Spring 4-16-2024

Potential for Telehealth Support to Improve Access to Care: A Needs Assessment Using Heat Maps of Ed Use and Avoidable Hospitalizations for the I/Dd Population in South Carolina

Daphanie Dean
Medical University of South Carolina

Recommended Citation

Dean, Daphanie, "Potential for Telehealth Support to Improve Access to Care: A Needs Assessment Using Heat Maps of Ed Use and Avoidable Hospitalizations for the I/Dd Population in South Carolina" (2024). *MUSC Theses and Dissertations*. 873.
https://medica-musc.researchcommons.org/theses/873

POTENTIAL FOR TELEHEALTH SUPPORT TO IMPROVE ACCESS TO CARE: A NEEDS ASSESSMENT USING HEAT MAPS OF ED USE AND AVOIDABLE HOSPITALIZATIONS FOR THE I/DD POPULATION IN SOUTH CAROLINA

BY

Daphanie J. Dean, MHA

A doctoral project submitted to the faculty of the Medical University of South Carolina
in partial fulfillment of the requirements for the degree
Doctor of Health Administration
in the College of Health Professions

Abstract of Doctoral Project Presented to the
Medical University of South Carolina
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Health Administration

POTENTIAL FOR TELEHEALTH SUPPORT TO IMPROVE ACCESS TO CARE: A NEEDS ASSESSMENT USING HEAT MAPS OF ED USE AND AVOIDABLE HOSPITALIZATIONS FOR THE I/DD POPULATION IN SOUTH CAROLINA

by

Daphanie J. Dean, MHA

Chairperson:	Dunc Williams, MHA, Ph.D.
Committee:	Kit N Simpson, Dr.PH.
	Laura Carpenter, Ph.D.

ACKNOWLEDGEMENTS

First and foremost, I am grateful to my husband, Craig Jenkins, for his support over the last three years. Weekly sacrifices to complete coursework invariably became yours, as my life centered around assignment deadlines and the semester calendar. Thank you so much for your patience and flexibility. I am beyond ready to find our new normal!

Thank you to my family. To mom, Andrea, and Belinda. Thank you for being there for me every step of the way and believing in me when I didn't believe in myself.

I had the most fantastic doctoral project committee! Thank you, Dunc, for your mentorship and encouragement. I am honored to have worked with you for the past few years. I cannot tell you how much I appreciate the opportunities you have opened up for me. I am truly grateful. To the incomparable Dr. Kit Simpson: I am fortunate to have worked with you in the short time we collaborated on this project, and I learned so much! I hope we can see this study through to publication. There are so many avenues for us to explore! Thank you again, Dr. Carpenter, for lending your time and expertise to this dissertation. It was important to me to include a researcher with deep knowledge and experience with the I/DD community. You fit in just perfectly, and your feedback was very much appreciated.

I am incredibly grateful for every member of Cohort 22. I am proud of how far we came from that first anxiety-filled day and am excited to see what we will accomplish next.

Thank you to the MUSC College of Health Professions faculty and staff. Attending MUSC was an incredible experience, and I attribute this to the professionalism and hardworking individuals who work for the University.

Last but not least, to God be the glory. No step I took was without him by my side.

DEDICATION

To Joshua – you have inspired me to face my fears and given me purpose. I truly hope this work makes an impact. Let's continue to move mountains together, you and I.

TABLE OF CONTENTS

Table of Contents

1 CHAPTER I BACKGROUND AND NEED

Two healthcare issues plague the population of intellectually and developmentally disabled (I/DD) population in the United States. First, research has documented that people with I/DD are high utilizers of non-emergent healthcare services and are frequently hospitalized for conditions that are treatable by a primary care provider (PCP) in an office setting (Yamaki et al., 2019). Furthermore, despite a considerable percentage of the I/DD population qualifying for Medicaid, access to primary care is inadequate and inequitable (Yamaki et al., 2019).

A developmental disability is defined as follows:

“A severe, chronic disability of an individual that: (a) is attributable to a mental or physical impairment or a combination of mental and physical impairments; (b) is manifest before the individual attains age 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in 3 or more major life activity areas; and (e) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, and other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated (DD Act, Sec. 102. (8)(A))” (Schalock et al., 2019).

Disorders associated with developmental disabilities include intellectual disabilities, autism, attention deficit disorder, down syndrome, fragile X syndrome, and cerebral palsy (Johnston et al., 2022). The etiology of developmental disabilities often stems from genetic anomalies or neurological or environmental conditions that permanently limit an individual's social or cognitive development (Johnston et al., 2022).

The American Association of Intellectual and Developmental Disabilities (AAIDD) defines an intellectual disability as "a condition characterized by significant limitations in both intellectual functioning and adaptive behavior." (AAIDD, n.d., para 1). Impairments may also affect an individual’s ability to perform in the classroom and model typical social behaviors (Johnston et al., 2022). When the developmental disability and intellectual disability terms are combined, we refer to this group of individuals as the intellectual and developmental disability (I/DD) population.

Although the actual prevalence is unknown, there are estimated to be over seven million people in the United States with I/DD, representing approximately 2% of the U.S. population (Centers for Disease Control & Prevention [CDC], 2023). In 2020, the Medicaid and CHIP Payment and Access Commission (MACPAC) reported that over 5 million of the diagnosed I/DD population are children and slightly more than two million adults (MACPAC, 2020). The 2016 study conducted by McKenzie et al. suggests that the differences in the distribution of I/DD cases between age groups can be explained by recent changes in diagnostic criteria, provider awareness, and changes in “exposure to known risk factors” (p. 104).

1.1 Problem Statement

Until September 26, 2023, the National Institute of Health's Office of Minority Health (OMH) officially designated the disability population as a group with significant health disparities. The OMH also established a need for additional research focused on health-related inequities (Stable-Perez & Valdez, 2023. Adults with I/DD receive less preventative care through annual visits, preventive screenings, and immunizations while also experiencing higher morbidity and mortality rates than the general population in the United States (Ruiz et al., 2019). Of the number of people in the U.S. living with disabilities, nearly 13% have cognitive deficits (NIMHD, 2023). Notably, adults with I/DD are also less likely to receive equitable or quality care than non-disabled adults in the United States (Friedman, 2021) despite needing comprehensive care due to multiple comorbidities (Landes et al., 2021). Access to health services for I/DD patients typically narrows after the transition from pediatric-based care to family care settings (Bryan et al., 2023). A popular framework developed by Pechansky and Thomas (1981, as cited in Hsiang et al., 2019) posits that healthcare access is related to the affordability and availability of treatment. For the I/DD population, the inequalities are compounded by the severity of their disability and social determinants such as lack of education, employment status, and transportation challenges (Hsiang et al., 2019). This disparity "is seen in care as AIDD (Adults with Intellectual and Developmental Disabilities) suddenly face barriers of low provider availability, decreased time with providers, uncoordinated care between specialties, and an inadequate healthcare infrastructure" (Bryan et al., 2023). Further complicating access to care in South Carolina, The county health rankings and roadmaps website (2023) reports fewer primary care providers per SC resident than the national average.

Just over 50% of adults with disabilities classify their health as only fair or poor (NIMHD, 2023). Intellectually disabled adults have higher rates of diabetes, obesity, hypertension, and mental health issues than the mainstream population (Landes et al., 2021), and research has found that children and adults with I/DD utilize the emergency department (ED) more heavily than their peers (Friedman, 2021). In a systematic review, Calleja et al. (2020) reported that the number and severity of the chronic conditions experienced by autistic adults are largely preventable, and autism is just one of the many diagnoses that fall under the I/DD spectrum. Thus, people with I/DD may have a shorter life span and experience poor outcomes and early mortality rates (McDermott et al., 2018). Higher care costs are also associated with a diagnosis of I/DD (Amin et al., 2021). According to one study (Murphy et al., 2016), healthcare expenditures for people with autism throughout their lives can reach up to $250K.

Research confirms that people with I/DD are living longer lives, but there is an insufficient number of providers to care for people with these disorders (Bryan et al., 2023). In addition, stigma and bias about the disability community often prohibit doctors from completing a full evaluation of I/DD patients for conditions that are unconnected to their disability, and misdiagnosis and underdiagnosis are common (Ervin et al., 2014). Moreover, clinician-patient conversation in person-centered I/DD care is especially challenging because disabled adults routinely have difficulty communicating their symptoms to clinical staff, and many clinicians have not learned to adapt their communication styles to be inclusive and respectful of the needs of adult ID/D patients (Werner et al., 2017).

Due to the number of chronic conditions and comorbidities experienced by the ID/D population, utilization of acute care services is typically higher than non-ID/D peers. In addition, nearly half the I/DD population remains unemployed during the first few years of adulthood; thus, fewer individuals have employer-sponsored healthcare coverage (Benevides et al., 2021). Persons with I/DD are mainly dependent on Medicaid's hybrid state and federally-funded program for low-income individuals and those with disabilities. Although Medicaid increases access to healthcare providers, disparities in care continue due to confusing patient eligibility requirements, a limited number of providers who accept Medicaid, and coverage gaps that do not address the I/DD population's specific healthcare needs (Vaitsiakhovich & Landes, 2023). Inequities also occur due to the I/DD patient's race and ethnicity, geographic location (rural vs. urban), severity of the disability, and type of comorbidity (Benevides et al., 2021).

1.2 Research Objectives and Approach

This retrospective, cross-sectional study will use the South Carolina All Payer Database to identify, assess, and compare ED and admission utilization patterns and episodic cost of care for adults with I/DD versus all other SC patients when matched by age, sex, race, and county for services rendered in 2021.

1.3 Research Questions

This study will examine whether intellectually disabled adults aged 20-49 living in SC have comparable access to primary care providers as the non-I/DD population by examining the questions below.

1. Is the ED utilization rate for adults with I/DD higher than adults without I/DD matched by age, sex, and race?
2. Which SC counties have poor access to primary care providers?
3. What are the mean charges per visit for adults with I/DD compared to the controls?
4. Are there differences in the insurance status and cost of care between the I/DD versus non-I/DD cases and the controls?

1.4 Population

Will the data confirm that the I/DD population has an increased number of preventable hospitalizations for ambulatory care-sensitive conditions (ACSCs) compared to the non-I/DD group?

For this research project, we will focus on adults ages 20-49 living in South Carolina with a diagnosis of I/DD. The study population will include all patients, regardless of race, sex, or insurance status, who were seen in the ED or admitted to the hospital during the measurement period.

2 CHAPTER II SCOPING LITERATURE REVIEW

For this scoping review, a search was conducted using the PubMed and Scopus databases, publicly available government websites, and statistical data. The investigation was limited to peer-reviewed journal articles and data published between 2013 and 2023. The following terms were used to conduct the initial search: "intellectual and developmental disabilities" AND "adults,"   The search identified research articles evaluating primary care, access to care, ambulatory care sensitive conditions, emergency room utilization, and cost and utilization in the intellectual and developmental disability (ID/D) population.

Although this search identified more than 2,000 examining the topics of interest, only 2% of the total fell into the purview of our research population and focus area. Thus, the existing healthcare-focused literature is skewed toward children with intellectual and developmental disabilities (ID/D). Furthermore, the search revealed that I/DD affects large populations, including those with autism, down syndrome, or cerebral palsy, which are increasingly popular areas of research. At the same time, rarer I/DD conditions like Prader-Willi and Fragile-X syndrome are understudied. The bulk of studies trended towards mental health as well as sexual health and pregnancy.

2.1 Overview

Over sixty years ago, most people with I/DD lived in institutional settings (Bryan et al., 2023), where onsite clinicians and staff provided care to the residents. Thus, physicians practicing in the community had little exposure to people with I/DD, and educational programs in medical school were non-existent as they were thought unnecessary. As more of the disabled population were transferred to home- and community-based settings and sought care at local hospitals and clinics, training requirements for providers failed to materialize (Bryan et al., 2023). The disparities in healthcare for the I/DD population continue to the present day. The health inequalities experienced by individuals with ID/D are exacerbated by poor access to quality care, the prevalence of comorbid conditions such as hypertension, diabetes, and obesity, and an inadequately trained provider community(Durbin et al., 2018). Moreover, individuals with I/DD are also more likely to underutilize preventative care, delay treatment, and overuse ED services (Friedman, 2021). Regrettably, the scope of the problem is not fully understood because "People with I/DD are often excluded from U.S. national health surveillance data and not always recognized as a disparate population" (National Council on Disability, 2009 (Blaskowitz et al., 2019, p. 128).

2.2 Access to Care for Individuals with I/DD

People with I/DD receive fewer preventative care visits and annual screenings, and health education programs rarely target this specific community (Ervin et al., 2014). Further, an increased number of visits to the ED and subsequent hospitalizations are linked to conditions that could be easily addressed in an ambulatory care setting. Pneumonia, behavioral health, diabetes, and gastrointestinal disorders have been identified as typical examples of disorders commonly resolved by visiting a PCP (Ervin et al., 2014). For practitioners, managing care for patients with I/DD, especially given the high number of comorbidities, is a resource-intensive endeavor. Additional care management and coordination efforts are required by primary care providers (PCP). In addition, delivering person-centered care to neurologically impaired individuals is challenging, particularly when providers lack knowledge about the complex needs of the population (McDermott et al., 2018).

Life expectancy for the I/DD community has increased over the past few decades and is nearly equal to that of non-disabled individuals (Bryan et al., 2023). Yet, their healthcare needs are substantial and unique to their population (Daaleman, 2016), and early death is preventable (Landes et al., 2021). Primary care providers, in particular, need comprehensive training to become familiar with the most common disorders that plague ID/D individuals. All providers should be skilled in communicating with disabled adults (Werner et al., 2017). During the transition to adulthood, access to high-quality preventative care becomes less available and is often unsuccessful at delivering a person-centered experience (Fremion et al., 2022). Furthermore, the lack of provider awareness about the physical and psychosocial disorders associated with specific diagnoses threatens the delivery of equitable care to the ID/D community (Bryan et al., 2023).

Access to specialists is critical for chronic disease management and crisis prevention to address the full range of comorbid conditions in the I/DD community and improve outcomes (Doherty et al., 2020). Research has suggested that the healthcare needs of the I/DD population may best be facilitated using a medical home model approach (Bobbette et al., 2021). Medical homes or PCP offices coordinate services across the care continuum and facilitate communication between interprofessional care team members, including behavioral health specialists and social workers. Without a PCP to assist the patient in navigating the system and making specialty care more accessible, non-emergent visits to the ED will remain high, and the triple aim in healthcare will never be achieved (Bowers et al., 2017).

Recently published studies see telehealth as an option for resolving barriers to accessing primary and specialty care services and preventing unnecessary hospitalizations, especially for patients living in rural areas (Doherty et al., 2020). Telemedicine can address the transportation issues plaguing the I/DD community, and the technology enables more frequent contact between the provider and patient. Also, patient monitoring, medication reconciliation, and discussions about socioeconomic concerns related to an individual's healthcare can be addressed during telemedicine visits, thereby decreasing costs and improving outcomes (Doherty et al., 2020).

2.3 Overutilization of Acute Care Services

The healthcare utilization patterns for the I/DD population are significantly impacted by their poor access to primary care and complex healthcare needs (Friedman, 2021). Approximately 10% of hospitalizations nationwide are linked to Ambulatory Care Sensitive Conditions (ASCSs). Those disorders can be managed in a lower acuity setting, such as a provider's office or ambulatory care location. Patients with I/DD are more likely to seek care for ACSCs if they are enrolled in Medicaid or are uninsured and have multi-morbidities (Hand et al., 2019). High utilization in acute care facilities for ACSC indicates that routine primary care access is limited or the care is of poor quality (McDermott et al., 2018).

From a quality and cost perspective, payers and providers are aggressively looking to reduce admissions for ACSCs because comprehensive care delivered by a PCP is less costly and results in better outcomes. Using 2017 cost data, McDermott and Jiang (2020) reported that adults had 3.5 million acute and chronic hospitalizations for ACSCs in the U.S., totaling nearly $34 billion. Furthermore, the majority of the hospitalizations were for chronic illnesses and mental health disorders. Several studies have revealed that rates of ED visits are somewhere between 10 and 30% higher for people with I/DD versus the general population (Yamaki et al., 2019).

Although limited, the available publications on outcomes research for the I/DD population confirm that they utilize the ED in disproportionately higher numbers than their non-I/DD peers, especially in locales with fewer community health facilities or care networks (Lauer et al., 2021). Age, race, gender, and income also impact the rate of ACSCs (McDermott & Jiang, 2020). Older people are more likely to be admitted for ACSCs, as are Black and Hispanic populations compared to White individuals. Lower-income populations were found to have twice the risk of being hospitalized with a preventable condition versus higher-income communities. Regarding gender, women were more commonly seen in the ED for acute care diagnoses, and men had higher rates of ACSCs for chronic diseases (McDermott & Jiang, 2020).

In South Carolina, McDermott et al., 2018 found that, on average, Medicaid members with disabilities visited the ED with an ACSC more often than non-disabled individuals on Medicaid. In addition, Medicaid beneficiaries with I/DD were more likely to be hospitalized with ACSCs versus their non-I/DD peers, even when controlling for health status, signifying that comorbidities may not explain the higher rate of admissions (Hand et al., 2019) (Phillips et al., 2021). Additional studies conducted on Medicaid patients with I/DD revealed that their preventative hospitalizations are three to five times higher than the general population, particularly for diabetes and asthma diagnoses (Phillips et al., 2021).

Current research also suggests that cost, accessibility, or the delivery model impact hospitalizations (Phillips et al., 2021; Yamaki et al., 2019). For example, differences in utilization have been documented between FFS Medicaid versus Managed Medicaid beneficiaries. Managed care is designed to drive members to use lower-cost ambulatory services; however, Yamaki et al. (2019) noted that some studies have documented decreased utilization of hospital admissions for ACSCs without the expected corresponding increase in PCP visits for adults enrolled in Medicaid Managed Care plans, especially those residing in rural areas (Yamaki et al., 2019).

2.4 Costs of Care

The cost of care for people with I/DD can be considerably higher compared to non-disabled patients (Panca et al., 2019), and those costs will remain high while the problems summarized above are unaddressed (Friedman, 2021). Socioeconomic barriers further exacerbate the issue as many patients with I/DD are unemployed, lack transportation, and live at or under the poverty line (Friedman, 2021).

People with I/DD are a small fraction of the people covered under Medicaid, yet costs may be up to five times higher for individuals with I/DD due to the increased acute care and ED services utilized by this population; therefore, focusing on ACSCs is critical for states seeking to reduce Medicaid spending (Vohra et al., 2016).

2.5 Insurance Status

Hospital expenditures may differ for I/DD patients in and out of .C.SC compared to the general population, depending upon their insured status; however, there is a shortage of studies in this area. Public insurance, including Medicare and Medicaid, covers 80-85% of people diagnosed with I/DD (Allen et al., 2021), although the ratios of commercial and Medicaid enrollment in SC are unknown (CDC, 2023). In a cross-sectional study, Allen et al. (2021) compared the cost, quality, and utilization of Medicaid versus private insurance enrollees. The researchers found that patients on Medicaid had fewer visits to primary care providers and more visits to the ED versus patients enrolled in private insurance, signaling potential challenges in accessing providers and cost barriers of treatment. According to Bowers et al. (2017), nearly half of the nation’s Medicaid expenditures are attributed to disabled enrollees, yet this group only constitutes 15% of the population funded by the program.

Moreover, the cost of care was higher for people with I/DD who accessed private or marketplace insurance coverage, which was related to higher utilization of outpatient services (Allen et al., 2021). As health oversight agencies and policymakers continue to examine ways to cut healthcare costs (Commonwealth Fund, 2021), it is essential to establish the average expense for providing care to vulnerable populations as a basis for determining if increased access can alleviate the need for people with I/DD to utilize costlier health services through the ED or inpatient facilities (Commonwealth Fund, 2021).

3 CHAPTER III METHODOLOGY

3.1 Objective

The objective of this descriptive research at the Medical University of South Carolina in Charleston, SC, is to identify patterns of ED utilization and acute inpatient admissions for the I/DD population compared to the non-ID/D population in South Carolina using SC All-Payer data from 2021 to inform program planning to improve access to primary care.

3.2 Research Design

This retrospective cross-sectional analysis will use data from the SC All-payer database for South Carolina ED visits and hospital admissions. The information gathered from medical claims will describe variations in acute care use for the ID/D population residing in SC compared to non-I/DD patients when matched by age, sex, race, and county. It is well established that variations in access to primary care providers affect the rates of ED visits and hospitalizations; therefore, the findings can be used to identify key geographic areas that should be considered as sites for innovative programs, such as telehealth or other programs aimed at improving access to primary care (Sarmento et al., 2020). Results from this initial evaluation may also be used to inform further studies to identify the rate differences for ACSC conditions and other investigations, as illustrated by Kim et al., 2019). (See Table 1).

3.3 Data Set Description and Collection

This study used de-identified archival billing data from the SC All-Payer Claims Database to include all ED and acute care admissions for people aged **20-49** with or without a diagnosis of an ID/D using the International Classification of Diseases, tenth revision (ICD-10), with diagnosis code(s) listed in Table 2, between ages **20-49** who visited an SC acute care facility or ED from January 1st, 2018, through December 31st, 2021. We used a retrospective case-control design for the data set construction. We identified a cohort of IDD patients using the diagnosis codes listed in Table 1.

Table 1: List of ID/D ICD-10 Diagnosis Codes

Intellectual and Developmental Disability Description	**ICD – 10 Code(s)**
Intellectual Disabilities	F70-F79
Other developmental disorders of speech and language	F80 – F80.9
Autistic Disorders	F84.0 - F84.5
Other pervasive developmental disorders	F84.8
Pervasive developmental disorder, otherwise unspecified	F84.9
Prader-Willi Syndrome	F87.11
Other specified neurodevelopmental disorders	F88
Developmental disorder NOS	F89
Attention-deficit hyperactivity disorders	F90.0 – F90.9
Cerebral Palsy	G80.9
Chromosomal abnormalities, including Angelman Syndrome, Down Syndrome, and Fragile X Syndrome	Q90-99

3.4 Study Population

The population included in the study's purposive sample will consist of all residents of South Carolina between ages 20 and 49 who were seen in the ED or admitted to the hospital over three years between January 1, 2018, and December 31, 2021, by I/DD diagnosis. The treatment group included all individuals with any primary or secondary diagnosis present in Table 1. A control population was identified from the same years in the data set. This control group consisted of patients who never had a recorded diagnosis of any of the diagnoses in Table 1. We used Propensity Score matching in SAS Proc Match (version 9.4) to extract two control patients for each IDD patient, matched on race, age, and sex. IDD and control patients were identified over three years to improve our ability to classify IDD and non-IDD patents correctly. Once identified and matched, we used the encrypted patient identifiers from the matched cohort to extract all ED and hospital admission records for this patient cohort for the calendar year 2021. This approach ensured that the observed utilization rates reflect annual utilization for the groups.

3.5 Independent and Dependent Variables

Dependent variables include the mean number of ED and hospital admissions, number of days in the hospital, total hospital days per year, and total charges for services in 2021. We examined variations in rates by SC county of residence and insurance coverage.

3.6 Data Analysis

We used descriptive statistics means and percentages to describe the populations and t-tests or non-parametric tests to compare differences between continuous measures. Percentages and Chi-square test were used for categorical variables. We used multivariable models to describe the combined effects of the patient's insurance status and county of residence as well as on ED visits, hospital admissions, days in hospital, and total charges for the care provided to IDD and control patients. We tested all linear models for effects of age, race, and sex, but the groups were so well matched that these variables were not different in the IDD and control groups.

3.7 Protection of Human Subjects

The study used de-identified data that was approved as non-human research by the MUSC IRB.

4 CHAPTER IV RESULTS

4.1 Demographics of the Population

The age, sex, and race variables were used to match the IDD and control groups, and the match was excellent, so we observed no differences between the groups in terms of these variables. Table 2 lists the demographic and clinical characteristics of 112,533 (n) I/DD and non-I/DD patients (matched controls) who visited Emergency Departments (ED) or were admitted to the hospital in South Carolina. For age, we split the adult patients into six groups: 20-24, 25-29, 30-34, 35-39, 40-44 and ages 45-49. Since the cases and controls were matched evenly at 1:2, the total percentage is the same for each age grouping. People between the ages of 20-24 represented 22.1% of the sample, while patients aged 24-29 comprised 19.5% of the study population. Patients aged 30-34 and 35-39 included 17.7% and 15.8% of the total group, respectively. The smallest age groups were the patients between 40-44 (12.8%) and 45-49(12.1%). No statistical significance existed between the I/DD group of any age (p= 1.000) and the non-I/DD population. The distribution between males and females (45.0% vs.55.0%) in the study population was evenly distributed and not considered statistically significant (p=1.000). We also found no statistical difference (p=1.000) between the white (75.7%), black (20.5%), or patients who identified as another race (3.8%) included in our study.

The insurance variable was statistically significant, p=<0.0001. Most I/DD and non-I/DD patients had Commercial insurance coverage (39.0% vs 44.0%). Self-pay was the second highest grouping for I/DD (19.6%) and Non-I/DD (27.0%) participants. Medicaid and Medicare insured people with an I/DD diagnosis at a rate of 19.3% and 11.3% compared to 11.2% and 3.2% of non-I/DD patients. Study participants with I/DD and covered by other insurance sources totaled (10.8%) compared to the controls (14.6%).

I/DD patients across the state of SC visited the ED at a rate of 40.2% compared to 23.6% of non-I/DD patients, and the difference was statistically significant. Inpatient admissions were also higher in the I/DD population than in the non-I/DD group (13.5% vs. 5.7%). The Chi-Square test for Inpatient admissions also yielded a significant result (p=<0.0001).

A T-test was performed to determine the risks associated with I/DD and non-I/DD patients visiting the ED or being admitted to the hospital. For the I/DD group, the risk of visiting the ED was 3.30 ± 6.74, contrasted with the mean and standard deviation of 1.94 ± 2.02 for the control population, and the result was statistically significant. There was a lower risk that both the cases and controls would be admitted as inpatients, 1.58 ± 1.39 for people with I/DD vs. 1.29 ± 0.91 for people that do not have a diagnosis of I/DD; however, the result is also statistically significant. Finally, the Charlson Comorbidity Index was measured for both groups, and I/DD patients had a higher Charlson Score (0.167 ± 0.55) than the matched controls (0.10 ± 0.42).

Table 2: Characteristics of I/DD and Non–I/DD patients seen in the ED or admitted to SC hospitals.

Patient Variables	IDD Patients	Matched Non-IDD Patients	p-value
n=112,533	37,511	75,022	
Age			1.000
20-24	8,277(22.1)	16,554(22.1)	
25-29	7,297(19.5)	14,594(19.5)	
30-34	6,648(17.7)	13,296(17.7)	
35-39	5,926(15.8)	11,852(15.8)	
40-44	4,815(12.8)	9,630(12.8)	
45-49	4,548(12.1)	9,096(12.1)	
Sex			1.000
Male	16,887(45.0)	33,774(45.0)	
Female	20,624(55.0)	41,248(55.0)	

Race			1.000
White	28,405(75.7)	56,810(75.7)	
Black	7,691(20.5)	15,382(20.5)	
Other	1,415(3.8)	2,830(3.8)	
Insurance Type			<0.0001
Medicare	4,244(11.3)	2,399(3.2)	
Commercial (Private)	14,631(39.0)	32,995(44.0)	
Medicaid	7,225(19.3)	8,382(11.2)	
Self-Pay	7,346(19.6)	20,269(27.0)	
Other	4,065(10.8)	10,977(14.6)	
Emergency Department (ED) Encounters			<0.0001
Yes	15,065 (40.2)	17,745(23.6)	
No	22,466(59.8)	57,277(76.4)	
Inpatient (IP) Admission			<0.0001
Yes	5,052(13.5)	4,266(5.7)	
No	32,459(86.5)	70,756(94.3)	
Charlson Score			<0.0001
Emergency Room Visit	3.30 ± 6.74	1.94 ± 2.02	
Inpatient Admission	1.58 ± 1.39	1.29 ± 0.91	
Charleson Score	0.167 ± 0.55	0.10 ± 0.42	

All values are expressed as n (%) or mean ±SD.

4.2 Difference in Resources Used for IDD and Control Patients

The variables we examined included the county of residence, the number of I/DD cases living in each of the 46 SC counties, the Total number of ED visits, the Total number of Inpatient Admissions, and the Total Charges. Using this data, we calculated the Total Cases (Total ED Visits + Total Inpatient Admissions) and the Mean Charges per Case (Total Charges/Number of I/DD Patients). Table 3 shows the statewide differences observed for the 54,900 patients diagnosed with IDD and a control group of a similar size for Total Charges in 2021 for the ED and IP encounters. The I/DD population incurred charges of more than $1 Billion for services in 2021 compared to $35 million for a same-size control population. Thus, the IDD population incurs an excess of $1,003,251,655 in annual medical care charges compared to an age, sex, and race-matched control population without an I/DD diagnosis. The mean .annual charges per case for all IDD patients was $18,915, exactly $12,348 higher than the mean charges per case in the control group.

Table 3: Total Annual Charges in 2021 for Similar numbers of I/DD and non-I/DD Cases, Charges per Case for a Cohort of 54,900 patients per group

	I/DD Cases	**Non-I/DD Controls**	**Difference IDD-Controls**
Total Cases	**54,900**	**54,900**	**NA**
Total Charges	**$1,038,458,978**	**$35,207,323**	**$1,003,251,655**
Mean Charges/Case	**$18,915**	**$6,567**	**$12,348**

4.3 County Ranking Process

Mean annual charges per IDD patient vary by location; thus, it is essential to identify geographic areas that have higher mean charges as well as sufficient numbers of IDD patients to have a critical mass of subjects who might benefit from an intervention, such as telehealth or other modality to improve access to primary care and reduces medical events that lead to ED and hospital use. To identify suitable candidates for pilot interventions, we examined ED and hospital admission volume by county of patient residence. Appendix A lists the I/DD patient data available for each of the forty-six counties in South Carolina, including the number of cases, ED visits, inpatient admissions, total charges, and mean charges per case. Appendices B and C show heat maps that provide a categorical representation of each county related to the mean charges per case and total charges for I/DD patients.

Our study aims to identify the counties where primary care access may be limited (as indicated by the high use of ED and hospital care) for people with I/DD. We followed the steps below to narrow down the counties where primary care expansion may be most needed.

1. Rank each county from 1 – 46 by the mean charges per case
2. Select the top 20 counties
3. Using the Rank EV tool in Excel, Rank each county based on the Mean Charges per Case (See Table 4)
4. Rank each county based on the number of I/DD patients (See Table 4)
5. Rank each county by the number of encounters (See Table 4)
6. Sort the list by the lowest number and select the top 10 (See Table 5)

Table 4 columns from left to right: County name, the total number of I/DD patients by county, total number of encounters (ED visits plus IP Admissions), mean charges per case, county rank of the mean charges per case, county ranking of the total number of I/DD patients, county ranking of the total encounters and the sum of all rankings is the addition of the three previous columns labeled 1-3.

Table 4: SC County Rankings

County Name	Total number of I/DD patients	Total Encounters	Mean Charge/Case	Ranking of the Mean Charges per Case[1]	Ranking of the total number of I/DD patients[2]	Ranking Total Encounters[3]	Sum of all Rankings
Colleton	453	1058	$33,674	1	15	12	**28**
Lee	166	370	$31,880	2	21	20	**43**
Bamberg	138	261	$31,550	3	22	22	**47**
Jasper	108	227	$31,400	4	23	23	**50**
Horry	2454	4009	$30,338	5	2	2	**9**
Lancaster	523	913	$28,623	6	13	15	**34**
Darlington	656	1090	$28,515	7	11	11	**29**
Dorchester	1893	3106	$28,053	8	4	4	**16**

Chester	353	614	$27,348	9	17	17	**43**
Barnwell	180	339	$25,881	10	20	21	**51**
Florence	1672	2471	$25,715	11	5	5	**21**
Orangeburg	869	1283	$24,737	12	10	10	**32**
Berkeley	2652	4139	$23,444	13	1	1	**15**
Georgetown	527	969	$23,205	14	12	14	**40**
Marion	389	565	$21,505	15	16	18	**49**
Sumter	1089	1934	$21,443	16	8	6	**30**
York	1241	1437	$21,400	17	6	8	**31**
Aiken	1205	1454	$21,377	18	7	7	**32**
Williamsburg	320	502	$21,069	19	19	19	**57**
Clarendon	338	617	$20,412	20	18	16	**54**
Anderson	2064	3281	$20,247	21	3	3	**27**
Edgefield	107	156	$20,193	22	24	24	**70**
Union	501	989	$19,678	23	14	13	**50**
Beaufort	909	1344	$19,028	24	9	9	**42**

Table 5: Counties to Target for Telehealth or Other Primary Care Programming

County Name	**Rank**
Horry	9
Berkeley	15
Dorchester	16
Florence	21
Anderson	27
Colleton	28
Darlington	29
Sumter	30
York	31
Orangeburg	32

4.4 Ambulatory Sensitive Conditions (ACSCs)

We had planned to include this data in the current study; however, during the analysis phase, we realized we had more than enough data for this project and decided to address the ACSCs in a separate study.

5 CHAPTER V DISCUSSION

5.1 Discussion

This study hypothesized that the I/DD population in South Carolina would have a higher rate of ED visits and Inpatient Admissions than the matched controls. We found that the rate of ED visits for people with I/DD visits was nearly 17% higher than for people of similar race, sex, and age. Hospitalizations occurred in the I/DD group 7.8% more than those without an I/DD diagnosis. The type of insurance coverage held by the cases and controls impacts the frequency of ED visits or the necessity for inpatient hospitalization. Claims data also found that 20% of people with I/DD presented at the hospital without coverage (self-pay), and the other top payers for the I/DD population are commercial insurance (40%) and Medicaid (19%). Further investigation is needed to determine if most I/DD patients with a commercial insurance status are those under 26 who remain on their parent's healthcare plan.

Due to the precision conducted during the propensity matching process, we found no difference between the case and control populations for age, sex, and race. However, the costs to care for people with I/DD are higher than for people of the same age, sex, and race in the state of SC. The difference in the total charges between the cases and controls is 59% and 74% for the mean charges per case.

We identified 59,400 individuals across the state who logged more than 81K encounters in the ED and were admitted to the hospital. The total costs were over $1B for our study population. We do not know how many of these encounters were related to emergent health situations versus conditions that could be easily treated in an ambulatory care setting. We aim to continue our research to determine how much of the costs are attributable to preventable treatment.

5.2 Opportunities to Expand Access Via Telemedicine in South Carolina Counties

Using the data derived from the SC All Payer database, we identified ten counties to target for telehealth programming with a high number of people with I/DD, high mean charges per case, and higher total cases (Table 5). We believe these counties possess the best opportunity to review patient-to-provider ratios, provide specific training related to the care needed by the I/DD population, and remove barriers to launching a comprehensive telehealth program that includes vulnerable populations such as those with disabilities. It should be noted that the ten counties we

5.3 Implications for Policy and Practice

As payers look to reduce costs to achieve the Triple Aim, the disabled population in general and, specifically, the developmentally disabled community may be a realistic group to examine if expanding primary care access via telemedicine will reduce non-emergent trips to the ED and lower the prevalence of comorbid conditions in adults with I/DD. Once the data related to ACSCs is available, we will also determine which chronic conditions are reasonable targets for providers and case workers to focus on when interacting with I/DD individuals in South Carolina. Further, while previous research has confirmed that adults with I/DD visit the ED at a higher rate and have multiple comorbidities, to our knowledge, no study has calculated the mean charges per case for this population in the state of South Carolina by county. Now that we have identified which counties have a considerable number of residents with an I/DD diagnosis and rank higher on our list of counties for mean charges per case, policymakers and local health agencies may want first to focus their efforts on removing any barriers to conducting telehealth visits in the areas listed in Table 5. Last, medical students must receive prolonged and repeated exposure to I/DD patients and their health concerns during their clinical training to reduce bias, improve patient communication, and boost their confidence in treating patients with developmental disabilities.

5.4 Limitations

This research study has several limitations. First, our research cannot be applied outside South Carolina since our data was confined to the SC All Payer Database 2021. Next, the population of I/DD cases in our study is likely to be undercounted, given that emergency room providers generally focus on the present crisis instead of the patient's complete health history. Additionally, an individual's developmental disability diagnosis may not be shared by the patient or their families during a trip to the ED unless specifically asked or related to the reason for the visit, nor was an applicable diagnosis documented in the electronic medical record. Therefore, we cannot rule out that an unknown number of individuals with an I/DD diagnosis may have incidentally been included in our control group. Last, the controls are not matched by county, so the data could not be used to compare patients at the county level.

5.5 Future Research

More healthcare studies involving the adult I/DD population are necessary to establish the specific needs of this population as they age and develop a framework for equitable care through the eyes of people with developmental disabilities. Future studies should gather data on social drivers of healthcare (SDOH) for the I/DD community, as many prefer to live independently. This data will help create health education and prevention plans that are accessible to the I/DD population. In addition, given that our study found that 80% of adults with I/DD have insurance coverage, researchers may consider surveying this group to understand their reasons for avoiding or delaying routine care.

Within the next twelve months, we hope to demonstrate what percentage of the services provided in the E.D. or the hospital are related to conditions that could be addressed in a lower acuity setting. With this information, insurers and practitioners can collaborate with I/DD community advocates to identify approaches for increasing primary care visit compliance. Further, we aim to determine whether age is a factor in the higher commercial insurance rate compared to Medicaid enrollment for the I/DD cases we identified in the state. Finally, additional analysis of the county-level data could help pinpoint the barriers to accessing care.

5.6 Conclusions

This study found that, in South Carolina, Emergency Department visits and Inpatient admissions are higher in the I/DD population than for those without an I/DD diagnosis when matching for age, sex, and race. Further, the type of insurance coverage a patient has when presenting to the hospital is a factor in the differences between the rate of encounters between the cases and controls.

Our analysis confirmed that the total charges and case averages are higher in the I/DD population statewide. Through a simple Excel ranking process, we identified ten counties with poor access to primary care. State agencies and policymakers should focus on expanding primary care and telehealth programs in counties where the total number of cases and patients is high and the mean charge per person appears excessive. Telehealth may be a solution to increasing access for people with I/DD as well as other groups with recognized health disparities.

References

AAIDD. (n.d.). Defining Criteria for Intellectual Disabilities. American Association on Intellectual and Developmental Disabilities. https://www.aaI/DD.org/intellectual-disability/definition

Allen, H., Gordon, S. H., Lee, D., Bhanja, A., & Sommers, B. D. (2021). Comparison of Utilization, Costs, and Quality of Medicaid vs Subsidized Private Health Insurance for Low-Income Adults. *JAMA network open*, *4*(1), e2032669.

Amin, M. R., Gentile, J. P., Edwards, B., & Davis, M. (2021). Evaluation of Health Care Disparities for Individuals with Intellectual and Developmental Disabilities in Ohio. *Community Mental Health Journal*, *57*(3), 482–489.

Blaskowitz, M. G., Hernandez, B., & Scott, P. W. (2019). Predictors of Emergency Room and Hospital Utilization Among Adults With Intellectual and Developmental Disabilities (I/DD). *Intellectual and Developmental Disabilities*, *57*(2), 127-145. https://doi.org/10.1352/1934-9556-57.2.127

Bobbette, N., Lysaght, R., Ouellette-Kuntz, H., Tranmer, J., & Donnelly, C. (2021). Organizational attributes of interprofessional primary care for adults with intellectual and developmental disabilities in Ontario, Canada: a multiple case study. *BMC Fam Pract*, *22*(1), 157. https://doi.org/10.1186/s12875-021-01502-z

Bowers, A., Owen, R., & Heller, T. (2017). Care coordination experiences of people with disabilities enrolled in Medicaid managed care. *Disabil Rehabil*, *39*(21), 2207-2214. https://doi.org/10.1080/09638288.2016.1219773

Bryan, J., Rabinowitz, C., Edwards, L., & Jacob, R. (2023). Primary Care of Adults with Intellectual and Developmental Disabilities Clinic: Coordination of Care

Challenges. Southern Medical Journal (Birmingham, Ala.), 116(4), 355–357. United States.

Centers for Disease Control and Prevention. (2023, May 12). Disability & Health .S.US State Profile Data: South Carolina. https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/south-carolina.html

Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2024].

County Health Rankings & Roadmaps. (2023). South Carolina. https://www.countyhealthrankings.org/explore-health-rankings/south-carolina?

Daaleman, T. P. (2016). Primary Care of Adults with Intellectual and Developmental Disabilities. Southern Medical Journal (Birmingham, Ala.), 109(1), 12–16. United States: by the Southern Medical Association.

Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP Open*, *4*(3). https://doi.org/10.3399/bjgpopen20X101030

Ervin, D. A., Hennen, B., Merrick, J., & Morad, M. (2014). Healthcare for persons with intellectual and developmental disability in the community. Frontiers in public health, 2, 83–83. Switzerland: Frontiers Media S.A.

Friedman C. (2021). Social determinants of health, emergency department utilization, and people with intellectual and developmental disabilities. *Disability and Health Journal*, *14*(1), 100964.

Fremion, E., Cowley, R., Berens, J., Staggers, K. A., Kemere, K. J., Kim, J. L., Acosta, E., & Peacock, C. (2022). Improved health care transition for young adults with developmental disabilities referred from designated transition clinics. *Journal of Pediatric Nursing*, *67*, 27–33.

Hand, B. N., Boan, A. D., Bradley, C. C., Charles, J. M., & Carpenter, L. A. (2019). Ambulatory Care Sensitive Admissions in Individuals With Autism Spectrum Disorder, Intellectual Disability, and Population Controls. *Autism Res*, *12*(2), 295-302. https://doi.org/10.1002/aur.2050

Johnston, K. J., Chin, M. H., & Pollack, H. A. (2022). Health Equity for Individuals With Intellectual and Developmental Disabilities. JAMA : the Journal of the American Medical Association, 328(16), 1587–1588. Chicago: American Medical Association.

Jones, K. B., Weedon, D., Singh, N., Carbone, P. S., & Kim, J. (2019). Cost and Utilization with Enrollment in a Medical Home for Individuals with an Autism Spectrum Disorder and/or Intellectual Disability. Journal of health care for the poor and underserved, 30(3), 1068–1082. United States: Johns Hopkins University Press.

Landes, S. D., Stevens, J. D., & Turk, M. A. (2021). Cause of death in adults with intellectual disability in the United States. *Journal of intellectual disability research: JIDR*, *65*(1), 47–59.

Lauer, E., Lindgren, S., Momany, E., Cope, T., Royer, J., Cogan, L., McDermott, S., & Armour, B. (2021). Health Service Utilization Patterns Among Medicaid-Insured Adults With

Intellectual and Developmental Disabilities: Implications for Access Needs in Outpatient Community-Based Medical Services. *J Ambul Care Manage*, *44*(2), 138-147. https://doi.org/10.1097/JAC.0000000000000373

McDermott KW, Jiang HJ. Characteristics and Costs of Potentially Preventable Inpatient Stays, 2017. 2020 Jun 16. In: Healthcare Cost and Utilization Project (HCUP) Statistical Briefs [Internet]. Rockville (M.D.): Agency for Healthcare Research and Quality (U.S.); 2006 Feb–. Statistical Brief #259. PMID: 32730017.

McDermott, S., Royer, J., Mann, J. R., & Armour, B. S. (2018). Factors associated with ambulatory care sensitive emergency department visits for South Carolina Medicaid members with intellectual disability. Journal of intellectual disability research, 62(3), 165–178. England: Wiley Subscription Services, Inc.

McKenzie, K., Milton, M., Smith, G., & Ouellette-Kuntz, H. (2016). Systematic Review of the Prevalence and Incidence of Intellectual Disabilities: Current Trends and Issues. Current developmental disorders reports, 3(2), 104–115. Cham: Springer International Publishing.

National Institute on Minority Health and Health Disparities. (2023, September 20). National Advisory Council on Minority Health and Health Disparities (NIMHD) Working Group on Persons Living with Disabilities. https://nimhd.nih.gov/docs/advisory-council/nacmhd_workGrpOnHealthDisparitiesAndPeopleWithDisabilities_report_2023sept.pdf

Ouellette-Kuntz, H., Garcin, N., Lewis, M. E. S., Minnes, P., Martin, C., & Holden, J. J. A. (2005). Addressing Health Disparities Through Promoting Equity for Individuals with Intellectual Disability. *Canadian journal of public health*, *96*(S2), S8–S22.

Panca, M., Buszewicz, M., Strydom, A., Hassiotis, A., Welch, C. A., & Hunter, R. M. (2019). Resource use and cost of annual health checks in primary care for people with intellectual disabilities. *Journal of intellectual disability research: JIDR*, *63*(3), 233–243.

Phillips, K. G., Wishengrad, J. S., & Houtenville, A. J. (2021). Ambulatory Care Sensitive Conditions Among All-Payer Claimants With Intellectual and Developmental Disabilities. *Am J Intellect Dev Disabil*, *126*(3), 203-215. https://doi.org/10.1352/1944-7558-126.3.203Reducing health care spending: What tools can states leverage? Commonwealth Fund. (2021, August 18). https://www.commonwealthfund.org/publications/fund-reports/2021/aug/reducing-health-care-spending-what-tools-can-states-leverage

Ruiz, S., Giuriceo, K., Caldwell, J., Snyder, L. P., & Putnam, M. (2019). Care Coordination Models Improve Quality of Care for Adults Aging With Intellectual and Developmental Disabilities. Journal of disability policy studies, 30(4), 191–201. Los Angeles, CA: SAGE Publications.

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2019). The contemporary view of intellectual and developmental disabilities: Implications for psychologists. Psicothema, 31(3), 223–228. https://doi.org/10.7334/psicothema2019.119

Stable-Perez, E. J. & Valdez, R. O. (2023, September 26). *People with disabilities designated as a population with health disparities*. National Institute of Minority Health and Health Disparities. https://nimhd.nih.gov/about/directors-corner/messages/health-disparities-population-designation.html

Vohra, R., Madhavan, S., & Sambamoorthi, U. (2016). Emergency Department Use Among Adults with Autism Spectrum Disorders (ASD). *J Autism Dev Disord*, *46*(4), 1441-1454. https://doi.org/10.1007/s10803-015-2692-2

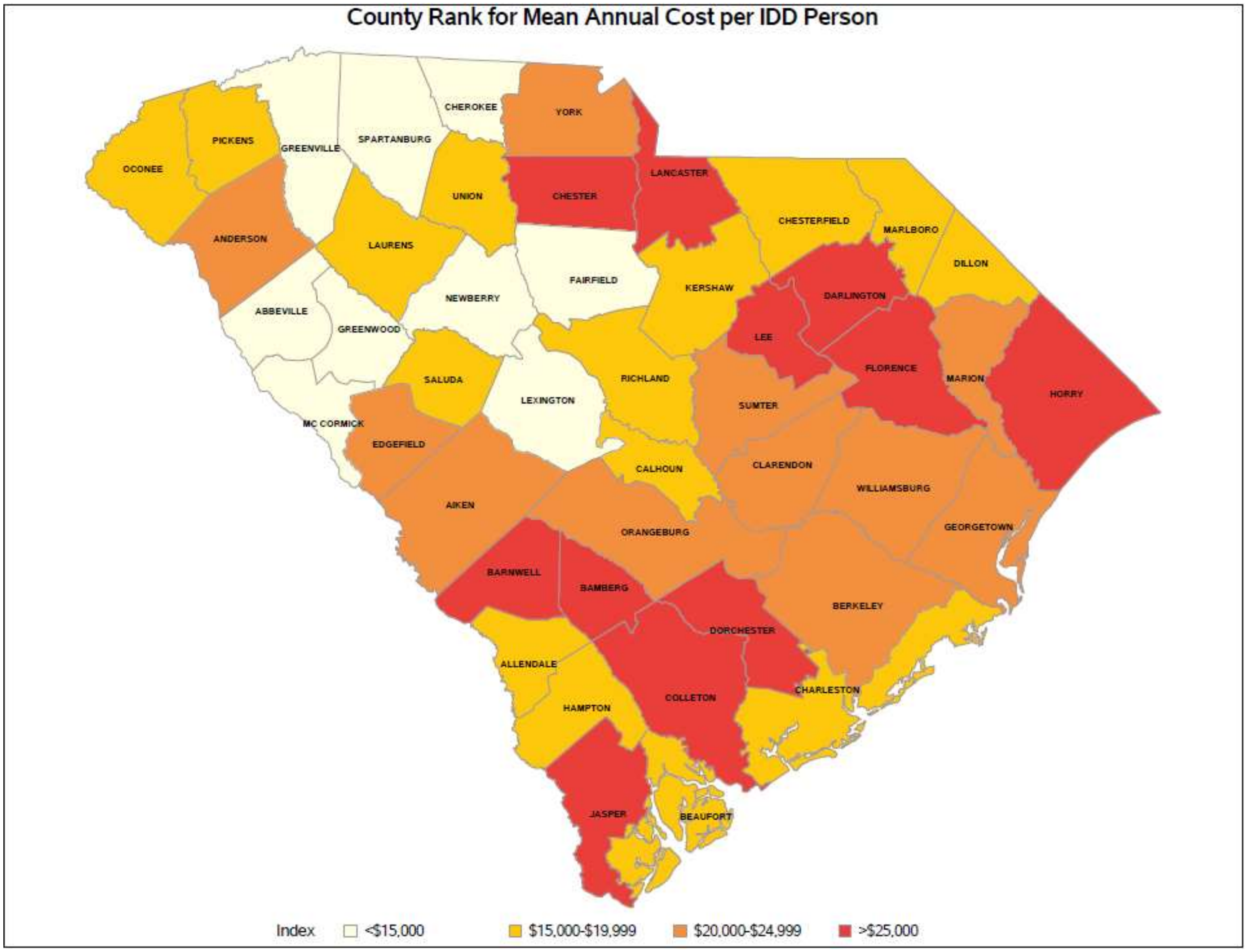
Weiss, J. A., Isaacs, B., Diepstra, H., Wilton, A. S., Brown, H. K., McGarry, C., & Lunsky, Y. (2018). Health Concerns and Health Service Utilization in a Population Cohort of Young Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *48*(1), 36–44.

Werner, S., Yalon-Chamovitz, S., Tenne Rinde, M., & Heymann, A. D. (2017). Principles of effective communication with patients who have intellectual disability among primary care physicians. *Patient education and counseling*, *100*(7), 1314–1321.

Yamaki, K., Wing, C., Mitchell, D., Owen, R., & Heller, T. (2019). The Impact of Medicaid Managed Care on Health Service Utilization Among Adults With Intellectual and Developmental Disabilities. Journal of *Intellectual & Developmental Disabilities*, *57*(4), 289-306. https://doi.org/10.1352/1934-9556-57.4.289

Appendix A

Heat Map: S.C. County Rank for Mean Cost per I/DD Case



Appendix B

SC County Heat Map for Total Charges (E.D. + IP Admits) of I/DD patients.