8, I69, I69.8*, I69.9, I97.8/I97.821
Obesity	278/278.03, 649.10/649.14, V77.8	E66/E66.01, E66.09, E66.1, E66.2, E66. 8, E66.9, O99.21/O99.215
Anxiety	293.84,300/300.09, 309.21/309.28	F06.4, F10.180, F10.280, F10.890, F12.180, F12.280, F12.980, F13.180, F13.280, F13.980, F14.180, F14.280, F14.980, F15.180, F15.280, F15.980, F16.180, F18.180, F18.280, F18.980, F19.180, F19.280, F19.980, F40, F40.8, F40.9, F41*, F43.22, F43.23, F93.0
Depression	290.13, 290.21, 296.22, 296.8, 301.12, 309.1, 311, V79.0	F06.31, F06.32, F25.1, F32*, F33*
Parkinson's Disease	O94.83, 332, 332.1, 996.4, E936.4	G20, G21*, T42, T42.8
Dementia	290.0, 290.10, 290.4/290.43, 291.2, 292.82, 294.1/294.11, 331.19, 331.82	F01, F01.5*, F01, F02.8*, F03, F03.9*, F10.27, F10.97, F1.27, F13.97, F18.17, F18.27, F18.97, F19.27, F19.97, G31, G31.09, G31.83
Alzheimer's Disease	331.0	G30*

In addition to obtaining quantitative data, we wanted to evaluate how adults with an ASD diagnosis perceive their own health care experiences. Two qualitative interviews were conducted in partnership with a Pittsburgh area group of adults with ASD. This group was found searching for <https://paautism.org> resource guide. The convener of the group was contacted. Members of the group agreed to learn more about the research being conducted and, if interested in participating, were contacted to be consented. The planned approach involved semi-structured interviews with a community-based participatory research component. Participants were free to decide if they wanted to take part in a focus group, individual interviews, or both.

Two qualitative interviews were completed to explore how adults in the Pittsburgh area are experiencing health care through the lens of ASD. These interviews explored the topics of access to care and related health disparities. Although attempts were made to consent additional participants, recruitment efforts were not successful.

## 2.0 Results

Cases and controls were matched using inverse probability weighting in R and STATA (Table 4). The covariates used were the last year of receiving medical care through a UPMC facility, birth year, gender, and race. Mean age of controls was 65.3 and mean age of cases was 59.2. The age range of cases was 40-96. The sample was primarily Caucasian, with 84.2% of controls and 86.7% of cases. The sample was mostly male, with 58.5% of controls and 72% of cases being male. The higher percentage of cases who are male is not a surprising statistic as the male-to-female ratio of those with ASD is 4:1 (Loomes, et al, 2017). The percentage of deaths was 24.8% of controls and 20.4% of cases. Both cases and controls had close to six years of follow-up during the time studied. The percentage of those who received care in 2019, the last year of EHRs reviewed, was 58.5% of control and 60% of cases. Controls demonstrated higher rates of diabetes, hypertension, heart disease, stroke, and depression while cases demonstrated higher rates of anxiety, schizophrenia, and Alzheimer's disease (Table 5). There were no significant differences between the groups in rates of Parkinson's disease and other dementias. Figures 1-2 show that the matching procedure produced adequate balance between groups, with birth year as an example (standardized mean difference < .1).



**Table 4. Matched Data Analysis**

1/1/2011-12/31/19 period of UPMC contact						
Age 40-96 with and without ASD diagnosis						
Covariates for matching (inverse probability weighting, STATA):						
last year receiving medical care, birth year, gender, race						
Check for covariate balance in case and control groups						
Initial covariate status						
	<b>control</b>	<b>case</b>	<b>p</b>			
<i>n</i>	1995	402				
age	65.3	59.2	<0.001			
race, white %	84.2	86.7	NS			
male, %	54.6	72	<0.001			
deaths, %	24.8	20.4	0.06			
follow-up, yrs	5.98	5.62	0.02			
2019 med care, %	58.5	60	NS			

**Table 5. Prevalence of Medical and Psychiatric Disorders Among Controls and Cases**

	control, %	case, %	p		
Anxiety	41.1	48.9	<.001		
Schizophrenia	3.7	16.0	<.001		
Obesity	33.4	27.7	0.039		
Diabetes	40.2	31.3	0.005		
Hypertension	72.9	62.2	<.001		
Heart disease	6.6	3.0	<.001		
Stroke	10	5.4	0.002		
Depression	30.2	29.0	NS		
Parkinson's	2.1	2.1	NS		
Dementia	6.7	6.7	NS		
Alzheimer's	1.8	5.1	0.02		

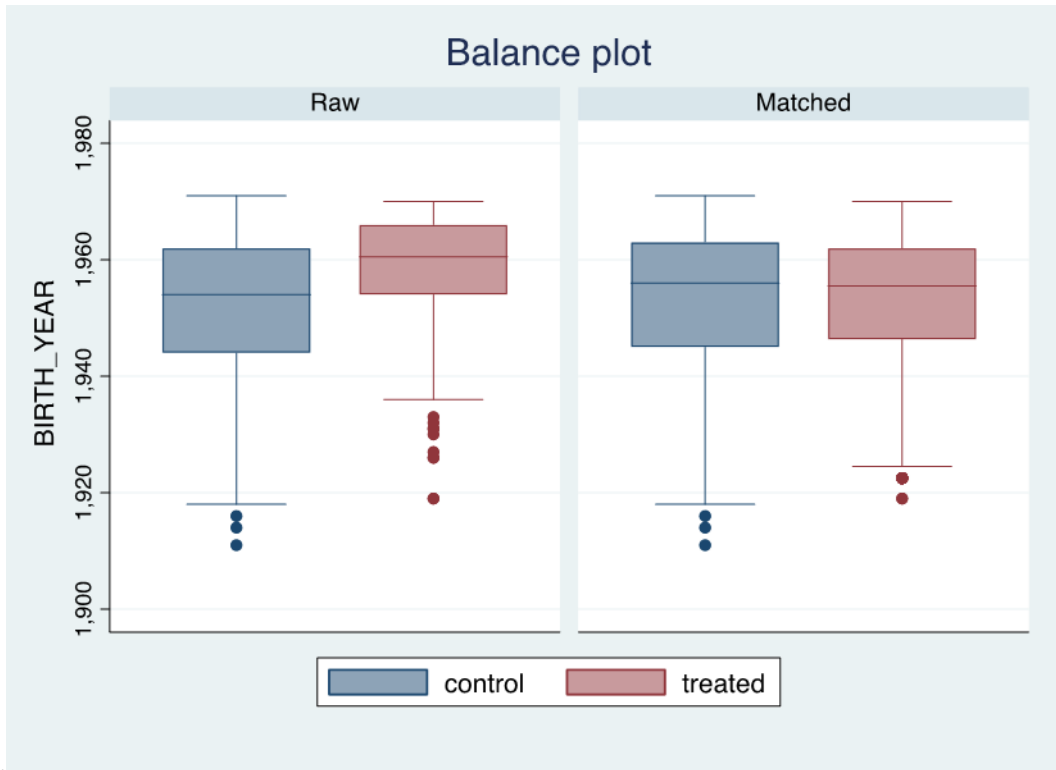
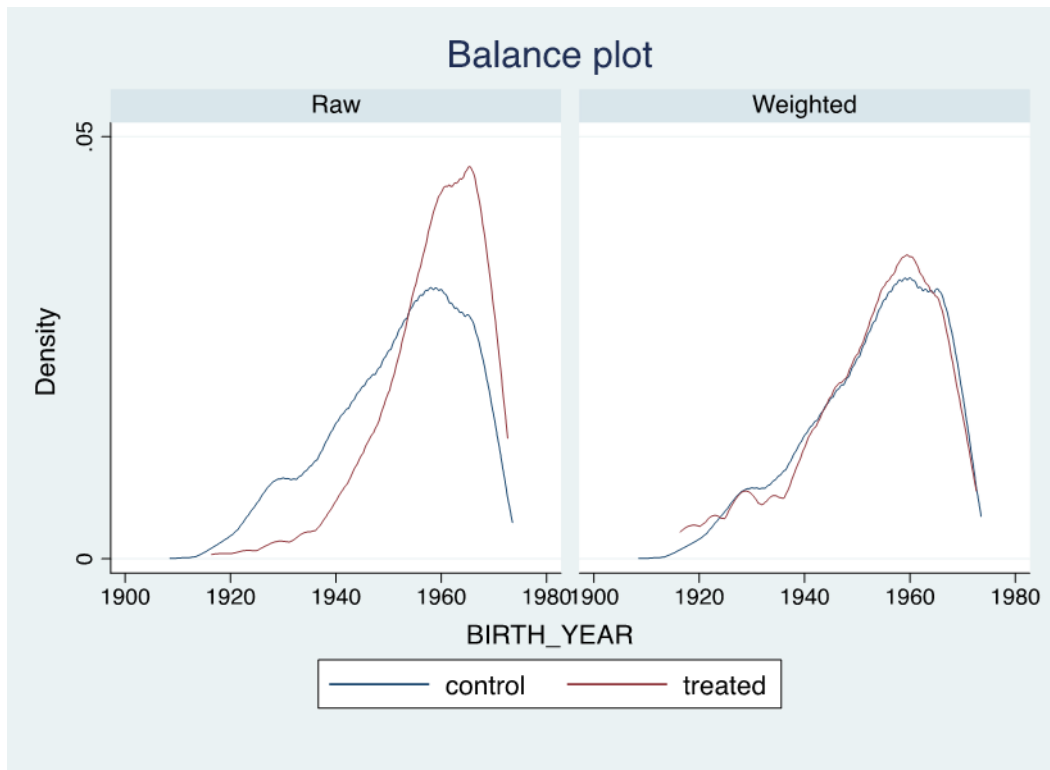


Figure 1. Raw and Matched BirthYears Balance Plot



**Figure 2. Raw and Matched Birth Years Balance Plot**

### 3.0 Discussion

Although we hypothesized that those with ASD are at higher risk of medical and psychiatric disorders, this was not necessarily the case across all conditions. In our sample, controls had higher rates of obesity, diabetes, hypertension, heart disease, and stroke. Cases were more likely to have schizophrenia, anxiety, and Alzheimer's disease. Our findings were different from some similar studies that utilized EHRs to examine the prevalence of conditions in those with ASD.

“Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults” (Hand, et al; 2019) discussed a cross-sectional retrospective cohort study that reviewed the medical conditions of Medicare patients aged sixty-five and over. Many of the health conditions included in Hand's study were also examined in our study. Although there were some findings that were in line with our findings, there were others that were not; however, it should be noted that the cohort examined was older than ours. One of their findings that may have been affected by the age of the cohort was the prevalence of cognitive disorders (25.2% for those with ASD vs. 4.9% for controls).

“The health status of adults on the autism spectrum” (Croen, et al; 2015) is another study that was also a case and control review of EHRs that was conducted through Kaiser Permanente from 2008-2012. The authors compared records of 1,507 cases to 15,070 controls. Their findings indicated that the ASD group was at higher risk of physiological and behavioral disorders than controls. However, over half of their sample was 18-24 with a mean age of twenty-nine and one-fifth of the sample was also diagnosed with intellectual disability. Although the results of our study

indicated differences in findings in rates of prevalence of conditions between cases and controls, it may be that those in our sample are healthier.

Another important result to note is that we did not find any significant difference in rates of mortality in our sample as shown in Table 6. These rates adjusted for birth cohorts and were like our findings in our raw data, which found that 24.8% of controls died compared to 20.4% of cases. The adjusted rates found that 24.30% of controls and 20.15% of cases died during the period of records reviewed.

However, it should be noted that the sample used in our research was predominantly white males who are most likely from a similar geographical area and who had survived to middle and older ages. One of the articles reviewed for this paper was “A Scoping Review of Health Disparities in Autism Spectrum Disorder” (Bishop-Fitzpatrick & Kind, 2017). The authors conducted a review of multiple studies and noted disparities in care regarding race, socioeconomic status, gender, and geographical location. Most of the studies that were reviewed in their article included children rather than adults and examined the utilization and availability of various health care services for those with ASD. The authors noted that older adults with ASD should be a focus of future research and expressed that “while the evidence characterizing physical health and beyond in ASD is being built, evidence about the impact of health disparities in ASD needs to be concurrently established.” As current cohorts of people with ASD age, we will hopefully be able to gain insight into these changes. As the qualitative interviews noted, autism affects all kinds of people and the ability to assess the specific needs of the wide variety of those impacted is new ground that will need to be explored.

Another potential explanation for the difference in our finding regarding no significant impact of ASD diagnosis and lifespan vs. other studies from our literature review is that it is

possible that those individuals who were included in our review in our quantitative data were older with an ASD diagnosis but had less health and functional difficulties at a younger age and were able to perform ADLs than others who have more profound health condition. In an article “Mortality in Individuals with Autism Spectrum Disorder: Predictors over a 20-year Period” (Smith DaWalt, et al; 2019), the authors studied a cohort of 406 individuals with ASD from 1998-2018 and found that “6.4% of the cohort died during the 20-year follow-up period, and the average age of death was 39 years” (Smith DaWalt, et al). This study examined the presence of intellectual disability, health status, ability to perform ADLs, and autistic behaviors. Individuals who had shorter lifespans tended to be in poorer health, had difficulty performing daily tasks, experienced intellectual disability and had fewer typical social responses to others. There were multiple causes of death, from natural causes such as cancer to accidental causes, choking and seizures. The age of our cohort was older, with cases having a mean age of about sixty, and while we did not investigate factors like intellectual disability, health quality, and severity of ASD symptoms, we may surmise there are factors that may have led to a healthier cohort examined in this study. Another consideration is that our records were obtained from a population that was accessing health care and living in or around a mid-size urban area with many local hospitals and various community health care providers. These results may not be able to be extrapolated to other populations that may have less access to health care, such as those who live in rural areas with fewer providers and more transportation challenges.

Therefore, this is a variable that warrants additional study. As Smith DaWalt noted, although there are some factors that are not able to be modified, such as intellectual disability, others may be modified through interventions and treatment, thereby potentially reducing early mortality rates for those with ASD.

One unexpected result was the prevalence of smoking in cases vs. controls. There was a significant difference here between the two groups. During the period of analysis, 10.2% of those with ASD were current smokers while 26.9% of controls were current smokers. However, these findings are consistent with an article published in 2003, “Low prevalence of smoking in patients with autism spectrum disorders” (Bejerot & Nylander, 2003). The authors found that 12.9% of those with ASD were smokers compared to 19% of controls. There was a larger difference with the Pittsburgh area sample with the p-value < .001. Although this may not influence some of the conditions we reviewed, it is possible that the higher prevalence of smoking among controls may have had an adverse impact on the health of our control population and also explain the higher percentage of deaths among controls in the period studied.

### **3.1 The Link Between ASD and Schizophrenia**

The prevalence of schizophrenia in those with ASD was 16% vs. 3.7% in those without. The rate we found was four times higher in the ASD population than the general population. This is consistent with the results from the literature review conducted. In the article “Association Between Schizophrenia and Autism Spectrum Disorder: A Systematic Review and Meta-Analysis” (Zheng, et al; 2018), the prevalence was from “3.4 to 52%”. As noted earlier, there are multiple factors that are considered to contribute to the development of ASD and many of these are also thought to lead to schizophrenia as well. Furthermore, there is the historic association between the two conditions. These have since been considered two separate diagnoses, but there appear to be enough commonalities between the two to indicate more than a causal relationship. Some of the common risk factors that are present in both conditions are pre-birth factors, including

age of the father and amount of pregnancy weight gained. Neuroimaging has suggested there may be similarities in brains of those with ASD and schizophrenia. In the article “Association Between Schizophrenia and Autism Spectrum Disorder: Systematic Review and Meta-Analysis,” the authors state “These two disorders exhibit lower gray matter volumes in the limbic-striato-thalamic circuitry than controls. Furthermore, abnormalities of the fusiform gyrus and amygdala are associated with a deficit in emotional perception processing in both schizophrenia and ASD” (Zheng, 2018, p. 1116). Another commonality is the presence of additional disorders, including anxiety, which was more prevalent in our cases than our controls (Buckley, 2009; Trevisan, 2020). In the article “Autism Spectrum Disorder and Schizophrenia Are Better Differentiated by Positive Symptoms than Negative Symptoms,” the authors note that “individuals with ASD are 3.55 times more likely to have a concurrent diagnosis of SZ than controls. Further complicating diagnostic precision, both disorders often co-occur with other conditions” including depression and anxiety (Trevisan, 2020).

Although this is a significant finding, it should be noted that since ASD has shared a diagnostic history with schizophrenia and since autism was not classified as a separate disorder until DSM-III in 1980, those in the sample may have received diagnosis of schizophrenia. In the article “Autism Spectrum Disorder and Schizophrenia: Do They Overlap?,” the authors note, “Looking at the classification of autism in the Diagnostic and Statistical Manual of Mental Disorders (DSM), it appears that in the first edition (DSM-I, APA, 1952, the diagnosis of autism did not exist and children with autistic symptoms were classified with a diagnosis of ‘schizophrenic reaction, childhood type’” (Barlati, 2016). The age group of our sample was born prior to 1980, therefore, those with an ASD diagnosis may have received a diagnosis of schizophrenia prior to the diagnostic separation of the two conditions.



### 3.2 The Link Between ASD and Alzheimer's Disease

The most significant finding from the data from the EHRs after the cases and controls were matched was the difference in prevalence of Alzheimer's disease in cases, at 5.1% vs. 1.8% in controls with a difference of 3.3% and a p-value=0.02. The data examined showed a mean age of diagnosis of Alzheimer's disease in the control group of 79.8 years and 70.9 in those with an ASD diagnosis. Using time to diagnosis, cases were twice as likely as controls to receive an Alzheimer's disease; 6% vs. 3% per 10,000 follow-up years with p-value of .03.

Alzheimer's disease was discovered in 1906 by Dr. Alois Alzheimer in a patient that presented with changes in memory, personality, and speech. The presence of amyloid plaques and tau tangles were noted in the patient's brain after her death. There are multiple similarities between ASD and Alzheimer's disease (AD). Both are neurological disorders that are increasing in prevalence. According to the Alzheimer's Association, there are 6.2 million people living with AD in the United States in 2020 and is projected to affect 12.7 million by 2050 (<https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>). The current cost associated with AD is \$355 billion dollars. As noted earlier in this paper, the prevalence and fiscal impact of ASD is also expected to continue to increase.

Alzheimer's disease is one of the "most common neurodegenerative disorders" (Jesko, 2020) and is characterized by "deposits of misfolded, aggregated proteins in the central nervous system" with "extensive accumulation of amyloid" and the "main single risk factor is aging". (Jesko, 2020).

The pathogenesis of both ASD and AD is still being determined and likely has multiple factors. Neurobiological lesions have been found in brains of those with ASD through various modalities, including imaging and autopsy. These findings include atypical neural connectivity, as

well as increased brain size (Augustyn, 2020). Dr. Augustyn wrote, “Compared with individuals without ASD, individuals with ASD have different total and regional gray and white matter volumes, sulcal and gyral anatomy, brain chemical concentrations, neural networks, cortical structure and organization, and brain lateralization” ([https://www.uptodate.com/contents/autism-spectrum-disorder-terminology-epidemiology-and-pathogenesis?search=autism%20&source=search\\_result&selectedTitle=6~150&usage\\_type=default&display\\_rank=6](https://www.uptodate.com/contents/autism-spectrum-disorder-terminology-epidemiology-and-pathogenesis?search=autism%20&source=search_result&selectedTitle=6~150&usage_type=default&display_rank=6)).

One of the similarities between ASD and AD, as well as schizophrenia, is impaired autophagy (Sragovich, 2017). ASD and AD are “partially associated with an imbalance of cholesterol homeostasis that leads to changes in the membrane cholesterol and oxysterol levels that, in turn, modulate key steps in the synaptic transmission” (Petrov, et al, 2017). Therefore, there could be a link between ASD and Alzheimer’s due to differing neural connectivity and poor regulation of brain cell communication. Also, in the article “Dysfunctional proteins in neuropsychiatric disorders: From neurodegeneration to autism spectrum disorders,” the authors note, “Alterations in key neurodegeneration – associated proteins such as A $\beta$ , tau, and probably  $\alpha$ -syn – are increasingly implicated in ASD etiopathology and might turn up as potential targets for autism research and possibly treatment” (Jesko, et al, 2020). Another point to consider is that socialization is thought to be a protective factor against AD and since decreased social behaviors are a hallmark of ASD, there is the possibility of reduced protective effects in those with ASD for developing AD.

While AD continues to be studied and remains enigmatic, the neurological impact of ASD in adults as they age remains even more ambiguous. Since there is limited research on older adults with ASD, there is little known about brain changes and the prevalence of neurological comorbidities. A literature review conducted on PubMed using the search term “Autism Spectrum

Disorder & Alzheimer's in Older Adults" yielded only thirty-two results. One of the articles reviewed was "Behaviors Characteristic of Autism Spectrum Disorder in a Geriatric Cohort with Mild Cognitive Impairment or Early Dementia" (Rhodus, et al; 2019). The authors asked caregivers of older adults with memory changes to complete rating scales that measured behaviors characteristically associated with ASD. The results were that individuals who scored higher for more characteristics tended to develop cognitive changes earlier and had more severe memory changes. Additional searches were conducted in PittCat using the term "aging memory changes & autism." This search yielded 13,245 results. One of the articles reviewed was "Age-related Differences in Cognition across the Adult Lifespan in Autism Spectrum Disorder" (Lever & Guerts, 2016). The authors "observed similar or reduced age -related differences across the lifespan in ASD...having an ASD diagnosis might be a protective factor to typically observed age-related decrease in functioning" and "ASD may indeed be a safeguard for age-related cognitive decline" (Lever & Guerts, 2016). ASD as a protective factor was a theme that continued throughout the literature review. In their article "Hyperplasticity in Autism Spectrum Disorder confers protection from Alzheimer's disease (Oberman & Pascual- Leone, 2013), the authors conducted their experiment on individuals with Asperger's Syndrome and controls using Theta Burst Stimulation to measure corticospinal excitability and their finding was that hyperplasticity serves as a protective factor against cognitive decline. The authors also searched a database to determine how many people had a diagnosis of dementia and ASD. Their finding was "out of the 265 patients over 55 with ASD that there were less than 10 individuals who had a comorbid diagnosis of AD or related dementia" (Oberman & Pascual-Leone, 2013). By contrast, we believe the results from the electronic health records have yielded significant findings with the most important result being that ASD is a risk factor for developing Alzheimer's disease as people age. Our results are in line

with the articles that indicate the presence of biological factors that are associated with ASD, AD, and other neurological disorders, including Parkinson's disease and schizophrenia. Our comparison of case vs. controls may be superior in that it is less affected by biases in clinical studies without comparison groups. We believe this is the first study that has found this result.

### **3.3 Qualitative Results Discussion**

Regarding the qualitative data, there was limited response from the group approached to complete interviews. Although a few group members reached out via email and received a copy of the consent form to review, only one participant completed a Zoom interview with me. However, this interview did yield insight into this participant's experiences with health care. The participant is a 32-year-old Caucasian male who received a formal diagnosis when he was in third grade, around the age of eight. He endorsed concurrent medical diagnoses of Type II diabetes and obsessive-compulsive disorder (OCD). When asked if he has ever delayed seeking medical care, he said he has "never denied [himself] medical care and has never needed anything as extreme but [he] still [goes] in for individual therapy on a regular basis." When asked about his experiences with interactions with medical staff, he stated that these interactions have "on average been at least adequate." However, he did endorse having negative experiences as well. One of the situations he described was having two practitioners, a psychologist, and a psychiatric nurse practitioner, who did not communicate directly with each other and relied on him to relay information. He noted that this is one of the reasons he stopped seeing these providers. Therefore, it seems that one of the barriers he experienced was challenges to communication that became a burden to the patient. A recommendation would be that if there are multiple care providers treating an ASD patient, there

should be a consensus shared amongst them for the best treatment plan, ideally developed along with the patient.

The interview with the licensed counselor who works with adults on the spectrum yielded many insights as well. One of the things we discussed was how age of diagnosis can affect an individual. Because autism was not diagnosed as frequently years ago, those who have experienced ASD without diagnosis until adulthood have learned how to survive in a neurotypical world but may experience greater mental health issues as they age. The support group leader pointed out that ASD is thought of a childhood disorder and as such, there are services that are multiple services that are provided to them, but once these children grow into adulthood, these services are no longer available and self-advocacy is generally not taught as a life skill as individuals age out of these supports. She stated that ASD is not a condition that people grow out of, but one they learn to live with. These challenges may be barriers to healthcare as supports are limited and asserting oneself may be difficult to do for those with ASD.

The support group leader noted that frequently ASD is not considered as a diagnosis for an adult until strategies developed to survive in a neurotypical world become too much to bear and “autistic burnout” occurs. Autistic burnout is described by Raymaker et al. (2020) as “a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus”. She noted this is more common in those who are born female because girls are taught to socialize in diverse ways than boys and this can cause symptoms of ASD to look different in females. One of the “camouflaging” techniques employed more commonly in females is adapting to the social cues provided by others around you, such as laughing along with a group, even if one is unsure of the reason (Schuck, et

al., 2019). Other examples of gender differences we discussed in the interview were that males tend to display classic symptoms of ASD, such as “pulling back [socially], less social, and less eye contact” and develop an intense focus in one area. Females will tend to observe others for their social cues and copy that behavior, eye contact may be more prolonged, and interests tend to be more varied.

She also noted that testing for autism is based on how autism presents in males rather than females, so this leads to women getting diagnosed much later than men. She said women can reach their 20s or 30s before they can no longer handle the pressure of hiding who they are. Alternatively, once a woman becomes a mother whose child receives an ASD diagnosis, she recognizes the symptoms in herself reflecting on her own childhood. The support group leader noted that it is common for those who are biological males to receive a formal ASD diagnosis. She stated that self-diagnosis and later diagnosis is much more common in biological females. She said that self-diagnosis among women has become more accepted, and this is due in part to the fact that the screening tools that are available are generally for use with children and the tools for adults have been established for male symptoms. She said that other barriers to formal diagnosis as an adult are the expense, noting it can cost up to \$6,000 and is rarely covered by insurance, as it is considered a mental health service. She also said that medical providers may dissuade people from “put[ting] that label on yourself,” particularly when seeking a diagnosis as an adult.

One of the other barriers to care for those with ASD is in the medical community itself. The support group leader noted that unless mental health care providers independently study autism during their education, they will not be educated in treating individuals with ASD. The lack of providers who can work with patients with ASD creates another challenge in seeking mental health services. This is also a problem with general practitioners. In one study, 1,000 health care

providers were interviewed, and the findings showed uncertainty regarding how to treat patients with ASD, particularly adults. (Wright, 2015). This is an issue that needs to be addressed at the community level among healthcare providers and medical training facilities. The support group leader stated that finding a therapist that is well-versed with working with those on the autism spectrum is “few and far between.” We also discussed utilization of health care services among adults with ASD. She noted that she finds that people with ASD will seek care when it is needed, but if providers are not asking the right questions or it is difficult for the patient to describe their symptoms to the provider, there may be barriers to care. She said clients may put off scheduling an appointment because of the steps that are needed to get there, such as contacting the office staff. She also talked about the uncertainty of not knowing what to expect at an appointment and how procedures may not be communicated effectively by the providers.

The support group leader also discussed how ASD seems to affect the LGBTQ community with higher rates of frequency than the cisgender, straight population. Studies have found that those who identify as a different sex than the one “they were assigned at birth are three to six times as likely to be autistic than cisgender people” (Dattoro, 2020). It is estimated that 15- 35% of people with ASD identify as gay, lesbian, or bisexual (Pecora, 2016). This intersectionality is important to note because this can impact frequency and quality of healthcare. In the article, “Health Disparities Among Sexual and Gender Minorities with Autism Disorder,” the authors discuss the increased challenges and poorer outcomes that are experienced by those with ASD and identifying as LGBTQ. Participants in the interviews that were captured in this article discussed having less access to care and insurance, but also noted refusal of care from some providers. One of the findings in this article was that adults who are both LGBTQ and autistic have significantly higher rates of mental illness and psychiatric disorders than those with ASD who non-LGBTQ are

(78.9 vs. 34.3). (Hall, et al; 2020). However, in the article “Autistic Traits in Treatment-Seeking Transgender Adults” (Nobili, et al; 2018), the authors note that “transgender individuals’ extreme marginalization and vulnerability might lead them to experience increased psychological, health, and especially social isolation, when compared to other social groups.” The impact this may have on the screening tool used by the authors of this article, the autism spectrum quotient short (AQ-short), may be increased self-report of symptoms due to the social challenges imposed by cisgender society.

Another topic we discussed was the impact of technology in accessing information and care. We talked about the impact of social media on adults with ASD and she said that this is a positive thing and closed support groups are helpful resources to learn more about the symptoms of ASD and allow people to recognize themselves and discuss with others in a safe environment. We also discussed the increase of video technology, like Zoom, and she said it has been a boon to those on the spectrum accessing health care services, particularly when seeking therapy services. She said that having control of keeping the camera turned off and being in one’s own familiar space allows her clients to connect on their own terms, and they have expressed how they like the shift to video conferencing. The pandemic has perhaps affected those on the spectrum in different ways than the neurotypical world. The support group leader said that for the past year, many people with ASD have been able to stay in their own homes and have not had to “mask” their autism symptoms. The reopening of society is challenging to those who have been comfortable in their own space and may contribute to escalating anxiety and depression. However, now that this technology is widely available and accepted, this may be helpful to those on the spectrum to continue to receive healthcare from providers over Zoom.



There were common themes that were found throughout the literature review and supported by our two qualitative interviews regarding barriers to care for those with ASD. One of the articles reviewed was “Service Needs Across the Lifespan for Individuals with Autism” (Turcotte, et al; 2016). Their article was based on the study, Pennsylvania Autism Needs Assessment Survey, and featured the results of a survey administered to caregivers of people in Pennsylvania with an ASD diagnosis. The demographic breakdown of their sample was similar to ours, with 81% of cases being male and 89% being Caucasian. Most responses received were from suburban and rural areas, with only 17% of respondents from urban areas of Pennsylvania. There was a response rate of about 12%, with a total of 3,440 surveys completed. The majority of those were from caregivers of those in high school and younger, but 467 (about 14%) were received from caregivers of adults aged 19-59. The authors noted that services were most received by children and once people age out of pediatric-based services, fewer services are available to adults. The services that were least likely to be received by adults were speech and language therapy, social skills training, medication management, occupational therapy, and one-to-one support. Mental health therapy was also less likely to be received by adults with ASD.

Using the social-ecological model as a starting point, we can see multiple challenges to accessing care. On the first level, looking at the individual, there are multiple factors that impact access to care. Certainly, socioeconomic status will function as a barrier to healthcare in adults with ASD, as many adults receive their health insurance through employment. The outcomes for employment for those with ASD are bleak, with some estimates of unemployment being as high as 85%. Gender identification may play a role as well. As noted earlier, those who identified as female tend to be diagnosed at a later age, if they receive a formal diagnosis at all. Those who identify as males may be less likely to seek mental health services. Racial identity may also have

an impact. African American children tend to be diagnosed less frequently and later than Caucasian counterparts. In their article “Racial Disparities in Autism Diagnosis,” the Organization for Autism Research noted that Hispanic children were “65% less likely” and African American children “19% less likely” to be diagnosed. African American children were “5.1 times more likely to be misdiagnosed with a behavior disorder” than Caucasian children (<https://researchautism.org/racial-disparities-in-autism-diagnosis>). This recent observation and reflection on how awareness of ASD has increased only recently in the last few decades begs the question how often ASD has been missed in populations with decreased access to health care and interventions and how this has impacted outcomes. Another factor that may impact access to care is difficulty with communication and decreased ability for self-advocacy.

On the interpersonal level of the social-ecological model, one of the barriers to healthcare may be the lack of adequate informal caregivers and fewer peer relationships. A report from Drexel University shows that about half of adults with ASD are living with a family member (Roux, et al, 2017). As these individuals age, people who provided care throughout their lifespan, particularly parents, will likely predecease their child, resulting in the loss of care, support, and advocacy.

For the community level of the social ecological barriers, it was noted that healthcare providers are a key element to care. However, both the qualitative interviews and literature review suggest that there is an inadequate number of healthcare providers trained in caring for and communicating with adults with ASD. While younger people with ASD have supports through school and community resources, these services are not as readily available for adults with ASD. In their article “Service Needs Across the Lifespan for Individuals with Autism (Turcotte, et al; 2016), the authors note that “the unmet needs of adults with ASD could suggest the capacity for providers to deliver these services to adults needs further development or that mechanisms to

provide and fund the delivery of these services to adults are not yet in place” (Turcotte, 2016, p. 2487).

This brings us to our next level of the social ecological model, the societal level. There are systemwide barriers to services for adults with ASD. Turcotte’s article notes that Pennsylvania has a waiver program in place for those with ASD, but there are requirements for income and level of functionality as well as a waitlist for services for adults. Moreover, as the support group leader noted, mental health services are not always covered by insurance and the cost for an autism diagnosis in adulthood can cost up to \$6,000 out-of-pocket. As those with ASD age, there will need to be more public policies in place to support and aid them.

### **3.4 Limitations**

The data harvested from the EHRs may not necessarily be representative of the population. Our data was extracted using diagnostic codes and there is the possibility that the diagnostic code may not be accurate. There was limited data available on non-white patients due to the sample results. This data may not be able to be extrapolated to all patient populations.

Another limitation of this study may be the healthy survivor effect. Those with ASD who survive to middle and later ages have avoided many health issues and mortality associated with ASD. This may explain the lower prevalence of comorbidities in our cases than controls.

There was limited participation in the qualitative reviews. The individual that completed an interview demonstrates a more typical experience for those on the spectrum; male gender with a formal diagnosis received during childhood. This may not reflect the experiences of others who are female, transgender, non-Caucasian, received a diagnosis later in life, or are self-diagnosed.

### 3.5 Future Directions

It seems clear that there is much more research to be done to increase our understanding of the aging process's impact on individuals with ASD. One of our recommendations for future studies is to strive for more diverse populations in ASD research to determine how racial identity, gender identity, and orientation, intersects with aging with ASD. Ideally, there will be longitudinal studies that include neuroimaging and additional procedures to examine brain structure and presence of amyloid, tau, and biomarkers to further strengthen the link between ASD and Alzheimer's disease.

Our qualitative data was not as robust as we had expected. Our interviews were limited due to recruitment failure. A suggestion for future researchers is to utilize technology to promote recruitment among those with ASD. Establishing a presence on Facebook, Instagram, and other social media outlets where individuals can choose to participate at their convenience, with the expectation of privacy and with limited risk might increase recruitment. There are also now mobile apps available to assist with recruitment and retention of participants.

The challenges facing those aging with ASD can be mitigated by increasing resources and services across the lifespan. Medical facilities and schools should develop and implement curriculum to educate health care professionals to treat patients with ASD. Health insurance plans should ensure that there are an adequate number of providers available for patients. Finally, there should be diagnostic tools developed that are more inclusive of age, gender, racial identity, and ethnic culture.

## Bibliography

- Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2021;17(3) Retrieved from <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>
- American Psychiatric Association (1980) *Diagnostic and Statistical Manual of Mental Disorders* (3<sup>rd</sup> ed.)
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed.).
- Augustyn, Marilyn (2020) Autism spectrum disorder: Terminology, Epidemiology, and pathogenesis Retrieved from [https://www.uptodate.com/contents/autism-spectrum-disorder-terminology-epidemiology-and-pathogenesis?search=autism%20&source=search\\_result&selectedTitle=6~150&usage\\_type=default&display\\_rank=6](https://www.uptodate.com/contents/autism-spectrum-disorder-terminology-epidemiology-and-pathogenesis?search=autism%20&source=search_result&selectedTitle=6~150&usage_type=default&display_rank=6)
- Autism Prevalence Higher in CDC's ADDM Network, 12/1/2021. Retrieved from <https://www.cdc.gov/media/releases/2021/p1202-autism.html>
- Autism Society (2015) *Facts and Statistics*. Retrieved from <https://www.autism-society.org/what-is/facts-and-statistics/>
- Autism Speaks (2017) *Autism and Health: A Special Report by Autism Speaks, Advances in Understanding and Treating the Health Conditions that Frequently Accompany Autism*. Retrieved from <https://www.autismspeaks.org/sites/default/files/2018-09/autism-and-health-report.pdf>.
- Barlatti, Stefano, DeSete, Giacomo, Ariu, Cassandra, & Vita, Antonio (2016) *Autism Spectrum Disorder and Schizophrenia: Do They Overlap?* *International Journal of Emergency Mental Health and Human Resilience*, Vol. 18 No. 1, pp. 760-763
- Baron-Cohen, Simon, et al. *The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/High-Functioning Autism, Males and Females, Scientists and Mathematicians*. 31: *J Autism Dev Disord* 5-17. 2001.
- Baron-Cohen, Simon. (2015). *Leo Kanner, Hans Asperger, and the discovery of autism*. Retrieved from *Leo Kanner, Hans Asperger, and the discovery of autism – The Lancet*. DOI: [https://doi.org/10.1016/S0140-6736\(15\)00337-2](https://doi.org/10.1016/S0140-6736(15)00337-2)
- Bejerot, Susanne & Nylander, Lena (2003) *Low prevalence of smoking in patients with autism spectrum disorders*, *Psychiatry Research* Vol 119, Issues 1-2: 177-182

- Bishop-Fitzpatrick, Lauren & Kind, Amy J.H (2017) A Scoping review of Health Disparities in Autism Spectrum Disorder, *J Autism Dev Disord*, 47:3380-3391, DOI: 10.1007/s10803-017-3251-9
- Bishop-Fitzpatrick, Lauren & Rubenstein, Eric (2019) The Physical and Mental Health of Middle-Aged and Older Adults on the Autism Spectrum and the Impact of Intellectual Disability, *Research in Autism Spectrum Disorders*, 63:7,34-41, <https://doi.org/10.1016/j.rasd.2019.01.001>
- Buckley, Peter F., et al. "Psychiatric Comorbidities and Schizophrenia." *Schizophrenia Bulletin*, vol. 35, no. 2, Oxford University Press, 2009, pp. 383-402, <https://doi.org/10.1093/schbul/sbn135>.
- Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities (2020) Data and Statistics on Autism Spectrum Disorder Retrieved from <https://www.cdc.gov/ncbddd/autism/data.html>
- Constantino, JN, Gruber CP (2012). *Social Responsiveness Scale, Second Edition (SRS-2)*. Torrance, CA: Western Psychological Services
- Croen, Lisa A., et al. (2015) The health status of adults on the autism spectrum, *Autism*, Vol 19(7) 814-823
- Dattoro, Laura (2020) Largest Study to Date confirms overlap between autism and gender diversity, *Spectrum*, 15 September 2020, <https://www.spectrumnews.org/news/largest-study-to-date-confirms-overlap-between-autism-and-gender-diversity/>
- Diagnostic and Statistical Manual of Mental Disorders: DSM-IV. (1994). Washington, DC: American Psychiatric Association
- Fombonne, Eric, Green Snyder, LeeAnne, Daniels, Amy, Feliciano, Pamela, Chung, Wendy, The SPARK Consortium (2020) Psychiatric and Medical Profiles of Autistic Adults in the SPARK Cohort, *Journal of Autism and Developmental Disorders*, 50:3679-3698, <https://doi.org/10.1007/s10803-020-04414-6>
- Fusar-Poli, Laura, Brondino, Natascia, Politi, Pierluigi, & Aguglia, Eugenio (2020) Missed diagnoses and misdiagnoses of adults with autism spectrum disorder, *European Archives of Psychiatry and Clinical Neuroscience*, <https://doi.org/10.1007/s00406-020-01189-w>
- Hall, Jean P., Batza, Katie, Streed Jr., Carl G., Boyd, Brian A., & Kurth, Noelle K. (2020) Health Disparities Among Sexual and Gender Minorities with Autism Disorder, *Journal of Autism and Developmental Disorders*, 50: 3071-3077
- Hand, Brittany N., Angell, Amber M., Harris, Lauren, & Arnstein Carpenter, Laura (2020) Prevalence of physical and mental health in Medicare-enrolled, autistic older adults, *Autism* Vol. 24(3) 755-764; DOI:10.1177/136261319890793
- Herman, Ellen (2019) Autism in the DSM, 1952-2013 | The Autism History Project ([uoregon.edu](http://uoregon.edu))

- Hirvikoski, Tatja, et al. (2016) Premature mortality in autism spectrum disorder, *The British Journal of Psychiatry*, 208, 232-238, doi: 10.1192/bjp.bp.114.160192
- Hollocks, MJ, Lerh JW, Magiati I, Meiser-Stedman R, Brugha TS. (2019) Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological Medicine* 49, 559-572. <https://doi.org/10.1017/S0033291718002283>
- Ianelli, MD Vincent (2020) A History and Timeline of Autism, VeryWell Health, updated 11/30/2020 Retrieved from <https://www.verywellhealth.com/autism-timeline-2633213>
- Jesko, Henryk, Cieslik, Magdalena, Gromadzka, Grayzna, & Adamczyk, Agata (2020) Dysfunctional proteins in neuropsychiatric disorders: From neurodegeneration to autism spectrum disorders *Neurochemistry International* 141 104853
- Kanner, Leo (1943) Autistic Disturbances of Affective Contact *Nervous Child* 2:217-250
- Leigh, J. Paul & Du, Juan (2015) Brief Report: Forecasting the Economic Burden of Autism in 2015 and 2025 in the United States, *Journal of Autism and Developmental Disorders* 45, 4135-4139
- Lever, Anne G. & Geurts, Hilde M. (2016) Age-related Differences in Cognition across the Adult Lifespan in Autism Spectrum Disorder, *Autism Research*, 9: 666-676
- Loomes, Rachael, Hull, Laura, Polmear, William, & Locke, Mandy (2017) What is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis, *J Am Acad Child Adolesc*, 56:6, 466-471
- Lundqvist, Lars-Olov, and Helen Lindner. "Is the Autism-Spectrum Quotient a Valid Measure of Traits Associated with the Autism Spectrum? A Rasch Validation in Adults with and Without Autism Spectrum Disorders." *Journal of autism and developmental disorders* vol. 47,7 (2017): 2080-2091. doi:10.1007/s10803-017-3128-y
- Maenner MJ, Shaw KA, Bakian AV, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. *MMWR Surveill Summ* 2021;70(No. SS-11):1–16. DOI: <http://dx.doi.org/10.15585/mmwr.ss7011a1external icon>
- Nobili, Anna et al. (2018) Autistic Traits in Treatment-Seeking Transgender Adults, *Journal of Autism and Developmental Disorders*, 48: 3984-3994, <https://doi.org/10.1007/s10803-018-3557-2>
- Oberman, Lindsay M. & Pascal-Leone, Alvaro (2014) Hyperplasticity in Autism Spectrum Disorder confers protection from Alzheimer's disease, *Medical Hypotheses*, 83: 337-342
- Organization for Autism Research (2018) Racial Disparities in Autism, *The Oracle*, 4 Dec 2018, Retrieved from <https://researchautism.org/racial-disparities-in-autism-diagnosis>

- Pecora, Laura A., Mesibov, Gary B., & Stokes, Mark A. (2016) Sexuality in High-functioning Autism: A Systematic Review and Meta-analysis, *J Autism Dev Disord*, 46: 3519-3556, DOI: 10.1007/s10803-016-2892-4
- Perkins, Elizabeth A. & Berkman, Karen A. (2012) Into the Unknown: Aging with Autism Spectrum Disorders, *American Journal on Intellectual and Developmental Disabilities* Vol. 117, No. 6, 478-496, DOI:10/1352/1944-7558-117.6.478
- Petrov, A.M., Kasimov, M.R., & Zefirov, A.L. (2017) Cholesterol in the Pathogenesis of Alzheimer's, Parkinson's Diseases and Autism: Link to Synaptic Dysfunction, *Acta Naturae* Jan-Mar 9 (1): 26-37
- Raymaker, Dora M. et al. (2020) "Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout, *Autism Adulthood*, 2:2, 132-143, <https://doi.org/10.1089/aut.2019.0079>
- Rhodus, Elizabeth K. et al (2019) Behaviors Characteristic of Autism Spectrum Disorder in a Geriatric Cohort With Mild Cognitive Impairment or Early Dementia. *Alzheimer Dis Assoc Disord* 2020; 34:66-71
- Roux, Anne M., Rast, Jessica E., Anderson, Kristy A., and Shattuck, Paul T. National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, 2017; Retrieved from [https://drexel.edu/~media/Files/autismoutcomes/publications/Natl%20Autism%20Indicators%20Report%202017\\_Final.ashx](https://drexel.edu/~media/Files/autismoutcomes/publications/Natl%20Autism%20Indicators%20Report%202017_Final.ashx)
- Schuck, Rachel K., Flores, Ryan E., Fung, Lawrence K. (2019) Brief Report: Sex/Gender Differences in Symptomology and Camouflaging in Adults with Autism Spectrum Disorder, *Journal of Autism and Developmental Disorders*, 49: 2597-2604, <https://doi.org/10.1007/s10803-019-03998-y>
- Smith DaWalt, Leann, Hong, Jinkuk, Greenberg, Jan S. & Mailick, Marsha R. (2019) Mortality in Individuals with Autism Spectrum Disorder: Predictors over a 20-year Period, *Autism*, 23:7, 1732-1739, DOI: 10.1177/136236131927412
- Stagg, Steven D. & Belcher, Hannah (2019) Living with autism without knowing: receiving a diagnosis in later life, *Health Psychology and Behavioral Medicine*, 7:1, 348-361, DOI: 10.1080/21642850.2019.1684920
- Scott D. Wright, Cheryl A. Wright, Valerie D' Astous & Amy Maida Wadsworth (2019) Autism aging, *Gerontology & Geriatrics Education*, 40:3, 322-338, DOI: 10.1080/02701960.2016.1247073
- Sragovich, Shlomo, Merenlender-Wagner, Avia, & Gozes, Illana (2017) ADNP Plays a Key Role in Autophagy: From Autism and Schizophrenia and Alzheimer's Disease, *BioEssays* 2017, 39, 1700054 DOI: 10.1002/bies.201700054



- Trevisan DA, Foss-Feig JH, Naples AJ, Srihari V, Anticevic A and McParland JC (2020) Autism Spectrum Disorder and Schizophrenia Are Better Differentiated by Positive Symptoms Than Negative Symptoms *Frontiers in Psychiatry* *Front. Psychiatry* 11:548. doi:10.3389/fpsy.2020.00548
- Turcotte, et al. (2016) Service Needs Across the Lifespan for Individuals with Autism, *J Autism Dev Disord*, 46:2480-2489
- Wright, Jessica (2015) Primary Care Doctors Unprepared to Help Adults with Autism, *Spectrum*, 16 May 2015, <https://www.spectrumnews.org/news/primary-care-doctors-unprepared-to-help-adults-with-autism/>
- Zerbo, Ousseney et al. (2019) Health Care Utilization and Cost Among Adults with Autism Spectrum Disorder in a U.S. Integrated Health Care System, *Autism in Adulthood*, 1:1, DOI:10.1089/aut.2018.0004
- Zheng, Zhen, Zheng, Peng, Zou, Xiaobing (2018) Association Between Schizophrenia and Autism Spectrum Disorder: A Systematic Review and Meta-Analysis, *Autism Research*, 11: 1110-1119