

**Evaluating Preventative Care and Post-Hospitalization Primary Care Follow-Up in
Adults with Intellectual and/or Developmental Disabilities**

by

Jason Robert Xenakis

M.P.H., New York Medical College, 2017

M.D., New York Medical College, 2015

B.A., Marist College, 2010

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NAME: **Jason Xenakis**

The signatures below certify that this dissertation has been examined and accepted with the following conditions:

- ☒ Approved no revisions
☐ Approved minor revisions
☐ Approved major revisions
☐ Not Approved

Adam E. Block, DrPH
Name

[Signature]
Signature

12/3/19
Date

Patricia A. Patrick, DrPH
Name

[Signature]
Signature

12/3/2019
Date

Kenneth A. Knapp, DrPH
Name

[Signature]
Signature

12/3/2019
Date

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Study Abstracts

Preventative Care Abstract

Title: Characteristics that are associated with preventative care utilization in adults with intellectual and/or developmental disabilities (IDD).

Background: Individuals with IDD are less likely than the general population to receive preventative services as recommended by the United States Preventative Service Task Force (USPSTF) and Centers for Disease Control and Prevention (CDC). What remains unclear are the risk factors that contribute to this healthcare disparity.

Objective: To explore the demographic, socioeconomic, and clinical variables that are associated with whether an adult with IDD will receive appropriate preventive services from their primary care provider.

Methods: A cross-sectional study reviewed 2017 medical records from an IDD-specific multi-specialty outpatient facility for demographic, socioeconomic, and clinical characteristics, as well as preventative service utilization data.

Results: A total of 1,162 adult patient records were reviewed. The level of intellectual disability of the sample was found to be mild (54.7%), moderate (20.2%), severe (13.5%), and profound (11.5%). Most patients reported living in a group home (81.1%) versus non-group home settings (17.3%). Preventative service utilization by eligible patients was distributed as follows: influenza vaccination (67.6%), pneumococcal

vaccination (80.2%), colorectal cancer screening (62.1%), breast cancer screening (68.8%), and cervical cancer screening (71.9%). Multivariate regression analysis discovered that clinical characteristics of patients (i.e., level of intellectual disability, communication ability, and number of medications) were not significantly associated with preventative service utilization. Multivariate regression analysis variables that were found to be associated with influenza vaccination included age over 40 (aOR: 2.1, 95% CI: 1.2-3.5), living in a group home (aOR: 3.4, 95% CI: 1.8-6.1), Medicaid only insurance (aOR: 1.8, 95% CI: 1.1-3.2), and having had an annual health assessment (aOR: 3.6, 95% CI: 2.1-6.0). Colorectal cancer screening was also associated with having had an annual health assessment (aOR: 2.3, 95% CI: 1.0-5.3). Cervical cancer screening was associated with living in a group home (aOR: 3.8, CI: 1.3-11.2).

Conclusion: Demographic and socioeconomic characteristics were associated with some preventative service utilization, whereas clinical characteristics, such as level of intellectual disability, communication ability, and number of medications, were not. Primary care providers should target patients who live at home for preventative service utilization, address any barriers or concerns families of patients with IDD have, and stress the importance of seeing a physician for an annual health assessment. Further research should continue to evaluate the success group homes have had in assuring preventative service utilization, as well as the broader implications of regulatory oversight at the state level.

Post-Hospitalization Primary Care Follow-Up Abstract

Title: Characteristics that are associated with primary care follow-up and discharge summary receipt post-hospitalization in adults with intellectual and/or developmental disabilities.

Background: Transition from an inpatient to an outpatient setting is a high risk time for patients. Studies in the general population find that poor post-hospitalization primary care follow-up results in higher rates of readmissions – a widely used indicator of healthcare quality. There is no research that evaluates post-hospitalization primary care follow-up or discharge summary receipt in the IDD population.

Objective: To explore the demographic, socioeconomic, and clinical characteristics that are associated with whether an adult with IDD will achieve timely post-hospitalization primary care follow-up.

Methods: A cross-sectional study evaluating 788 hospitalizations of adults with IDD from January 1, 2012 to December 31, 2016 and their primary care follow-up at an IDD-specific multi-specialty outpatient facility. Applicable inpatient admissions were identified using Medicare Quality and Resource Use Reports and linked to the outpatient facilities' electronic medical records in order to capture demographic, socioeconomic, clinical, and follow-up variables on each subject.

Results: A total of 788 hospital admissions completed by 341 unique individuals were identified. This population had a high rate of primary care follow-up (94.8%), and

hospitalization discharge summary receipt (83.5%) within 30 days. Multivariate regression analysis, which controlled for demographics, living situation, level of intellectual disability, hospital, and principal hospital diagnosis, identified that living in non-group home settings was associated with a lower likelihood of timely primary care follow-up and discharge summary receipt when compared to adults with IDD who live in group homes. This analysis also detected that age over 40 was associated with a lower likelihood of primary care follow-up within 7 days (aOR: 0.2, 95% CI: 0.1-0.8) and non-Caucasian race to be associated with a higher likelihood of primary care follow-up within 14 days (aOR: 2.3, 95% CI: 1.0-5.3).

Conclusion: The major variable that predicted timely primary care follow-up and discharge summary receipt was living in a group home. This is most likely due to state-mandated audits of group home policies and procedures. Nevertheless, primary care follow-up for the population evaluated in this study was much better than the general Medicare population. Primary care providers and hospital discharge teams should be cognizant of the challenges and barriers that adults with IDD who live in non-group home settings face. Further research should continue to evaluate the success that group homes have had in post-hospitalization primary care follow-up and communicate their success to other state regulatory groups.

Chapter 1: Introduction

Background

Adults with intellectual and/or developmental disability (IDD) represent 7% of the United States' population (Zablotsky et al., 2017; Krahn & Fox, 2014; Maulik et al., 2011). There is substantial evidence that this group of adults suffer from a range of healthcare disparities when compared to the general population (U.S. Department of Health and Human Services, 2002; Lunskey et al., 2013). These disparities result in inferior health outcomes and higher healthcare expenditures per capita (Fujiura, Li & Magana, 2018). Although there is evidence that healthcare disparities exist, there is a scarcity of research evaluating what is driving these disparities within the population of adults with IDD.

Research in the general population has identified that age and gender appropriate preventative services (e.g., biannual breast cancer screening, yearly influenza vaccination, etc.), as well as timely post-hospitalization primary care follow-up reduce morbidity and mortality of patients, as well as decrease per capita healthcare costs (Winawer et al., 1993; Centers for Disease Control and Prevention [CDC], 2019a). These two distinct, but important healthcare processes, have been important targets for healthcare quality improvement at the organizational and policy levels. However, there is limited research into both of these processes as they pertain to adults with IDD. Adults with IDD are less likely to receive preventative medical care when compared to the general population (Ouellette-Kuntz et al., 2015). However, this research has not

evaluated why or which adults with IDD are less likely to receive these preventative services. Likewise, post-hospitalization primary care follow-up studies exist for the general population, but not for a population of adults with IDD.

This dissertation fills the knowledge gap that exists regarding the characteristics associated with preventative service uptake and timely post-hospitalization primary care follow-up in adults with IDD. This was done through two separate institutional review board approved studies: a study focused on preventative care and a study focused on post-hospitalization primary care follow-up. The primary research objective of the preventative care study was to identify characteristics (i.e., demographic, socioeconomic, and clinical variables) related to whether or not an adult with IDD will receive United States Preventative Service Task Force (USPSTF) or Center for Disease Control and Prevention (CDC) recommended age and gender specific preventative services (i.e., colon, breast, and cervical cancer screening, as well as influenza and pneumococcal vaccinations). The following preventative study's hypotheses can be seen in Table 1.1.

Table 1.1
Preventative Care Study Hypotheses

Hypothesis	Statement
Hypothesis 1	Living in a group home is associated with preventative service utilization, when compared to adults with IDD that do not live in a group home
Hypothesis 2	Nonverbal communication ability is associated with preventative service utilization, when compared to adults with IDD and a communication ability within normal limits
Hypothesis 3	Having had an annual health assessment is associated with preventative service utilization, when compared to adults with IDD that did not have an annual health assessment
Hypothesis 4	High level of intellectual disability is associated with preventative service utilization, when compared to adults with IDD with a lower level of intellectual disability

The primary research objective of the hospitalization study was to evaluate characteristics (i.e., demographic, living situation, level of intellectual disability, and discharge hospital variables) related to whether or not an adult with IDD will receive timely post-hospitalization primary care follow-up (e.g., follow-up within 30 days). A secondary research objective of the hospitalization study was to evaluate characteristics (i.e., demographic, living situation, level of intellectual disability, and discharge hospital variables) that impact whether the primary care practice will receive the post-hospitalization discharge summary. The following hospitalization study's hypotheses can be seen in Table 1.2.

Table 1.2
Hospitalization Study Hypotheses

Hypothesis	Statement
Hypothesis 5	Living in a group home is associated with timely post-hospitalization primary care follow-up, when compared to adults with IDD that do not live in a group home
Hypothesis 6	Living in a group home is associated with timely post-hospitalization discharge summary receipt, when compared to adults with IDD that do not live in a group home

This research is significant because a better understanding of the contributing risk factors that reduce preventative medical service utilization in the IDD population can lead to targeted strategies at the physician–patient encounter and on an organizational or policy level. Sustained increases in preventative service utilization by adults with IDD have the potential to result in improved clinical outcomes and reduced per capita cost of this expensive population (Fujiura, Li & Magana, 2018). Likewise, understanding the trends and challenges with post-hospitalization primary care follow-up can lead to evidence-based operational changes that could transform transitions of care for adults with IDD. The policy implications of this dissertation will be described in the discussion section along with future research questions and hypotheses.

Chapter 2: Literature Review

Definition of Intellectual and/or Developmental Disability (IDD)

A developmental disability is defined as a debilitating long-term condition that appears before the age of 22 and affects an individual's cognition, physical functioning, or both (National Institute of Health [NIH] 2018). Intellectual disability is a subset of developmental disability defined by an individual's limitations in both intellectual capacity and adaptive behavior in conceptual, social, or practical life skills (American Association on Intellectual and Developmental Disabilities [AAIDD], 2018). This specific type of disability originates before the age of 18, and could include physical causes, such as cerebral palsy, or nonphysical causes, such as lack of social stimulation (NIH, 2018).

Categorical distinction between intellectual and/or developmental disability, intellectual disability only, or disability in general (e.g., vision problems, hearing problems, etc.) is important because these are distinct populations with very specific challenges and trends. Although the population of interest for this dissertation is adults with intellectual and/or developmental disability, studies from populations of individuals with intellectual disabilities only and disability in general are also reviewed where applicable.

Prevalence and IDD-Specific Medical Challenges

The prevalence of intellectual and/or developmental disabilities varies between studies. This is attributed to conflicting terminology, diagnostic acumen, data collection, and public health surveillance methods, as well as variability in national administrative databases (Friedman et al., 2018; McConkey et al., 2019). One recent study in the United States using data from the National Health Interview Survey (NHIS) determined that 7% of children between the ages of 3 and 17 have a developmental disability (Zablotsky et al., 2017). This study, among others, have discovered that the subset of individuals with intellectual disabilities make up approximately 1% of the total population (Zablotsky et al., 2017; Krahn & Fox, 2014; Maulik et al., 2011). Again, it is important to note that intellectual disability is a subset of developmental disability and its concomitant prevalence should be lower.

There are a number of demographic trends seen in individuals with IDD. Previous studies have established that intellectual disability prevalence is significantly higher among men than women (i.e., 1.48% vs. 0.90%) (Zablotsky et al., 2017). Although a greater prevalence exists in men, this particular study did not find a significant difference in the prevalence of intellectual disability between races and ethnicities. Nevertheless, researchers have observed that healthcare disparities between minority groups within the population of adults with IDD do exist. One study using the National Core Indicators Consumer Survey, a standardized quality management protocol specifically created for individuals with developmental disabilities, revealed that being a racial minority resulted

in a significantly decreased odds of having recent dental care, primary care, and influenza vaccination (Scott et al., 2014). This same study also found that Hispanic patients were less likely to receive cancer screenings (Scott et al., 2014). This is just one example, but it should be understood that individuals with IDD face many challenges common to the general population, in addition to the challenges that are specific to their particular disability.

Many of the challenges that individuals with IDD face result in healthcare disparities when compared to the general population (US Department of Health and Human Services, 2002; Scheepers et al., 2005; Robertson et al., 2015). Some of these challenges include, but are not limited to, living situation (Lewis et al., 2002), lack of self-determination and empowerment (Shogren et al., 2006), transportation to healthcare appointments (Friedman & Rizzolo, 2008), decreased health literacy and ability to communicate signs and symptoms of disease (Sullivan et al., 2018), caregiver fear of complex medical decision-making and providing consent for treatment (Greenwood et al., 2014), provider dissatisfaction with the required intensity of care and concomitant low reimbursement (Havercamp, S., et al 2004), and the lack of specialized models of care that target the inequalities that individuals with IDD experience across the spectrum of healthcare settings (Wallace, R. A., & Beange, H. 2008; O'Hara, D. 2008).

Many studies have revealed that individuals with IDD suffer from significant clinically-based issues that result in increased morbidity and mortality when compared to the general population (Morin et al., 2012). One large Canadian study detected that adults

with developmental disabilities have three times the prevalence of congestive heart failure, almost twice the prevalence of chronic obstructive pulmonary disease, and are 60% more likely to have diabetes when compared to individuals without IDD (Lunsky et al., 2013). This study also discovered that just under 50% of individuals with developmental disabilities also fit into the dual diagnosis category with at least one behavioral health diagnosis (Lunsky et al., 2013). The reasons for increased medical complexity are multifactorial and stem from the inherent clinical challenges that individuals with IDD face, as well as a lack of agency and self-direction that results in the need for functional and social support (Shogren et al., 2006). This growing evidence of increased medical complexity, resource use, healthcare navigation requirements, and IDD-specific challenges in adults with intellectual and/or developmental disability represents a well-defined and active area of investigation. As such, this dissertation will evaluate preventative care and hospitalization transitions through the framework of these specific challenges.

Preventative Care

One of the primary research objectives of this dissertation was to identify risk factors associated with preventative service utilization. Receiving preventative medical services following guidelines set forth by expert organizations, such as the USPSTF and CDC are important contributors to decreasing patient morbidity and mortality (Winawer et al., 1993; CDC 2019a). Despite this knowledge, when compared to the general

population, individuals with IDD are less likely to receive age and gender appropriate preventative medical services. Although there are many different preventative services for which an individual could be eligible, colorectal, breast, and cervical cancer screenings as well as influenza and pneumococcal vaccinations are standard of care services used frequently in everyday primary care practices. For this reason they are commonly cited measures in evaluating the quality of healthcare that an individual or population is receiving. Standard screening guidelines for colorectal, breast, and cervical cancer, as well as vaccination guidelines for influenza and pneumococcal can be seen in Table 2.1 below.

Table 2.1**United States Preventative Service Task Force (USPSTF) and Center for Disease Control and Prevention (CDC) Preventative Care Recommendations**

Preventative Service	Guidelines Organization	Recommendation
Cervical Cancer Screening	USPSTF	Women 21-64 years of age should be up to date with any of the following screenings: (1) women age 21-64 can have a cervical cytology performed every 3 years; (2) women age 30-64 can have cervical cytology/human papillomavirus (HPV) co-test performed every 5 years (USPSTF 2018).
Breast Cancer Screening	USPSTF	Women 50-74 years of age should have a mammogram at least every 2 years (USPSTF 2016a).
Colorectal Cancer Screening	USPSTF	Adults 50-75 years of age should be up to date with any of the following screenings: (1) fecal occult blood test (FOBT) every 1 year; (2) flexible sigmoidoscopy every 5 years; (3) colonoscopy every 10 years (USPSTF 2016b).
Influenza Immunization	CDC	All adults aged 18 years and older should receive a yearly influenza vaccination (CDC, 2019c).
Pneumococcal Vaccination	CDC	All adults aged 65 years or older should receive the pneumococcal vaccination (CDC, 2019d).

Note: United States Preventative Service Task Force (USPSTF) and Centers for Disease Control and Prevention (CDC)

Following the above screening guidelines is an important health service as colorectal cancer is the fourth most common cancer in the United States. In fact, in 2019 the number of new colorectal cases is estimated to reach 145,600, which represents 8.3% of all new cases of cancer (National Cancer Institute, 2019a). The 5-year survival rate of

colorectal cancer is currently 64.4% with an estimated 51,020 deaths expected in 2019 (National Cancer Institute, 2019a). Although there are a number of different recommended screening methods, a colonoscopy is the most effective method of colorectal cancer screening because the removal of precancerous lesions or polyps has been shown to reduce colorectal cancer incidence by 76-90% (Winawer et al., 1993). This speaks to the importance of regular screening in order to reduce the morbidity and mortality caused by this disease.

Breast cancer is also a very common type of cancer. It is expected to cause 268,600 new cases in the United States in 2019, which represents 15.2% of all new cases of cancer (National Cancer Institute, 2019b). The 5-year survival rate of breast cancer is currently 89.9% with an estimated 41,760 deaths in 2019 (National Cancer Institute, 2019b). This high survival rate can be attributed to early detection and advances in disease treatment. Again, this signifies the importance of adherence to current screening guidelines.

While not the deadliest, cervical cancer is set to account for an estimated 13,170 new cases in 2019, which represents 0.7% of all new cases of cancer (National Cancer Institute, 2019c). The 5-year survival rate of cervical cancer is currently 65.8% with an estimated 4,250 deaths in 2019 (National Cancer Institute, 2019c). This makes cervical cancer an easy target for primary care prevention that can result in decreased disease incidence.

Although it is not a type of cancer, the influenza (flu) virus causes a large disease burden each year in the United States which can be reduced by yearly influenza vaccination. The CDC estimate that from October 1, 2018 through May 4, 2019 there were between 37.4-42.9 million influenza illnesses, 17.3-20.1 million influenza-associated medical visits, 531,000-647,000 influenza hospitalizations, and 36,400-61,200 influenza deaths (CDC, 2019a). It is important to note that these are estimated ranges because influenza is not a reportable disease in many areas of the United States. Nevertheless, the morbidity, mortality, and total healthcare expenditure for combating influenza is high, especially in vulnerable populations (Lewis et al., 2002; Tacken et al., 2002).

Pneumonia is a respiratory disease caused by either bacteria or viruses and results in a large disease burden in the United States each year. The CDC attributed 49,157 deaths in the United States population to pneumonia in 2017 (CDC 2019b). That is approximately 15.1 deaths per 100,000 individuals. Although the pneumococcal vaccination only targets the pneumococcal virus, it is the most common cause of pneumonia. The pneumococcal vaccination is especially important in adults with IDD because of their increased risk of aspiration and the concomitant pneumonia that often follows (Sheppard et al., 2017).

There have been a number of previous studies of adults with IDD and the preventative care they receive. Table 2.2 below provides a list of select preventative care studies in adults with IDD and their corresponding screening and vaccination rates. These

studies were identified using the PubMed database with search terms “preventative care,” “IDD,” “intellectual disability,” “disability,” “colorectal cancer screening,” “breast cancer screening,” “cervical cancer screening,” “influenza vaccination,” and “pneumococcal vaccination.” Following this table is a discussion of the significant findings of each specific study.

Table 2.2**Select Preventative Care Studies in Adults with Intellectual and/or Developmental Disabilities**

Author	Journal	Data Source	Influenza Vaccination Rate (n)	Colon Cancer Screening Rate (n)	Breast Cancer Screening Rate (n)	Cervical Cancer Screening Rate (n)
Xingling et al., 2017	Preventive Medicine	South Carolina Medicaid/Medicare Data (2000-2010)	N/A	N/A	22.2% (2912)	24.3% (5490)
Deroche et al., 2017	Preventive Medicine	South Carolina Medicaid/Medicare Data (2000-2009)	N/A	34.32% (7,778)	N/A	N/A
Cobigo et al., 2013	Journal of Intellectual Disability Research	Ontario Health Administration Database (2009-2010)	N/A	N/A	41.6% (5,171)	34.3% (16,663)
Ouellette-Kuntz et al., 2015	Journal of Applied Research in Intellectual Disabilities	Ontario Health Administration Database (2009-2010)	N/A	32% (15,791)	52.2% (7,022)	33.7% (26,301)
Horner-Johnson et al., 2014	Health Services Research	U.S. Medical Expenditure Panel Survey (2002-2008)	N/A	45.3% (540) ^a	N/A	N/A
Shin et al., 2018	Journal of Oncology	South Korea National Disability Database (2015)	N/A	N/A	N/A	22% (20,226)
Sullivan et al., 2003	Preventive Medicine	Australian National Database (1982-2000)	N/A	N/A	34.7% (380)	N/A
Tretarre et al., 2016	Journal of Intellectual Disability Research	Disabled Persons Healthcare Survey (France; 2009)	N/A	N/A	64.2% (310) ^b	N/A
Lewis et al., 2002	Public Health Reports	Medical Record Review (California; 1997)	45.5% (325)	N/A	N/A	39.1% (169)

^acognitive disability only,^binstitutionalized individuals only

Xinling et al. (2017) used South Carolina Medicaid and Medicare data between 2000 and 2010 to evaluate breast and cervical cancer screenings. This study's primary objective was to compare screening rates between women with and without IDD. Within the IDD population this study identified a breast cancer screening rate of 22.2% (n=2,912) and cervical cancer screening rate of 24.3% (n=5,490). Xinling et al. (2017) revealed that women with IDD were less likely to undergo both breast cancer screening (aOR: 0.63, 95% CI: 0.55-0.72) and cervical cancer screening (aOR: 0.17, 95% CI: 0.16-0.19) when compared to women without IDD. This study's secondary objective was to identify characteristics associated with breast and cervical cancer screenings among women with and without IDD. Using a multivariate regression analysis, this study observed that insurance type (i.e., Medicaid only, Medicare and Medicaid) and type of residence (i.e., alone/with family, group home, medical facility) were associated with both breast and cervical cancer screenings. More specifically, women with IDD who lived in a group home and had Medicaid and Medicare (dual insurance) were more likely to undergo full adherence to breast (aOR: 7.52, 95% CI: 2.24-25.25) and cervical cancer screening (aOR 6.27, 95% CI: 1.95-20.16) guidelines when compared to women living alone/with family and those with Medicaid only insurance (Xinling et al., 2017).

Similar to the above study, Deroche et al. (2017) also used South Carolina's State Medicaid and Medicare database between 2000-2009. The primary research objective was to compare colorectal cancer screening between adults with and without IDD. The study determined that adults with IDD who were eligible for colorectal cancer screening

were much less likely to receive the service when compared to adults without IDD (aOR: 0.55, 95% CI: 0.52-0.59) (Deroche et al., 2017). Both Xinling et al. (2017) and Deroche et al. (2017) derive their strength from a reliable state level data source and its ability to follow adherence over a large time period. However, it is important to note that this study does not use any private payer data and using ICD codes has its own limitations in appropriately identifying all adults with IDD because often times an IDD specific code is not used for billing purposes (Lin et al., 2013).

Cobigo et al. (2013) published a population study using health administrative databases and registries from Ontario, Canada for 2009 and 2010 showing breast and cervical cancer screening rates for women with and without IDD and then compared these rates between the two groups. Using a multivariate logistic regression model that controlled for age, rurality (i.e., rural vs. urban), income, and healthcare resource utilization, the researchers found that women with IDD were less likely to undergo cervical cancer screening (aOR: 0.21, 95% CI: 0.20-0.21) and breast cancer screening (aOR 0.46, 95% CI: 0.43-0.49) when compared to women without IDD (Cobigo et al., 2013). One of the strengths of this study is the fact that it was the first of its kind controlling for age, rurality, income, and healthcare utilization.

In addition, Cobigo et al. (2013) mentions that there is little evidence regarding the impact of living situation on health outcomes in the IDD population and specifically on preventive care utilization (Cobigo et al., 2013). It is also suggested that the variations in screening rates of the IDD population in this study, as well as previous studies, may be

due to differing national healthcare delivery systems which may or may not include IDD-specific preventative care programs run by the government that may play some causative role (Cobigo, et al 2013).

Using the same health administrative databases and registries from Ontario, Canada, Ouellette-Kuntz et al. (2015) also examined colorectal cancer screening adherence for adults with and without IDD between 2000 and 2010. This study observed that the percentage of Ontarians who adhered to recommended colorectal screening guidelines was higher for individuals without IDD (47.2%) than with IDD (32.0%), a difference of -15.2% (Ouellette-Kuntz et al., 2015). This study also produced similar results for breast (-18.5% difference) and cervical cancer screenings (-33.0% difference) as Cobigo et al. (2013) (Ouellette-Kuntz et al., 2015).

Horner-Johnson et al. (2014) used data from the Medical Expenditure Panel Survey (MEPS), which is administered by the Agency for Healthcare Research and Quality (AHRQ) to evaluate disability status and colorectal cancer screening in the United States. Using data between 2002 and 2008, one of this study's objectives was to compare disability type (i.e., hearing, vision, physical, and cognitive) and colorectal cancer screening. Using a multivariate model that controlled for perceived physical and mental health status, body mass index, diabetes, arthritis, stroke, cardiovascular disease, lung disease, gender, age, race/ethnicity, and complex activity limitations, this study determined the odds of never having had any colorectal cancer screening (i.e., colonoscopy, sigmoidoscopy, or blood stool tests) in the various disability groups to be

distributed as follows: hearing (Reference aOR: 1) visual (aOR: 1.55, 95% CI: 1.27-1.89); physical (aOR: 1.19, 95% CI: 1.01-1.4); cognitive (aOR: 1.66, 95% CI: 1.26-2.17); and more than one disability category (aOR: 1.16, 95% CI: 0.98-1.38) (Horner-Johnson et al., 2014). It is important to mention that although cognitive disability had the highest adjusted odds ratio, the confidence interval bands overlap between all categories except hearing. This means that cognitive disability is significantly associated with a higher likelihood of never undergoing colorectal cancer screening when compared to hearing, but not the visual, physical, and more than one disability categories. This study is also subject to respondent bias due to the survey methodology used.

Shin et al. (2018) evaluated cervical cancer screening rates in South Korea between 2014 and 2015 using the Korean National Health Insurance Service (NHIS) database, which accounts for 97% of Koreans. One of the primary objectives was to evaluate if cervical cancer screening rates were dependent upon degree (e.g., mild vs. severe) and type of disability (e.g., hearing, visual, hearing, intellectual, speech and language, etc.). Their multivariate model that controlled for age, income, and place of residence, discovered that screening for cervical cancer was lower among intellectual disability (aOR: 0.25, 95% CI: 0.25-0.26) when compared to no disability (ref. 1), physical disability (aOR: 0.95, 95% CI: 0.94-0.95), visual disability (aOR: 0.79, 95% CI: 0.78-0.80), hearing disability (aOR: 0.62, 95% CI: 0.62-0.63), and speech and language disability (aOR: 0.58, 95% CI: 0.54-0.62) (Shin et al., 2018). When comparing disability severity, this study found severe disability (aOR: 0.42, 95% CI: 0.42-0.42) to be

associated with a lower likelihood of cervical cancer screening than mild disability (aOR: 0.92, 95% CI: 0.92-0.93) (Shin et al. 2018). It is important to note that disability severity in this study only includes physical disability, whereas the disability severity variable used later in this dissertation accounts for intellectual disability severity (i.e., mild, moderate, severe, and profound) based off subjective intelligence quotient (IQ) determinations by a healthcare provider.

In a smaller study, Sullivan et al. (2003) evaluated breast cancer screening rates in Western Australia between 1982 and 2000 using the Western Australia Disability Service database which was linked to the Western Australia Cancer Registry and Mammography Screening Registry. This study observed that breast cancer screening was lower for individuals with IDD (34.7%) when compared to the general population (54.6%). In addition to this, the multivariate model determined that both levels of disability (i.e., mild, moderate, and severe) and institutional care to be nonsignificant characteristics associated with breast cancer screening in this population.

Tretarre et al. (2016) evaluated breast cancer screening among women living in institutions in France using the nationally recognized disabled person's survey. As seen in Table 2.2 above, 64.2% of the 310 eligible women with IDD living in institutions received a mammography within the last two years, which is in adherence with the recommended national screening schedule (Tretarre et al., 2016). This study also identified that women with IDD living in community-style residential facilities were screened for breast cancer more often than women with IDD living in specialized

institutions (85.9% vs. 68.3%, $P=0.001$) (Tretarre et al., 2016). One limitation of this investigation is that the researchers did not account for confounders by using a multivariate model evaluating breast cancer screening success and instead employed the Chi-squared test, which is subject to omitted variables bias. Other limitations of this study include the introduction of response bias due to the nature of the self-reported survey data used, as well as the lack of power from the small sample size ($n=310$).

There are very few studies evaluating yearly influenza and pneumococcal vaccinations in the IDD population. Lewis et al. (2002) presented results from a retrospective medical chart review on 325 adults (18 years of age and older) with developmental disability. Of the 325 subjects, this study determined that 45.5% (169) had their yearly influenza vaccination in 1997 (Lewis et al., 2002). This study also used a multivariate analysis that evaluated living situation and influenza vaccination while controlling for sex, ethnicity, severity of mental retardation, bladder continence, ability to perform activities of daily living (ADL's), and physician graduate status. It discovered that developmentally disabled individuals living in community settings were more likely to receive their yearly influenza vaccination when compared to developmentally disabled individuals living at home with or without assistance (aOR: 0.15, 95% CI: 0.07-0.35) or living with family/friends (aOR: 0.16, 95% CI: 0.08-0.36) (Lewis et al., 2002).

The limitations of Lewis et al. (2002) include a small sample size from a single ambulatory center, as well as the potential for incompleteness of the medical records used as the data source (i.e., undocumented influenza vaccination). Proper documentation of

the receipt of any age and gender appropriate preventative health service is important in order to track that an individual is meeting their applicable healthcare milestones. This is especially important for the influenza vaccination because of both its high morbidity and mortality, as well as the multiple healthcare facilities that now offer the yearly influenza vaccination (e.g., primary care provider, pharmacy, health fair, etc.). Documentation of the influenza vaccination is especially important because previous research has shown that adults without IDD will over report vaccination, stating that they had previously received vaccination when in fact they did not (Torres & Alzuria, 2018).

Similarly, Khan et al. (2018) also evaluated the association between race/ethnicity, disability status, and the receipt of an influenza vaccination within the previous 12 months and whether or not an individual has ever had a pneumococcal vaccination. This study used telephonic survey data from the Florida Behavioral Risk Factor Surveillance System (FBRFSS) for 2011 through 2015. Khan et al. (2018) only included adults 65 years of age or older and identified individuals as having a disability if they responded yes to one of two questions: (1) “Are you limited in any way in any activities because of physical, mental, or emotional problems?” and/or (2) “Do you now have any health problems that requires you to use special equipment, such as a cane, a wheelchair, or a special telephone?” (Khan et al., 2018). The multivariate analysis of this study controlled for age, gender, education, employment, income, marital status, insurance, and primary care continuity. The analysis detected that when compared to individuals without a disability, individuals with a disability were both more likely to

have received the influenza vaccination in the last twelve months (aOR: 1.26, 95% CI: 1.15-1.39) and to have received the pneumococcal vaccination at least once in their lifetime (aOR: 1.43, 95% CI: 1.27-1.60) (Khan et al., 2018).

The major limitations of Khan et al. (2018) include the respondent bias introduced by the survey methodology, as well as the sampling bias (i.e., certain subgroups of individuals with intellectual disability may not have access to a telephone). The influenza data is also only for older adults and not directly applicable to this dissertation's evaluation of the influenza vaccination compliance of all aged adults.

In summary, research into preventative care utilization in adults with IDD is a relatively new domain with few studies, especially from the United States. Nevertheless, there is a great deal of variation in the available results, suggesting that country or state policy and programs might have a significant impact on the preventative care utilization of their population. There have been no prior studies in New York State looking into the preventative service utilization of adults with IDD. This is important because state regulations and policy strongly contribute to healthcare quality and access for individuals with IDD.

In addition to a novel geographic catchment area and governing body, this dissertation will also evaluate novel variables (i.e., communication ability, number of medications, annual health assessment) that have not been used in previous studies, but may be associated with preventative service utilization. This is possible because of its

electronic medical record review methodology, which allows for the capture of health data elements that are not as readily available using the current IDD literature's most commonly used data sources (i.e., insurance billing codes, national registries). For example, a patient's communication ability (e.g., nonverbal vs. within normal limits) or the number of medications they are on (e.g., 12 medications) would not be searchable data elements using national registries. That said, this study has multiple opportunities to provide an innovative approach to identifying characteristics associated with preventative service utilization.

Post-Hospitalization Primary Care Follow-Up

Another primary aim in this study is to evaluate characteristics associated with timely post-hospitalization follow-up and hospitalization discharge summary receipt in adults with IDD. Transitions of care from an inpatient to outpatient setting is a high risk period. Both the role and responsibility of the receiving primary care provider and hospital discharge team are critical in ensuring that a smooth transition is achieved. Transition of care research has focused on the general population with little evaluation into the IDD population. This dissertation, therefore, evaluated the current literature surrounding hospitalizations in the IDD population, as well as readmissions, and post-hospitalization transitions in the general population (Table 2.3). These studies were discovered using the PubMed database with search terms "hospitalizations," "IDD,"

“intellectual disability,” “disability,” “readmissions,” “primary care follow-up,” and “post-hospitalization follow-up.”

Table 2.3

Select Hospitalization Studies in Adults with Intellectual and/or Developmental Disabilities

Author	Title	Journal	Data Source	IDD Study	Major Applicable Findings
Ailey et al., 2014	Hospitalizations of adults with intellectual disability in academic medical centers.	Intellectual and Developmental Disabilities	Medical Records (University Health System Consortium; 2011-2013)	Yes	Major admission diagnosis provided. Adults with IDD are more likely to stay in the ICU and have complications for certain diagnostic categories.
Hosking et al., 2017	Preventable emergency hospital admissions among adults with intellectual disability in England.	Annals of Family Medicine	United Kingdom National Health Administration Database (2009-2013)	Yes (intellectual disabilities)	Adults with intellectual disabilities have a much higher admission rate than adults without intellectual disabilities for all conditions and for ambulatory care-sensitive conditions.
Blaskowitz et al., 2019	Predictors of emergency room and hospital utilization among adults with intellectual and developmental disabilities (IDD).	Intellectual and Developmental Disabilities	Residential Housing Records (New York City; 2011)	Yes	Age and chronic conditions increase the likelihood of hospitalization in adults with IDD.

Balogh et al., 2018	All-cause, 30-day readmissions among persons with intellectual disabilities and mental illness	Psychiatric Services	Ontario Health Administration Database (2010-2011)	Yes	Compared with those with mental illness only, individuals with IDD and mental illness were 1.7 times more likely to experience a hospital readmission within 30 days.
Bailey et al., 2019	Characteristics of 30-day all-cause hospital readmissions, 2010-2016	Healthcare Cost and Utilization Project	National Readmissions Database (United States; 2010-2016)	No	Readmissions for the Medicare population was its lowest at 17.1% in 2016. Readmissions were highest among Medicare patients aged 21-64 at 21.2% in 2016.
Jencks et al., 2009	Rehospitalizations among patients in the Medicare Fee-for-service program	The New England Journal of Medicine	Medicare Claims (United States; 2003-2004)	No	Readmissions for the Medicare fee-for-service population was 19.6%. Total cost of unplanned readmissions in 2004 was \$17.4 billion. Of readmissions, 50.1% did not have an outpatient office visit within 30 days of discharge.
Delia et al., 2014	Post-discharge follow-up visits and hospital utilization by Medicare patients, 2007-2010	Medicare & Medicaid Research Review	Medicare Claims (United States; 2007-2010)	No	Black, Hispanic, and Medicaid/Medicare beneficiaries were less likely to follow up post-hospitalization.
Misky et al., 2010	Post-hospitalization transitions: Examining the effects of timing of primary care follow-up	Journal of Hospital Medicine	In-hospital interview followed by phone interview 4 weeks later (University of Colorado	No	Adults without timely follow-up are 10 times more likely to be readmitted.

			Hospital; 2007)		
Mainous et al. 1998	The importance of continuity of care in the likelihood of future hospitalization: Is site of care equivalent to a primary clinician?	American Journal of Public Health	Medicaid Claims (Delaware; 1993-1995)	No	Higher continuity of care with both a single clinician and/or practice result in a lower likelihood of hospitalization.
Rayan-Gharra et al., 2019	Patients' ratings of the in-hospital discharge briefing and post-discharge primary care follow-up: The association with 30-day readmissions.	Patient Education and Counseling	Discharge instruction questionnaire (Israel; 2013-2014)	No	Adults with primary care follow-up within 2 weeks were less likely to be readmitted. Primary care provider discharge instruction reviews were superior to in-hospital discharge instruction reviews. The quality of primary care provider discharge instruction reviews significantly impacted readmission rates.

Ailey et al. (2014) used descriptive data from the University Health System Consortium (115 U.S. academic medical centers) to evaluate common hospitalization causes, the need for intensive care units (ICU), and complication rates for adults with IDD. Using data from 2011 through 2013 based off Medicare Severity Diagnosis Related Groups (MS-DRGs), this study identified the top five hospitalization causes for adults with IDD as psychoses (16.9% of total discharge MS-DRGs), seizure disorders (7.9%),

septicemia (5.4%), respiratory infections (3.1%), and pneumonia (2.8%) (Ailey et. al., 2014). In addition to presenting the top 5 diagnosis, this study used Chi-square statistics to detect differences in the percentage of ICU stays and complications between adults with and without IDD for these top 5 diagnosis. Ailey et. al. (2014) found that when compared to adults without IDD, adults with IDD had a statistically significant larger percentage of ICU stays for psychoses ($p<0.01$), septicemia ($p<0.01$), and pneumonia ($p<0.01$), as well as a statistically significant larger percentage of complications for psychoses ($p<0.01$), seizures ($p<0.01$), and respiratory infections ($p<0.01$) (Ailey et al., 2014). The findings in this study speak to the complex nature of managing care for individuals with IDD.

One of the major caveats of Ailey et al.'s 2014 study is that intellectual disability may not have been identified for all admissions if it was not listed as a secondary diagnostic code in the medical record. For example, an individual might meet the criteria for IDD, but if the IDD code was not entered into the medical record, this individual would have been incorrectly included in the adults without IDD group. Based on my three years of experience working at Westchester Institute of Human Development (WIHD) with this population, the frequency of this error is low; but, it has the potential to skew diagnostic prevalence and comparison results to some unknown degree in an unknown direction.

Hosking et al. (2017) conducted a retrospective matched cohort study in the United Kingdom comparing the hospitalizations of adults with and without intellectual

disabilities using a national health administrative database with information from both primary care practices and hospitals. This study gained its strength from its large sample size of 16,666 adults with intellectual disabilities and 113,562 matched (i.e., age, sex, primary care practice) adults without intellectual disabilities (Hosking et al., 2017). One of the major research findings was that adults with intellectual disability have a much higher admission rate than adults without intellectual disability overall (Incidence Rate Ratio [IRR]: 2.16, 95% CI: 2.02-2.30), as well as for specific admission reasons such as aspiration (IRR: 85.9, 95% CI: 45.3-162.9), constipation (IRR: 6.79, 95% CI: 5.17-8.91), epilepsy/seizures (IRR: 31.2, 95% CI: 24.6-39.5), pneumonia (IRR: 5.59, 95% CI: 4.85-6.45), and urinary tract infections (IRR: 4.76, 95% CI: 3.99-5.68) (Hosking et al., 2017).

Hosking et al. (2017) also evaluated these specific diagnosis through the framework of ambulatory care-sensitive conditions (ACSCs), which are well-defined conditions wherein effective primary care management could limit or eliminate the need to be hospitalized for the specific diagnosis. This category of common ambulatory care-sensitive conditions is used as an indicator of the quality of primary care management to which an individual or population has access. When comparing ACSCs between adults with and without intellectual disability, matched based on age, sex, and practice, adults with intellectual disabilities are much more likely to be admitted for these ambulatory sensitive conditions (aIRR: 3.6, 95% CI: 3.25-3.99) (Hosking et al., 2017). The results of this study support the complex nature of adults with intellectual disability, as well as the

increased likelihood of both general admission and admission for conditions that could be treated on an outpatient basis.

Blaskowitz et al. (2019) evaluated predictors of emergency room and hospitalization of 597 adults with IDD who live in New York City and the surrounding area during 2011. However, unlike this dissertation's use of Medicare data and electronic medical records, this study utilizes a survey that was completed by New York residential program nurses. Blaskowitz et al. (2019) collected data on age, sex, type of disability, level of intellectual disability, chronic conditions, presence of mental illness, polypharmacy, and supported living arrangement (i.e., institutional settings, group home, or supported living). In the multivariate model used to predict hospitalization, the only characteristics that were predictive included age and the number of chronic health conditions (Blaskowitz et al., 2019). Every additional year of age resulted in a 4% increase in the odds of hospitalization (aOR: 1.04, CI: 1.02-1.06, $p=0.001$) and each additional chronic condition resulted in about a 20% increase in the odds of hospitalization (aOR: 1.19, CI: 1.04-1.37, $p=0.02$) (Blaskowitz et al., 2019).

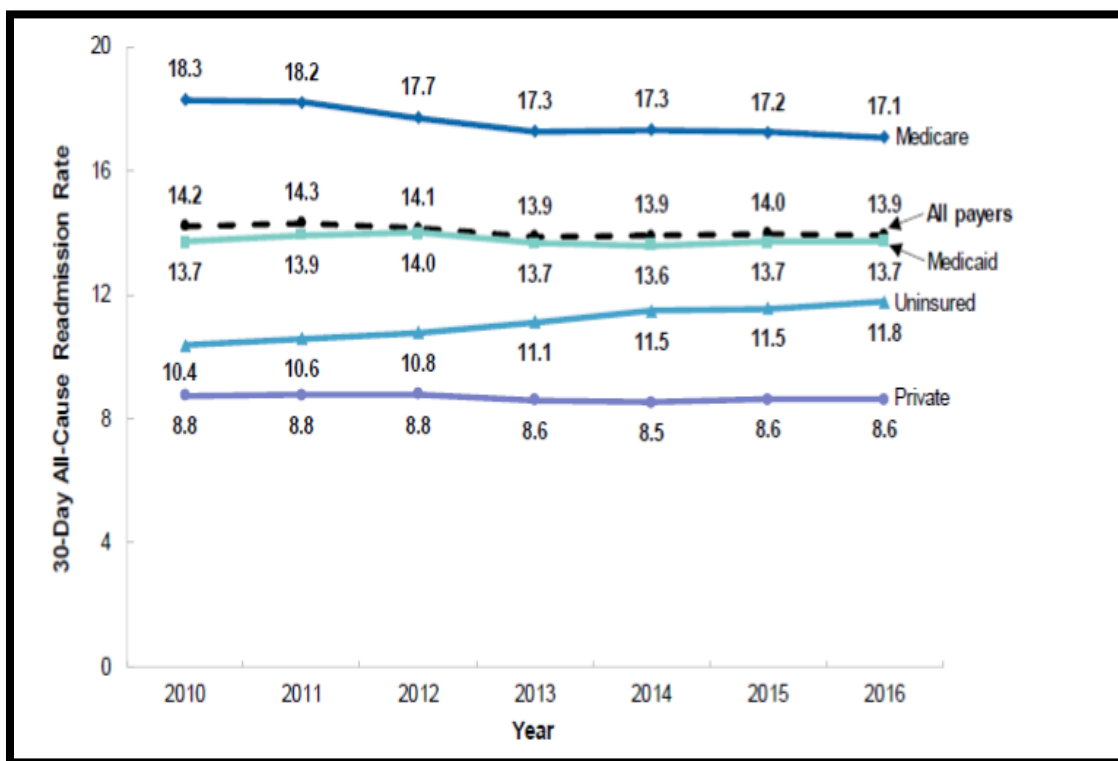
The generalizability of this study is limited by its power. More specifically, only 91 of the 597 adults had any hospital admission during the study period, resulting in a relatively broad confidence interval. Also, the data collection methodology used was a survey completed by nurses in residential programs, which has the potential to incorporate respondent bias that could affect the study's internal validity. There was also potential for information bias as the nurses were supposed to base their survey responses

off medical records housed in the residence that may not be complete (e.g., missing information on a hospitalization that occurred). In addition to this, this study did not compare adults with IDD who live in non-group home settings, which is a primary knowledge gap that this dissertation will evaluate in terms of post-hospitalization primary care follow-up.

Balogh et al. (2018) uses 2010-2011 data from an Ontario-based health administrative database to compare all-cause 30-day readmissions between three separate groups: (1) adults with IDD; (2) adults with IDD and mental illness; and (3) adults with mental illness only. Researchers uncovered a 10.2% readmission rate for individuals with IDD, a 14.7% readmission rate for individuals with IDD and a mental illness, and an 8.2% readmission rate for adults with mental illness only (Balogh et al., 2018). This amounts to a readmission rate that is 1.7 times greater for adults with IDD and mental illness when compared to adults with mental illness only (Balogh et al., 2018). Such a large sample study is also important because it reveals an interaction effect between an IDD diagnosis and mental illness causing all-cause 30 day hospital readmissions.

Bailey et al. (2019) conducted another readmission study with the Agency for Healthcare Research and Quality (AHRQ) in the United States as part of the federally funded Healthcare Cost and Utilization Project (HCUP). Unlike the previous studies presented in this section, this study sampled from the entire United States population from 2010 through 2016 using information taken from the National Readmissions Database. The readmission rates for different payer types can be seen in Figure 2.1 below

(Bailey et al., 2019). Bailey et al. (2019) detected that Medicare patients have the highest readmission rate among payer types; however, this rate decreased significantly from 18.3% in 2010 to 17.1% in 2016. This decrease in readmission rates is likely a result of the linking of readmission rates with lower hospital claim payments (Bailey et al., 2019).



Note: Agency for Healthcare Research and Quality (AHRQ), Center for Delivery, Organization, and Markets, Healthcare Cost and Utilizations Project (HCUP), 2010-2016 Nationwide Readmissions Database (NRD)

Figure 2.1 - Rate of 30-day all-cause readmissions by expected payer, 2010-2016

Bailey et al. (2019) also identified the highest readmission rates in Medicare patients to occur in the 21-64 age bracket (21.2%). This is important for this study as only certain populations of individuals can be eligible for Medicare under the age of 65. More specifically, this eligible group between 21-64 years of age is made up of individuals who meet the criteria for social security disability, individuals with end stage renal disease (ESRD), or Amyotrophic Lateral Sclerosis (ALS) (Center for Medicare Advocacy, 2019). As such, most adults with IDD qualify for social security disability and as a result make up a large portion of the Medicare population aged 21-64 (Center for Medicare Advocacy, 2019). It is important to mention, Social Security Disability is a federally-funded process, states are responsible for the “disability determination process” and the concomitant Medicare benefits that come with a successful social security disability claim (Social Security Administration [SSA], 2019).

In an older study out of *The New England Journal of Medicine*, Jencks et al. (2009) used Medicare claims data from 2003-2004 to evaluate rehospitalizations among all fee-for-service payers. This study observed similar rehospitalization rates to Bailey et al. (2019) amounting to 19.6% of all hospitalizations, but also estimated the total cost of unplanned reshospitalizations in 2004 to amount to \$17.4 billion of the \$102.6 billion Medicare hospital payments made that year (Jencks et al., 2009). This study also found New York to have a higher rehospitalization rate than the national average at 20.7% (Jencks et al., 2009). The top four most frequent medical reasons for rehospitalization, in order of decreasing frequency, were heart failure, pneumonia, psychoses, and chronic

obstructive pulmonary disease (Jencks et al., 2009). An important finding in this study is that 50.1% of patients who were rehospitalized did not have a bill associated with an outpatient visit within 30 days of discharge (Jencks et al., 2009). This suggests that primary care follow-up soon after discharge is lacking and may be protective against readmission and a target for healthcare quality improvement. The timely post-hospitalization transition of care is precisely what this dissertation is evaluating in adults with IDD.

Delia et al. (2014) further evaluated post-discharge follow-up trends using Medicare claims data for index admissions of heart failure, acute myocardial infarction, and community-acquired pneumonia. The major findings include a significant increase in the incidence of post-discharge follow-up among the three diagnostic cohorts from 2007 to 2010 (Delia et al., 2014). In addition, the researchers also sought to identify the characteristics associated with post-hospitalization follow-up. Using a regression analysis, they determined that follow-up visits were less likely for patients with racial designation of black, ethnicity designation of Hispanic, and dual insurance coverage (Medicaid and Medicare) (Delia et al., 2014). These racial, ethnical, and socioeconomic follow-up disparities have been documented previously and are a strong reason why these variables have been included in this dissertation's analysis.

Another smaller study out of the University of Colorado Hospital, conducted by Misky et al. (2010) using a prospective cohort of 65 patients, evaluated post-hospitalization transitions of care and the impact of timely primary care follow-up (i.e., 4

weeks) on readmission rates. Misky et al. (2010) noted the successfully completion of timely primary care follow-up to be 49.2% for the entire sample, which was a similar result to Jencks et al. (2009). Using a multivariate logistic regression model controlling for demographics, insurance type, and readmission condition (i.e., same condition, other care for same condition, and any other condition), Misky et al. (2010) observed that readmission for the same condition was almost 10 times more likely for those without timely primary care follow-up (aOR: 9.9, 95% CI: 1.20-84.7, $p=0.4$) and that a lack of insurance was associated with primary care follow-up noncompliance (i.e., 29% vs. 56%, $p=0.06$). This study benefited from the prospective design, but would have benefited from a larger sample size in order to reduce the size of the confidence interval bands and the p-value for lack of insurance to see if it was truly associated with primary care follow-up.

Despite its age, Mainous et al.'s 1998 study in the *American Journal of Public Health* evaluated both primary care clinician continuity and practice continuity with their related effect on hospitalizations. This study evaluated the general adult population in Delaware using Medicaid claims data from 1993-1995. The study defined high clinician or practice continuity as accounting for greater than 50% of an individual's total visits. Mainous et al. (1998) reported a 9.8% hospitalization rate in the high clinician continuity group, a 13.4% hospitalization rate in the high practice/low clinician continuity group, and a 14.0% hospitalization rate in the low practice/low clinician continuity group

($p=0.0001$). These rates suggest that both high clinician and high practice continuity result in lower hospitalization rates.

In addition, using a multivariate logistic regression analysis that controlled for age, gender, race, county of residence, Medicaid eligibility (i.e., social security income vs. aid to families with dependent children/extended eligibility), number of ambulatory visits, and case mix (i.e., 34 ambulatory diagnostic categories), Mainous et al. (1998) identified that there was a lower probability of hospitalization in the high clinician continuity group (aOR: 0.75, 95% CI: 0.66-0.87) when compared to the high practice/low clinician continuity group. This study points to the importance of both the patient-physician and patient-practice relationship in reducing hospitalizations in the general adult population.

More recently, Rayan-Gharra et al. (2019) studied transitions of care at a tertiary medical-center in Israel. The researchers compared patients' ratings of the in-hospital discharge briefing to the post-discharge primary care follow-up visit and whether or not the quality of instructions provided in the hospital or office had an effect on 30-day all-cause hospital readmissions. Rayan-Gharra et al. (2019) employed a prospective cohort design to administer a quantitative (score of 1-5) baseline questionnaire regarding the quality of the discharge instructions in the hospital (i.e., medication review, referral and diagnostic test instructions, warning signs and symptoms, self-care, and a review of what happened in the hospital) to 594 patients, followed by telephonic surveying of these patients to see if they had completed their primary care visits post-discharge. If they had,

the same quantitative questionnaire was used to assess the quality of the discharge instructions provided by their primary care provider. Lastly, each patient's records were subsequently reviewed using the hospital database to check for readmissions (Rayan-Gharra et al., 2019).

Using *t*-tests to compare the mean scores of in-hospital and primary care provider discharge ratings, Rayan-Gharra et al. (2019) determined that patients rated the primary care provider post-discharge review higher than the in-hospital discharge instructions (3.46 vs. 3.17, $p < 0.001$). The particular component items that were rated significantly higher for the primary care provider included referral and diagnostic test instructions (3.62 vs. 3.34, $p < 0.001$), warning signs and symptoms (3.28 vs. 2.67, $p < 0.001$), and self-care (3.45 vs. 3.02, $p < 0.001$) (Rayan-Gharra et al., 2019). Using a multivariate logistic model, this study also showed that having a primary care visit within two weeks of discharge was associated with a lower likelihood of readmission (aOR: 0.25, 95% CI: 0.11-0.56) and that the primary care provider post-discharge summary score was also associated with a lower likelihood of readmission (aOR: 0.35, 95% CI: 0.26-0.45) (Rayan-Gharra et al., 2019). The magnitude of these results highlight the importance of different components of a transition of care from the hospital to the community. Specifically, timely follow-up with a primary care provider and the quality of discharge instruction review (as reported by the patient) significantly impacts readmission rates while most likely improving health outcomes.

Evaluating transitions of care and their impacts on readmission rates and the health of newly discharged patients is difficult because the investigator needs both accurate hospitalization and primary care practice level data. Previous studies in the IDD population have only utilized hospitalization and hospitalization readmission data. Based on these studies, the IDD population is subject to higher hospitalization and readmission rates, as well as complications and more critical stays (i.e., ICU utilization). Additionally, the IDD population tends to go to the hospital more for ambulatory care sensitive conditions relative to the general population. From studies in the general population, readmissions are costly and frequent, especially in individuals that have Medicare, while timely post-hospitalization follow-up and thoroughly explained discharge instructions can result in reduced readmissions.

This study aims to leverage access to both the electronic medical record at an IDD-specific outpatient medical practice, the Westchester Institute for Human Development (WIHD), and the practices concomitant in Medicare Quality and Resource Use Reports (QRURs), which provide accurate hospitalization data on patients attributed to this practice. The objective is to use this research as an opportunity to describe hospitalizations in the Medicare IDD population, as well as the characteristics (i.e., demographic, living situation, and level of intellectual disability variables) associated with outpatient follow-up and discharge summary receipt post hospitalization. Filling this knowledge gap is vital because a better understanding of transitional care in the Medicare IDD population can lead to targeted regulatory, policy, and operational strategies to

reduce hospitalization readmission, improve patient outcomes, decrease per capita costs, and improve patient satisfaction.

Chapter 3: Research Methods

Study #1 Methodology – Characteristics Associated with Preventative Care Utilization in Adults with Intellectual and/or Developmental Disabilities.

Study Design

This study utilized a cross-sectional study design utilizing electronic medical records from January 1, 2017 through December 31, 2017.

Setting Description

The Westchester Institute for Human Development (WIHD) is an Article 28 Diagnostic and Treatment Center located in Westchester County, New York. This integrated multi-specialty outpatient medical facility provides comprehensive health services to over 5,000 adults with intellectual and/or developmental disabilities (IDD) each year (WIHD, 2019a). These individuals complete over 30,000 visits to over 50 medical professionals who comprise the staff at WIHD and focus on a range of

specialties including, but not limited to, primary care, cardiology, dermatology, endocrinology, otolaryngology, nutrition, ophthalmology, physiatry, podiatry, psychiatry clinical and behavioral psychology, urology, assistive technology, dentistry, audiology, and speech-language pathology (WIHD, 2019b). The catchment area for this facility includes the Hudson Valley and New York City, but the two primary counties of residence are Westchester (72.6%) and Bronx County (23.0%) (seen in Table 4.2 of the Results section).

Study Population

The study population included individuals with encounters that occurred at the WIHD from January 1, 2017 through December 31, 2017. Participants were adult patients (18 years of age and older) who had at least one documented encounter with a primary care provider during the study period. Although all patients who come to WIHD have an IDD-related diagnosis, patients were excluded from the sample if their chart did not contain an ICD-10 related intellectual disability code (i.e., F70, F71, F72, or F73). Patients were also excluded from the sample if their only visit with a primary care provider was for an annual gynecological exam and/or cerumen removal encounter. These patients were excluded because they are not considered to be empaneled to a primary care provider at the WIHD and most likely receive their primary care services at another location. There were 1,162 patients with medical records that met these criteria during the stated time period (January 1, 2017 – December 31, 2017).

Institutional Review Board and Ethical Considerations

After an expedited review, this study received approval permission from the New York Medical College Institutional Review Board on July 2, 2018 to conduct the study with a waiver of consent and a waiver of HIPAA Authorization (IRB #12679).

Confidentiality and Privacy

To minimize the risk of a confidentiality breach, all study data were kept on password-protected Microsoft Excel spreadsheets in a secure folder on the WIHD server. Only the research team had access to the data. Initially, the Principal Investigator requested that the manager of the Health Information Systems at WIHD provide the research assistants with a list of patients who meet the study eligibility criteria noted above. The research assistants temporarily stored each patient's medical record number on a password-protected Microsoft Excel spreadsheet subject log and assigned each patient a study number (seen in the Table 3.1 below).

Table 3.1
Microsoft Excel Spreadsheet Subject Log Example (Preventative Care Study)

Subject	Medical Record Number
1	123456
2	#####
3	#####
4	#####
5	#####

The two independent research assistants then extracted data from the electronic medical record (CureMD) on each subject and entered it into a different password-protected Microsoft Excel spreadsheet separate from the subject log. After data extraction, the subject log was permanently deleted and the de-identified data were migrated into Stata 14 for aggregate analysis.

Data Source and Collection

The data source was the Westchester Institute for Human Development's electronic medical record–CureMD. CureMD houses all internal and externally received patient information. The retrospective chart review in CureMD took approximately three months between July 2018 and September 2018.

The data extracted from the electronic medical record included demographic, socioeconomic, diagnosis, clinical characteristic, utilization, and preventative service elements. All data elements, aside from preventative service utilization, were extracted into Microsoft Excel format using analytical aggregate reports created with a December 31, 2017 reference date and based on the patient medical record number of eligible subjects identified as having had a visit between January 1, 2017 and December 31, 2017. The preventative service data elements were extracted manually. All variables used in the study can be seen in Table 3.2.

Table 3.2
List of Original Variables (Preventative Care Study)

Variable	Data Collection Process	Variable Type	Data Type
Age	Aggregate Report	Independent	Continuous
Zip code	Aggregate Report	Independent	Categorical
Gender	Aggregate Report	Independent	Categorical
Ethnicity	Aggregate Report	Independent	Categorical
Race	Aggregate Report	Independent	Categorical
Living Situation	Aggregate Report	Independent	Categorical
Insurance	Aggregate Report	Independent	Categorical
Communication Ability	Aggregate Report	Independent	Categorical
Level of Intellectual Disability	Aggregate Report	Independent	Categorical
Medications	Aggregate Report	Independent	Continuous
Annual Health Assessment	Aggregate Report	Independent	Categorical
Behavioral Health Services	Aggregate Report	Independent	Categorical
Colorectal Cancer Screening	Manual Chart Review	Dependent	Categorical
Breast Cancer Screening	Manual Chart Review	Dependent	Categorical
Cervical Cancer Screening	Manual Chart Review	Dependent	Categorical
Pneumococcal Vaccination	Manual Chart Review	Dependent	Categorical
Influenza Vaccination	Manual Chart Review	Dependent	Categorical

Data Validation

For quality assurance to maintain internal validity, the researchers extracted all manual data elements using a standardized location key going in the order presented to ensure that they searched in all of the same places that a data element might be located in the electronic medical record. This standardized location sheet can be seen in Table 3.3.

Table 3.3
Electronic Medical Record (CureMD) Manual Data Collection Standardized
Location Key (Preventative Care Study)

Variable	Data Search Locations
Colorectal Cancer Screening	<ol style="list-style-type: none"> 1. Provider Notes <ol style="list-style-type: none"> a. Annual Physical Examination note b. Gastroenterology note 2. Orders & Results <ol style="list-style-type: none"> a. Acknowledged Procedures 3. Documents <ol style="list-style-type: none"> a. Past Medical Records b. Diagnostic Procedures c. All Documents
Breast Cancer Screening	<ol style="list-style-type: none"> 1. Provider Notes <ol style="list-style-type: none"> a. Annual Physical Examination note b. Annual GYN 2. Orders and Results <ol style="list-style-type: none"> a. Acknowledged Radiology 3. Documents <ol style="list-style-type: none"> a. Past Medical Records b. Diagnostic Procedures c. All Documents
Cervical Cancer Screening	<ol style="list-style-type: none"> 1. Provider Notes <ol style="list-style-type: none"> a. Annual GYN note 2. Orders and Results <ol style="list-style-type: none"> a. Acknowledged Labs 3. Documents <ol style="list-style-type: none"> a. Past Medical Records b. Diagnostic Procedures c. All Documents
Influenza Vaccination	<ol style="list-style-type: none"> 1. Provider Notes <ol style="list-style-type: none"> a. Annual Physical Exam note b. Flu Vaccine Order 2. Orders and Results <ol style="list-style-type: none"> a. Immunizations 3. Documents <ol style="list-style-type: none"> a. Immunization Folder

Pneumococcal Vaccination

1. Provider Notes
 - a. Annual Physical Exam note
 2. Orders and Results
 - a. Immunizations
 3. Documents
 - a. Immunization Folder
-

As noted above, the research assistants used guidelines from the United States Preventative Service Task Force (USPSTF) and Center for Disease Control and Prevention (CDC) to manually extract data on colon, breast, and cervical cancer screenings, as well as influenza and pneumococcal vaccinations. Using the guidelines in Table 3.4, the research assistants first determined which patients were eligible or ineligible for each preventative service. If a patient was eligible for a service based on their age and gender, the research assistant would use the standardized location key above to determine if the subject met or did not meet the appropriate preventative service guideline criteria.

For breast cancer screenings, it is important to note that the USPSTF does not recommend screening or adjuvant screening with a whole breast ultrasound primarily due to its low specificity and operator variability (Geisel et al., 2018). However, individuals with intellectual and/or developmental disabilities have a high incidence of an inability to tolerate the mammography screening procedure (Greenwood et al., 2014). This is a result of many providers having improper equipment for breast cancer screening that is not adapted for patients with physical disability or the patient simply just having problems

standing for mammography or transferring from a wheelchair to consultation table (Kirby & Hegarty 2010; Willis et al. 2008). As such, we included whole breast ultrasound as sufficient to meet breast cancer screening criteria because WIHD offers this as a secondary option to mammography as a breast ultrasound has a much higher screening success rate in this particular population (Litt, A., personal communication, 2019).

Table 3.4
Preventative Service Variable Guidelines

Variable Name	Guidelines Organization	Recommendation
Cervical Cancer Screening	USPSTF	Eligible patients for cervical cancer screening included women 21-64 years of age. Successful screening included either of the following criteria: (1) women age 21-64 who had cervical cytology performed within 3 years of their last encounter date of the study period; (2) women age 30-64 who had cervical cytology/human papillomavirus (HPV) co-testing performed within 5 years of the last encounter date of the study (USPSTF 2018)
Breast Cancer Screening	USPSTF	Eligible patients for breast cancer screening included women 50-74 years of age. Successfully screening included women who had a mammogram and/or whole breast ultrasound (WBUS) to screen for breast cancer within 2 years of their last encounter date of the study (USPSTF 2016a).

Colorectal Cancer Screening	USPSTF	Eligible patients for colorectal cancer screening included adults 50-75 years of age. Successful screening for colorectal cancer included any one of the following criteria: (1) fecal occult blood test (FOBT) within 1 year of the last encounter date of the study period; (2) flexible sigmoidoscopy within 5 years of the last encounter date of the study period; (3) colonoscopy within 10 years of the last encounter date of the study period (USPSTF 2016b).
Influenza Immunization	CDC	All subjects in the study were considered eligible. Documentation of influenza vaccination anytime during the study period was considered a successful vaccination.
Pneumococcal Vaccination	CDC	Eligible subjects include adults aged 65 years or older. Documentation of pneumococcal vaccination at any time was considered a successful vaccination.
Note: United States Preventative Service Task Force (USPSTF) and Centers for Disease Control and Prevention (CDC)		

The research assistants did not record any direct patient identifiers during extraction (e.g., date of birth was changed to age). The two independent research assistants then compared their results of manually-extracted data and reconciled any discrepancies. After data extraction, the subject log was permanently deleted and the de-identified data was migrated into Stata. Research analysis did not begin until the subject log was permanently deleted.

Variable Coding

Independent variables

This section discusses the decision-making process in taking the original independent variable values and coding them to promote an evidence-based, meaningful analysis of the data. The independent variable coding can be seen below in Table 3.5 and the discussion of each variable follows.

Table 3.5
Stata Independent Variable Value Coding (Preventative Care Study)

Original Variable Name	Original Dataset Variable Values	Stata Analysis Variable Name	Stata Analysis Dataset Variable Value
age	range of 17 - 96	ageoverunder40	0 = 18 - 39 1 = 40+
zip code	11 three digit zip code's identified	zipcode3	Left as three digit numbers
gender	Female; Male	gendercode	0 = Female; 1 = Male;
ethnicity	Non-Hispanic or Latino; Hispanic or Latino Unknown	ethnicitycoded	0 = not Hispanic or Latino; 1 = Hispanic or Latino; "." = unknown

race	Caucasian; Caucasian, White; White; White Earth; White Mountain; African; African American; Black; Black or African American; American Indian or Alaska Native; Spanish American Indian; Asian; Other Race; Unknown;	racebinary	0 = Caucasian; Caucasian, White; White; White Earth; White Mountain 1 = African; African American; Black; Black or African American; American Indian or Alaska Native; Spanish American Indian; Asian; Other Race; "." = Unknown;
housingstatus	None Lives at Home; Group Home ^a ; Unknown;	housingstatusco ded	0 = None Lives at Home; 1 = Group Home; "." = Unknown;
planname	Medicare and Medicaid; Only Private ^b ; None;	medicaremedica id	0 = Medicare and Medicaid; 1 = Medicaid Only; "." = Private; None;
comunication	Within Normal Limits; Few Words; Nonverbal; Hesitant; Dysarthric; Unknown;	commucommun icationWNLand Nonverbal	0 = Within Normal Limits; 1 = Nonverbal; "." = Few Words; Hesitant; Dysathric; Unknown;
levelofdisabilit y	Mild; Moderate; Severe; Profound;	binarydisability	0 = Mild; Moderate; 1 = Severe; Profound;
medication	range (0 - 43)	medicationbinar y	0 = 0-14 1 = 15+

annualhealthass essment	yes; no;	annualhealthass essmentyesno	0 = No 1 = Yes
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^a53 different group homes

^b33 different private insurance companies

It is important to note that certain variables may change over the course of the study period. For example, a subject's age will always change or the number of medications a subject is on might change. For this reason, all aggregate reports were used with a December 31, 2017 reference date.

The age variable for each individual is entered into the demographic section of the electronic medical record upon registering for a first appointment. The range of the age variable in the sample is 17-96 years. A new variable for age, "agebucket," was created in order to evaluate the distribution of age among the sample by decade, starting with 18-30, 31-40, and so on. This "agebucket" variable was used in the descriptive statistics section. The age of 40 was utilized because it is a significant cut off in general as it is considered the beginning of middle age, which is a time where chronic and acute disease risk increases in parallel to both socioeconomic-related aging disparities in the general and IDD population (McCarron et al., 2011; CDC, 2019a).

The three digit zip code variable, also from the demographics section of the electronic medical record of each individual, was collected and presented in the descriptive results section, but not used in analytical results section. There were 11 different three digit zip codes collected. It is important to note that the zip code variable

came in both five and nine digit forms initially. In order to aggregate the data, and protect patient privacy, all five and nine digit zip codes were reduced to three digit zip codes.

The gender variable for each individual is entered into the demographic section of the electronic medical record upon registering for a first appointment. The variable for gender was named “gendercode” and contained zero missing values.

The race variable for each individual is entered into the demographic section of the electronic medical record upon registering for a first appointment. For race, there were originally 14 different variable values with much overlap, and many were not demographically meaningful. For example, there were five different values from the electronic medical record that could be considered Caucasian (i.e., Caucasian, Caucasian White, White, White Earth, and White Mountain). For this reason, a new variable called “racecoded” was created that had five different racial categories including Caucasian, African American, Native American, Asian, and Other. This “racecoded” variable was used in the descriptive statistics section. However, due to the limited amount of subjects in each of the racial categories, another final analysis variable called “racebinary” was created and it consisted of Caucasian (47%), Non-Caucasian (41%), and Unknown (12%). The “racebinary” variable was used in the analytical statistics.

The living situation variable was also taken from the demographics section of the electronic medical record. It is important to note that this variable is sometimes updated as individuals move from different living situations (i.e., from a group home to non-group home setting). For living situation, there were 55 different variable values. Of these 55

values, 53 values were for different group homes, 1 was for individuals who lived at home, and 1 was for no response (i.e., unknown). The analysis variable “housingstatuscoded” was created and all 53 group homes were aggregated together into a category called group home. The categorization of living situation into individuals who live at home and individuals who live in a group home has been identified as an important determinant in an individual’s health as previously described in the literature (Sullivan et al., 2003; Lewis et al., 2002).

The insurance variable is entered into the profile component of the electronic medical records and is updated periodically. The insurance variable, named “planname,” had 33 different variable values. Of these 33 values, 30 were the names of different private insurance companies, 1 was Medicare/Medicaid dual eligible insurance, 1 was straight Medicaid, and 1 value was no insurance. This “planname” variable was coded with all private insurance companies representing 1 value renamed to “plannamecoded” and used in the descriptive statistics section.

However, the majority of individuals had “dual eligibility” with Medicare/Medicaid insurance (56%) followed by straight Medicaid (35%). For this reason, the analysis variable “medicaremedicaid” was created with the values of Medicare/Medicaid and Medicaid only, leaving out the small proportion of the sample who had private or no insurance (n=92). The analysis of individuals with IDD who have Medicaid only versus those individuals who are dual eligible is important because of the differing level of healthcare support from each insurance plan and a commonly used

variable in both the general population and specifically in the IDD population (Xingling et al., 2017; Deroche et al., 2017)

The communication variable was taken from the most recent physical examination assessment by a primary care provider. Initially the variable was coded as “communicationcoded” with a value for each possible response. This “communicationcoded” variable was used in the descriptive statistics section. However, after discussion with the primary care provider, it was determined that an analysis variable called “communicationWNLandNonverbal” only contained individuals who had communication that was within normal limits or were completely nonverbal (Litt, A., personal communication 2019). The reason for this was because of the greater clinical meaningfulness in the difference between being able to communicate normally and not being able to communicate at all, which has also been previously employed in IDD specific studies (Shin et al., 2018). This approach resulted in a category with normal communication representing 27% of the total population and nonverbal communication representing 23% of the total population.

The level of intellectual disability is a commonly cited variable in IDD studies (Havercamp et al., 2004; Sullivan et al., 2003; Lewis et al., 2002). The variable was taken from the active diagnosis codes in the electronic medical record. It is important to note that sometimes an individual may have more than one level of intellectual disability codes cited in the medical record. In these instances, the diagnostic code that was cited more often by physicians was chosen as the actual value assigned to that individual. In a

few circumstances, there were cases where an individual had an even number of level of intellectual disability codes entered in the electronic medical record (e.g., F70 Mild Disability twice and F71 Moderate Disability twice). In these cases, we assigned the less severe disability code to the individual.

Initially, the disability variable was coded as “levelofdisability” with 4 values representing the 4 possible levels of disability. This “levelofdisability” variable was used in the descriptive statistics section. However, since there were low numbers of severe and profound disability diagnosis codes in the sample and the objective was to identify an association between level of intellectual disability and the dependent variables, we dichotomized the analysis variable into Mild/Moderate Disability and Severe/Profound Disability and named it “binarydisability.” After dichotomizing the variable, the proportion of Mild/Moderate Disability represented 75% of the sample and Severe/Profound Disability represented 25% of the sample.

The medication variable is taken from the individuals’ number of active medications as noted in the electronic medical record. The range of the medication variable in the sample is 0-43. A new variable for medication, “medicationbucket,” was created in order to evaluate the distribution of the number of medications in strata of ten (i.e., less than 10, 11-20, 21-30, etc.). The “medicationbucket” variable was used in the descriptive statistics section.

The medication variable is taken from the number of active medications the individual is on as noted in the electronic medical record with a December 31, 2017

reference date. The range of the medication variable in the sample is 0-43. A new variable for medication, “medicationbucket” was created in order to evaluate the distribution of the number of medications in strata of ten (i.e., less than 10, 11-20, 21-30, etc.). The “medicationbucket” variable was used in the descriptive statistics section.

However, for analysis, the medication variable was dichotomized into a new variable called “medicationbinary.” This variable was split into individuals on 0-14 medication or greater than 15 medications. This dichotomization resulted in 62% (726) of subjects falling into the 0-14 medication category and the remaining 38% (436) into the equal or greater than 15 medication category. It is important to note that the cutoff value for what is considered polypharmacy is extremely variable in both the general population and IDD-specific studies; as a result, we arbitrarily used 15 medications as the cutoff (Storz et al., 2014; O’Dwyer et al., 2016; Haider et al., 2014).

The annual health assessment variable is based off whether or not an individual had an annual health assessment (also known as a yearly physical exam or “health check”) within one calendar year. It is important to note that some individuals had more than one annual health assessment in the calendar year. In the newly created variable for analysis, “annualhealthassessmentyesno,” these individuals were included in the yes category.

Dependent variables

This section discusses the decision-making process in taking the original dependent variable to promote an appropriate evidence-based analysis of the data. The dependent variable coding can be seen below in Table 3.6 and the discussion of each variable follows.

Table 3.6
Stata Dependent Variable Value Coding (Preventative Care Study)

Original Variable Name	Original Dataset Variable Values	Stata Analysis Variable Name	Stata Analysis Dataset Variable Value
colorectalcancer	Met Not Met Ineligible	colorectalcancercoded	0 = Not Met 1 = Met 2 = Ineligible
breastcancer	Met Not Met Ineligible	breastcancercoded	0 = Not Met 1 = Met 2 = Ineligible
cervicalcancer	Met Not Met Ineligible	cervicalcancercoded	0 = Not Met 1 = Met 2 = Ineligible
pneumococcalvaccination	Met Not Met Ineligible	pneumococcalvaccinationcoded	0 = Not Met 1 = Met 2 = Ineligible

influenzaimmunization	Met Not Met	influenzaimmunizationcoded	0 = Not Met 1 = Met

The data elements for the dependent variables were extracted manually as described above. If a patient was ineligible for a preventative service, that was recorded as the value for that individual. For example, a male individual would be ineligible for cervical cancer screening. If an individual was eligible, the research assistant went through the standardized location key and determined if the preventative service criteria were met or not met and recorded this information accordingly. All preventative service variables were then coded appropriately, presented as descriptive statistics, and incorporated into analytical analysis.

Data Analysis Plan

Descriptive statistics are presented first. Demographic, socioeconomic, utilization, and clinical characteristic variables of the sample are reported in aggregate. This is followed by a summarization of the patients who were eligible for and met each specific preventative service recommendation.

Analytical statistics begin with bivariate analysis. All variables from the study are used in bivariate logistic regression analysis. The independent variables are the demographic, socioeconomic, utilization, and clinical characteristic variables. The dependent variables (outcomes of interest) are the success or failure of receiving applicable preventative services. It is important to note that some variable combinations were not applicable (e.g., male sex and breast cancer screening) and therefore excluded. The bivariate analyses are presented with odds ratios and concomitant confidence intervals. Results are considered significant at $p \leq 0.05$.

Lastly, multivariate logistic regressions were run with every study variable included and presented on each specific preventative service as a dependent binary outcome variable (i.e., met factor vs. failed factor). The covariates included the demographic, socioeconomic, utilization, and clinical characteristic variables. Like the bivariate logistic regression analysis, some variable combinations were not applicable (e.g., age under 40 and colorectal cancer screening). Unlike the bivariate logistic regression, some variable combinations were omitted due to a lack of sample size (e.g., ethnicity and pneumococcal vaccination). Adjusted odds ratios and confidence intervals were reported. Results are considered statistically significant at $p \leq 0.05$.

Study Limitations

This study derives its strength from primary care level data that was used. This allowed for an analysis at the practice level. However, incomplete or incorrect medical records could lead to information or measurement bias. A patient may have received his or her colonoscopy as directed by their primary care provider within the study eligibility period; however, if the practice did not receive receipt of the result in the form of a consultation report, then we were unable to ascertain that the patient actually had this service rendered. It is expected that this inability to capture all preventative services rendered actually reduces our reported screening rates to an unknown degree. This measurement bias most likely would result in an underestimation of the preventative services that were rendered because of missing information. This type of bias is much less likely to occur in studies using billing codes (Lin et al., 2013).

Another limitation of the study is that data collection was from one year, allowing only a cross-sectional analysis. If future studies were prospective instead, this would allow for a more robust analysis of explanatory variables. In addition to this, the data collection only occurred at one ambulatory center site. Although this allows for an analysis of IDD-specific care, it limits the sample size and cannot be fully generalized to the New York State IDD population. This studies limited external validation is a methodological issue that can be corrected with state level data.

Study #2 Methodology – Characteristics Associated with Primary Care Follow-Up and Discharge Summary Receipt Post-Hospitalization in Adults with Intellectual and/or Developmental Disabilities.

Study Design

This study utilized a cross-sectional study design utilizing electronic medical records and Medicare Quality and Resource Use Reports (QRURs) from January 1, 2012 through December 31, 2016.

Setting Description

This study was performed at WIHD as described in the previous section.

Study Population

The study population included adult (18 years of age and older) patients with any encounter that occurred at the Westchester Institute for Human Development (WIHD) from January 1, 2012 through December 31, 2016 and who were also listed in the Medicare Quality and Resource Use Report (QRUR) during the study period. Although all patients who come to WIHD have an IDD-related diagnosis, patients were excluded

from the sample if their chart did not contain an ICD-related code (e.g., F70, F71, F72, or F73). There were 341 subjects hospitalized a total of 788 times between January 1, 2012 through December 31, 2016 who met the criteria for inclusion into the study.

Institutional Review Board and Ethical Considerations

After an expedited review, this study received permission from the New York Medical College Institutional Review Board on July 7, 2019 to conduct the study with a waiver of consent and a waiver of HIPAA Authorization (IRB #12918). Before permission was granted, the IRB did request a copy of the data collection tool.

Confidentiality and Privacy

To minimize the risk of a confidentiality breach, all study data were kept on password-protected Microsoft Excel spreadsheet in a secure folder on the WIHD server. Only the research team had access to the data. Initially, the Principal Investigator requested that the manager of the Health Information Systems at WIHD provide the research assistant with a list of patients who met the study eligibility criteria noted above. The list of patients was then compared to the patients identified on the Medicare Quality and Resource Use Report. The research assistant temporarily stored each patient's medical record number that could be linked from both reports on a password-protected

Microsoft Excel spreadsheet subject log and assigned each patient a study number (as can be seen in the Table 3.7).

Table 3.7
Microsoft Excel Spreadsheet Subject Log Example (Hospitalization Study)

Subject	Medical Record Number
1	123456
2	#####
3	#####
4	#####
5	#####

Two independent research assistants then extracted data from the electronic medical record (CureMD) on each subject and entered it into a different password-protected Microsoft Excel spreadsheet separate from the subject log. After data extraction, the subject log was permanently deleted and the de-identified data were migrated into Stata 14 for aggregate analysis.

Data Source and Collection

The data source was the Westchester Institute for Human Development's electronic medical record (CureMD) and Quality and Resource Use Report (QRUR). CureMD houses all internal and externally received patient information. The Medicare QRUR is an annual data report released by the Centers for Medicare and Medicaid

Services (CMS) that provides an overview of quality of care and resource use based on a medical practice's Medicare-Enrolled Tax Identification Number (TIN) and the Medicare-fee-for-service (FFS) patients it provides service to (CMS, 2015). The QRUR delineates the quality of care a practice is delivering to its Medicare beneficiaries and identifies opportunities for improvement (CMS, 2015). The QRUR also provides hospitalization data on Medicare beneficiaries attributed to a practice's specific TIN (e.g., admitting hospital, length of stay, principal diagnosis, etc.) (CMS, 2015). The linking of the QRUR and the electronic medical was based off date of birth and took approximately one week during June 2019. All electronic medical record reports were aggregate analytical reports created with a reference date of December 31, 2016. All variables used in the study can be seen in Table 3.8 on the next page.

Table 3.8
List of Original Variables (Hospitalization Study)

Variable	Data Source	Variable Type	Data Type
Age	Medical Record	Independent	Continuous
Gender	Medical Record	Independent	Categorical
Ethnicity	Medical Record	Independent	Categorical
Race	Medical Record	Independent	Categorical
Living Situation	Medical Record	Independent	Categorical
Level of Intellectual Disability	Medical Record	Independent	Categorical
Date of Admission	QRUR	Independent	Continuous
Date of Discharge	QRUR	Independent	Continuous
Length of Stay	QRUR	Independent	Continuous
Hospital	QRUR	Independent	Categorical
City	QRUR	Independent	Categorical
State	QRUR	Independent	Categorical
Principal Diagnosis Code	QRUR	Independent	Categorical
Principal Diagnosis Description	QRUR	Independent	Categorical
CCS Grouper Level 1	QRUR	Independent	Categorical
CCS Grouper Level 2	QRUR	Independent	Categorical
Discharge Status	QRUR	Independent	Categorical
Primary Care Follow-Up	Medical Record	Dependent	Continuous
Discharge Summary Receipt	Medical Record	Dependent	Continuous

The only two variables that required manual extraction were primary care follow-up and discharge summary receipt. For quality assurance, the two research assistants extracted these data elements using a standardized location key in order to ensure that they searched in all of the same places where a data element might be identified in the electronic medical record. After the research assistants extracted the data, they reconciled any differences. The standardized location sheet can be seen in Table 3.9 below.

Table 3.9
Electronic Medical Record (CureMD) Manual Data Collection Standardized
Location Key (Hospitalization Study)

Variable	Data Search Locations
Primary Care Follow-Up	1. Appointment a. Status
Discharge Summary Receipt ^a	1. Documents a. Post Hospitalizations b. Past Medical Records c. All Documents

^aDischarge summary receipt is based off the electronic medical record upload time stamp (not the date on the document)

After data extraction was complete, the subject log was permanently deleted and the de-identified data were migrated into Stata. Research analysis did not begin until the subject log was permanently deleted.

Variable Coding

This section discusses the decision-making process in coding the original independent variable values to promote an appropriate evidence-based analysis of the data. The variable coding can be seen below in Table 3.10 and the discussion of each variable follows.

Table 3.10
Stata Independent and Dependent Variable Value Coding (Hospitalization Study)

Original Variable Name	Original Dataset Variable Values	Stata Analysis Variable Name	Stata Analysis Dataset Variable Value
age	range of 27 - 98	agebucket	0 = 18 - 30 1 = 31 - 40 2 = 41 - 50 3 = 51 - 60 4 = 61 - 70 5 = 71 - 80 6 = 80+
		ageunderover40	0 = 18 - 39 1 = 40+
gender	Female Male	gender	0 = Male 1 = Female
ethnicity	Non-Hispanic or Latino; Hispanic or Latino Unknown	ethnicity	0 = Not Hispanic or Latino 1 = Hispanic or Latino
race	Caucasian; Caucasian, White; White; African; African American; Black; Black or African American;	racecoded	0 = Caucasian; Caucasian, White; White; 1 = African; African American; Black; Black or African American; 2 = American Indian or Alaska Native; Spanish American Indian; Asian; Other Race "." = Unknown

	American Indian or Alaska Native; Spanish American Indian; Asian; Other Race; Unknown;	racebinary	0 = Caucasian; Caucasian, White; White; 1 = African; African American; Black; Black or African American; American Indian or Alaska Native; Spanish American Indian; Asian; Other Race "." = Unknown
levelofdisability	Mild Moderate Severe Profound	levelofdisabilitycoded	0 = Mild 1 = Moderate 2 = Severe 3 = Profound
		binarydisability	0 = Mild; Moderate 1 = Severe; Profound
doa ^a	##/##/####	N/A	N/A
dateofdischarge ^b	##/##/####	N/A	N/A
lengthofstay	Range of 1 - 212	N/A	N/A
followupdays	Range of 1 – 29 ^c	followupdays7	0 = 1-7 days follow-up 1 = 8-30 days follow-up
		followupdays14	0 = 1-14 days follow-up 1 = 15-30 days follow-up
		followupdaysyesorno	0 = 30+ days follow-up 1 = 1 – 30 days follow-up
dischargesummarydays	Range of 1 – 28 ^d	dischargesummarydays7	0 = 1-7 days follow-up 1 = 8-30 days follow-up
		dischargesummarydays14	0 = 1-7 days follow-up 1 = 8-30 days follow-up
		dischargesummarydaysyesorno	0 = 1-7 days follow-up 1 = 8-30 days follow-up
hospital	44 unique hospitals (e.g., Westchester Medical Center)	N/A	N/A

city	25 unique cities (e.g., White Plains)	N/A	N/A
state	4 unique states (e.g., New York)	N/A	N/A
Principaldiagnosiscode ^e	264 unique variables (e.g., 5920)	N/A	N/A
principaldiagnosisdescription	264 unique variables (e.g., Septicemia NOS)	N/A	N/A
CCS Grouper Level 1	16 unique variables (e.g., Mental Illness)	ccslvl1	N/A
CCS Grouper Level 2	68 unique variables (e.g., Ear conditions)	ccslvl2	N/A
dischargestatus	19 unique discharge statuses (e.g., Disch Home)	N/A	N/A

^aDate of admission range was 01/03/2012 – 12/28/2016

^bDate of discharge range was 01/05/2012 – 12/30.2016

^cGreater than 30 days was not included

^dGreater than 30 days was not included

^eIncludes both ICD-10 and ICD-9 coding

It is important to note that certain variables may change over the course of the study period. For this reason, all aggregate electronic medical record reports were created with a December 31, 2016 reference date.

The age variable for each individual is entered into the demographic section of the electronic medical record upon registering for a first appointment. The age variable is also present on the Medicare QRUR Reports. The range of the age variable in the sample is 27-98. A new variable for age, “agebucket,” was created in order to evaluate the distribution of age among the sample by decade (i.e., 18-30, 31-40, etc.). The “agebucket” variable was used in the descriptive statistics section. For analysis, the age variable was dichotomized into a new variable called “ageunderover40.” Similar to the preventative care study reasoning, the age of 40 was utilized because it is considered the beginning of middle age—a time where chronic and acute disease risk increases in parallel to both socioeconomic related ageing disparities in the general and IDD population (McCarron et al., 2011; CDC, 2019a).

The gender variable for each individual is entered into the demographic section of the electronic medical record upon registering for a first appointment. The gender variable was also available from the QRUR Reports. The variable for gender was named “gender” and contained zero missing values.

The race variable for each individual is entered into the demographic section of the electronic medical record upon registering for a first appointment. For race, there were originally 12 different variable values. For this reason, a new variable called “racecoded” was created that had three different racial categories including Caucasian, African American, and Other. This “racecoded” variable was used in the descriptive statistics section. However, due to the limited amount of subjects in each of the racial

categories, another final analysis variable called “racebinary” was created: Caucasian (68.4%) and Non-Caucasian (31.6%). The “racebinary” variable was used in the analytical statistics section.

The living situation variable was also taken from the demographics section of the electronic medical record. Using the same approach as the previous study, an analysis variable “housingsituation” was created, and group homes were aggregated together into a category called group home. The separation of living situation into individuals who live at home and individuals who live in a group home has been identified as an important determinant of an individual’s health and wellbeing (Sullivan et al., 2003; Lewis et al., 2002).

The level of intellectual disability is a commonly cited variable in IDD studies (Havercamp et al., 2004; Sullivan et al., 2003; Lewis et al., 2002). This variable was taken from the active diagnosis codes in the electronic medical record. As discussed above, an individual may have more than one level of intellectual disability codes cited in the medical record. In these instances, the diagnostic code that was cited more often by physicians was chosen as the actual value assigned to that individual. In a few circumstances, there were cases where an individual had an even number of level of intellectual disability codes entered in the electronic medical record (e.g., F70 Mild Disability twice and F71 Moderate Disability twice). In these cases, we assigned the less severe of the disability code to the individual. Initially, the disability variable was coded

as “levelofdisability” with four values representing the four possible levels of disability. This “levelofdisability” variable was used in the descriptive statistics section.

However, since there were low numbers of severe and profound disability diagnosis codes in the sample and the objective was to identify an association between level of intellectual disability and the dependent variables, we dichotomized the analysis variable into Mild/Moderate Disability and Severe/Profound Disability and named it “binarydisability.” After dichotomizing the variable, the proportion of Mild/Moderate Disability represented 79% of the sample and Severe/Profound Disability represented 21% of the sample. The “binarydisability” variable was used in the analytical statistics section.

The date of admission (doa) and date of discharge were available for each hospital admission on the QRUR. These dates were provided in a calendar format (e.g., 01/15/2019). Using Microsoft Excel, the length of stay in days was calculated. The range of length of stay was between 1-212 days.

The number of days until follow-up as a variable was calculated by using the date of discharge on the QRUR reports and the next primary care visit identified by the research assistants in the electronic medical record. Another variable, the number of days until discharge summary receipt, was calculated by using the date of discharge on the QRUR reports and the date the discharge summary was uploaded and timestamped in the electronic medical record. It is important to note that we only counted these variables when they occurred within a 30-day time frame. This is a common methodological

practice as many studies have shown that primary care follow-up within 30 days reduces costs by avoiding expensive readmissions (Balogh et al., 2018; Rayan-Gharra et. al., 2019). After excluding values larger than 30 days, the range of “followupdays” was 1-29 days and the range for “dischargesummarydays” was 1-28 days. These variables were then further divided into more granular variables that evaluated 7 and 14-day primary care follow-up and discharge summary receipt. These were coded as “followupdays7,” “followupdays14,” “dischargesummarydays7,” and “dischargesummarydays14.”

The QRUR report also provided the name of the hospital, city, and state, which resulted in 44 unique hospitals from 25 unique cities in four unique states. This information is provided in the descriptive results section.

The principal diagnosis code variable provides the International Classification of Disease (ICD) code that is the primary reason why an individual was admitted to the hospital for care (CMS, 2018). The principal diagnosis description variable is a description of the admission reason. It is important to note that hospitals used the ICD-9 coding version up until September 30, 2015 and then used the ICD-10 coding version thereafter. These coding schemes are not completely compatible and cannot be aggregated for research purposes. As such, this study dropped the ICD-10 data (i.e., principal diagnosis code and principal diagnosis description variables) from the descriptive section of the results. After dropping this data, the ICD-9 codes yielded 525 principal diagnosis codes and principal diagnosis descriptions, of which 264 were unique. Using the Agency for Healthcare Research and Quality (AHRQ) ICD-9-CM Clinical

Classification Software (CCS), the 264 ICD-9 codes were next grouped into more clinically meaningful categories (AHRQ, 2018). The CCS Level 1 Grouper Variable has 16 unique values and the CCS Level 2 has 69 unique values. The grouping of diagnostic codes into meaningful categories for analysis can be better appreciated by looking at Table 3.11 below, which shows an example of how diagnoses are grouped.

Table 3.11
Example of the Agency for Healthcare Research and Quality (AHRQ) ICD-9-CM Clinical Classification Software (CCS) Grouping

principal diagnosis description	CCS Level 2 Grouper	CCS Level 1 Grouper
Joint pain-pelvis	Non-traumatic joint disorders	Diseases of the musculoskeletal system and connective tissue
Difficulty in walking	Non-traumatic joint disorders	Diseases of the musculoskeletal system and connective tissue
Joint dislocation. NOS-pelvis	Non-traumatic joint disorders	Diseases of the musculoskeletal system and connective tissue
Cervical Spondylopathy with myelopathy	Spondylosis; intervertebral disc disorders; other back problems	Diseases of the musculoskeletal system and connective tissue
Olecranon bursitis	Other connective tissue disease	Diseases of the musculoskeletal system and connective tissue

The far left column contains the principal diagnosis description (the most exact diagnosis description). The second level contains the first grouping. As seen, the first two principal diagnosis descriptions (i.e., Joint pain-pelvis and Difficulty in walk) both grouped into the Level 2 Non-traumatic joint disorders category. All five unique principal diagnosis descriptions and the three unique CCS Level 2 group into the CCS Level 1 group “Diseases of the musculoskeletal system and connective tissue.” This commonly used grouping system allows for analysis of coding on different levels. The frequency and proportions of the most common CCS Level 1 and 2 groups are provided in the results section.

The last variable, discharge status, is from the Quality and Resource Use Reports. This variable had eight unique values (e.g., Discharge Home, Discharge to Hospice, Expired, etc.). The data is displayed in the Results section.

Data Analysis Plan

Descriptive statistics are presented first. Demographics, living situation, and level of intellectual disability are reported in aggregate. This is followed by descriptive statistics of the hospitals and the features of the hospital admissions. Next, principal diagnosis of the hospitalization in CCS grouper format is presented. Then primary care follow-up and discharge summary receipt statistics and means are reported.

Analytical statistics begins with bivariate analysis. Bivariate logistic regressions of the top five most frequented hospitals and primary care follow-up within 30 days and hospital discharge summary receipt within 30 days are presented. The hospital is the independent variable and achieving primary care follow-up within 30 days or hospital discharge summary receipt within 30 days are the dependent variables. The bivariate analysis is presented with odds ratios and concomitant confidence intervals. Results are considered significant at $p \leq 0.05$.

The next bivariate analysis included demographics, living situation, and level of intellectual disability as the independent variables and achieving primary care follow-up within 7 and 14 days or hospital discharge summary receipt within 7 and 14 days as the dependent (outcomes of interest) variables. These bivariate analyses are also presented with odds ratios and confidence intervals as the measures of association. Results are considered statistically significant at $p \leq 0.05$.

Multivariate logistic regressions were then run first including demographics, living situation, and level of intellectual disability as the independent variables and achieving primary care follow-up within 7 and 14 days. These were run separately on hospital discharge summary receipt within 7 and 14 days as the dependent (outcome) variables. The next model also added the top five frequented hospitals into the model as additional independent variables. Lastly, a final multivariate model that added the Level 1 CCS groupers as independent variables was created. It is important to note that the top five hospitals and the 16 unique level 1 CCS groupers were added to the model using a

fixed effect that created dummy variables because these variables have greater than two categories. Adjusted odds ratios and confidence intervals were reported. Results are considered statistically significant at $p \leq 0.05$.

Study Limitations

This novel study garnered its strength from using both Medicare data and practice level data. However, because the study used only linked Medicare data, it automatically did not include individuals who have Medicaid or private insurance. That said, these populations might have some significant differences, therefore generalizability to these IDD sub-populations is limited. Also, similar to the preventative care study, information could have been received, but not documented in the medical record. For example, an individual might have brought a discharge summary to the practice at their post-hospitalization visit and given it to the provider or ancillary staff, but if it was not uploaded into the medical record, it would not have been captured by this study. This could lead to measurement bias and most likely an underestimate of the discharge summary receipt count. Conducting a prospective study and ensuring discharge summary receipt into electronic medical record could improve internal validity.

Also, similar to the preventative care study, this investigation has limited external validity. Generalizability to the IDD population is limited because it was conducted at

one ambulatory center and individuals visited hospitals primarily in the surrounding catchment area.

Chapter 4: Results

Study #1 Results – Characteristics Associated with Preventative Care Utilization in Adults with Intellectual and/or Developmental Disabilities

Descriptive Statistics

A total of 1,162 patient charts were reviewed and included in the study.

Demographic characteristics of the sample are shown in Table 4.1 on the next page. The sample showed a bimodal age distribution with the 18-30 and 51-60 year old strata being the two largest groups with 269 and 255 patients, respectively. Both the median and mean age of the sample was 45 years old. Sex of the sample was predominantly male (58.6%) and ethnicity was predominantly non-Hispanic or Latino (72.9%). Race is predominantly Caucasian (46.6%) with African American (24.7%) accounting for the second largest subpopulation. Patient insurance is distributed as Medicare and Medicaid (56.2%), Medicaid only (35.4%), and private (7.9%). The majority of patients were identified as living in group homes (81.1%), as opposed to living in non-group home settings (17.3%).

Table 4.1
Demographic Characteristics of the Study Sample (Preventative Care Study)

	Frequency (%)
Total Unique Individuals	1,162
Age Strata	
18-30 years	269 (23.2%)
31-40 years	227 (19.5%)
41-50 years	223 (19.2%)
51-60 years	255 (21.9%)
61-70 years	132 (11.4%)
71-80 years	42 (3.6%)
80 > years	14 (1.2%)
Sex	
Male	681 (58.6%)
Female	481 (41.4%)
Ethnicity	
Non-Hispanic or Latino	847 (72.9%)
Hispanic or Latino	218 (18.8%)
Unknown ^a	97 (8.4%)
Race	
Caucasian	541 (46.6%)
African American	287 (24.7%)
Asian	11 (1.0%)
Native American	6 (0.5%)
Other	182 (15.7%)
Unknown ^a	135 (11.6%)
Insurance	
Medicare and Medicaid (Dual)	653 (56.2%)
Medicaid Only	411 (35.4%)
Private	92 (7.9%)
None	6 (0.5%)
Living Situation	
Group Home	942 (81.1%)
Non-Group Home	201 (17.3%)
Unknown ^a	19 (1.64%)

^aUnknown data consists of fields in the medical chart where data elements were never entered

Using the three digit zip code variable, the geographic distribution of the study sample can be seen in Table 4.2. The majority of subjects reside in Westchester (47.9%) and the Bronx (23.1%).

Table 4.2
Three Digit Zip Code Distribution of the Study Sample
(Preventative Care Study)

Location	Frequency (%)
Total	1,162
Westchester, NY	541 (47.9%)
Bronx, NY	268 (23.1%)
Yonkers, NY	175 (15.1%)
New Rochelle, NY	75 (6.5%)
White Plains, NY	76 (6.5%)
Mid-Hudson, NY	12 (1.0%)
New York, NY	7 (0.6%)
Other	8 (0.7%)

Table 4.3 reveals the clinical and utilization characteristics of the study sample. The level of intellectual disability of the sample is mild (46.3%), moderate (20.2%), severe (13.5%), and profound (11.5%). The three major communication ability classifications of the sample were nonverbal (22.7%), few words (33.1%), and within normal limits (26.6%). The range of actively prescribed medications is 1-43, following a normal distribution with a median of 12. This distribution can also be seen in Figure 4.1

below. Most patients (31.8%) fall into the 11-15 actively prescribed medications strata. In terms of utilization at the multispecialty outpatient facility, 851 patients (73.2%) received an annual health assessment in 2017.

Table 4.3
Clinical and Utilization Characteristics of the Study Sample (Preventative Care Study)

	Frequency (%)
Total Unique Individuals	1,162
Level of Intellectual Disability ^a	
Mild	636 (54.7%)
Moderate	235 (20.2%)
Severe	157 (13.5%)
Profound	134 (11.5%)
Communication Ability ^b	
Within Normal Limits	309 (26.6%)
Few Words	385 (33.1%)
Nonverbal	264 (22.7%)
Hesitant	53 (4.6%)
Dysarthric	49 (4.2%)
Unknown	102 (8.8%)
Medications ^c	
0 - 5	116 (10.0%)
6 - 10	309 (26.6%)
11 - 15	370 (31.8%)
16 - 20	222 (19.1%)
21 - 25	102 (8.8%)
26+	44 (3.8%)
Annual Health Assessment	
Yes	851 (73.2%)
No	311 (26.8%)

^aLevel of Intellectual Disability is determined by most frequently used ICD code

^bCommunication ability as determined by the primary care provider during physical examination

^cPrescribed medications that were current and actively prescribed during the study period

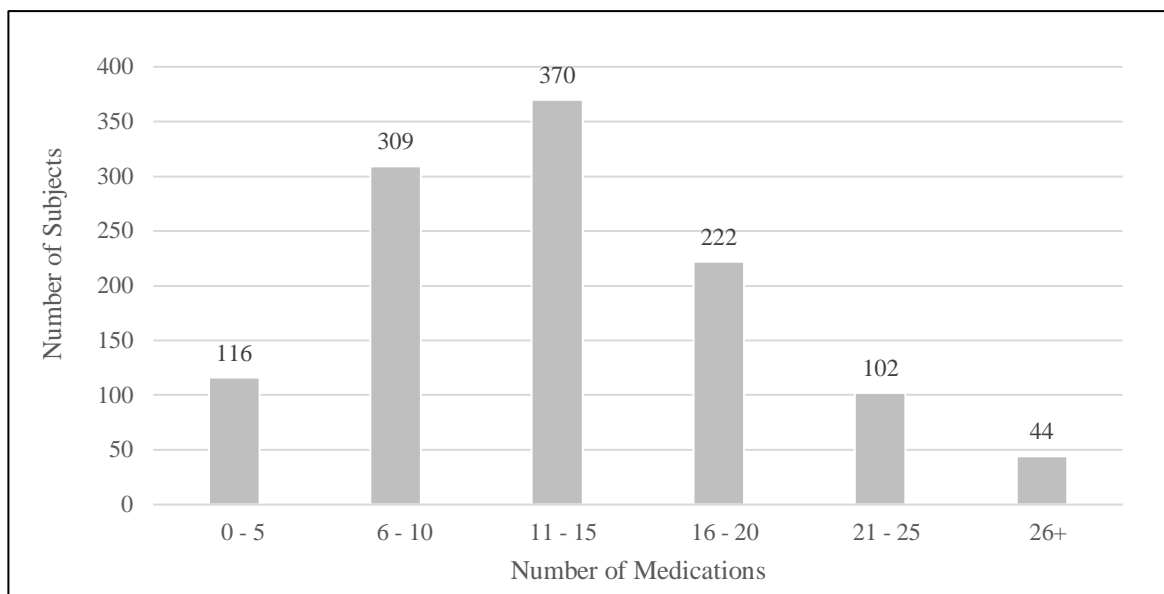


Figure 4.1 - Medication Distribution of the Study Sample (Preventative Care Study)

Figure 4.2 on the next page shows the preventative service utilization of the study sample for patients who were eligible for each service. Of eligible patients, utilization percentages are: influenza vaccination (67.6%), pneumococcal vaccination (80.2%), colorectal cancer screening (62.1%), breast cancer screening (68.8%), and cervical cancer screening (71.9%). Figure 4.3 below shows preventative service utilization stratified by living situation (i.e., group home vs. non-group home). For all preventative services analyzed, the patients who lived in group homes had a higher proportion of preventative service utilization than those who did not live in group homes.

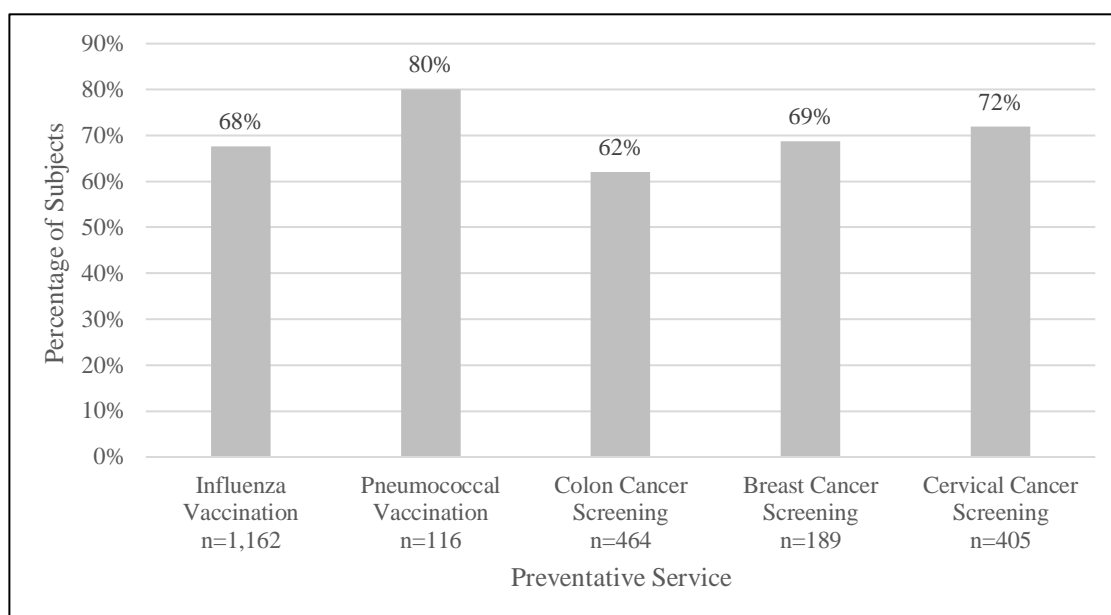


Figure 4.2 Preventative Service Utilization of Eligible Study Sample

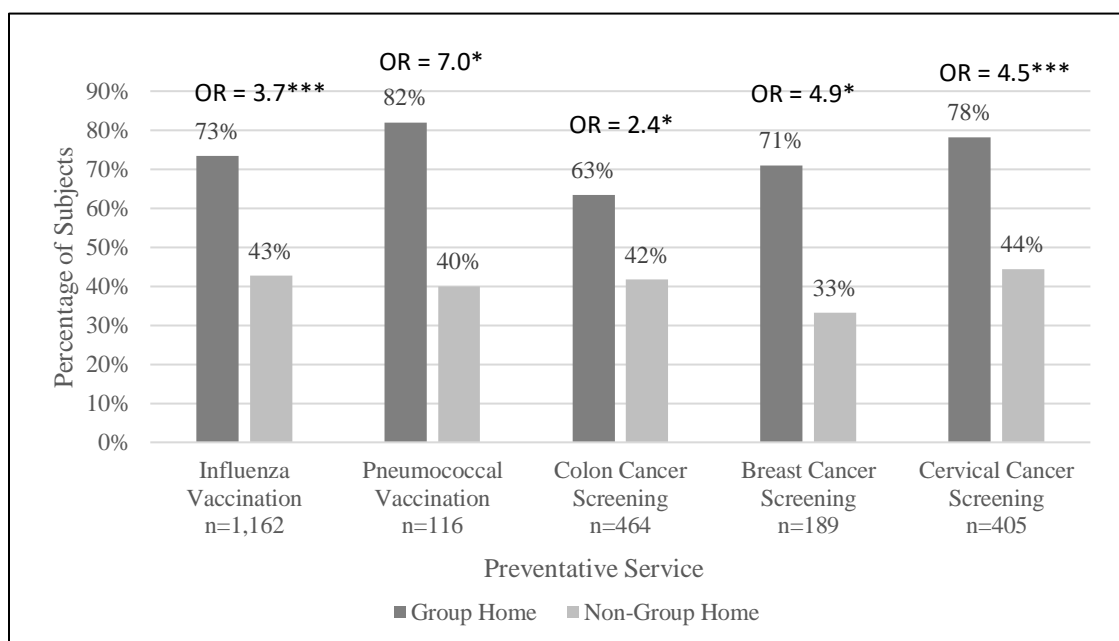


Figure 4.3 - Preventative Service Utilization Stratified by Living Situation with Bivariate Odds Ratios (Group Home vs Non-Group Home).

Analytic Statistics

Bivariate analysis can be seen in Table 4.4 on the next page. This analysis discovered that living situation (group home vs. non-group home) is associated with influenza vaccination (OR 3.7, 95% CI 2.7–5.1), pneumococcal vaccination (OR 7.0, 95% CI 1.1–45.0), colorectal cancer screening (OR 2.4, CI 1.1–5.6), breast cancer screening (OR 4.9, 95% CI 1.2–20.4), and cervical cancer screening (OR 4.5, 95% CI 2.6–7.7). The bivariate regression analysis also detected that having had an annual health assessment is associated with influenza vaccination (OR 5.2, 95% CI 3.9 – 6.8), pneumococcal vaccination (OR 4.9, 95% CI 1.8 – 12.9), and colorectal cancer screening (OR 2.1, 95% CI 1.4 – 3.2). Certain independent variables were omitted because some of variable values were not eligible for the preventative service (e.g., colorectal cancer screening for individuals aged 18-40).

Table 4.4
Bivariate Logistic Regression of Preventative Service Utilization (Preventative Care Study)

Independent Variables	Influenza Vaccination OR (95% CI)	Pneumococcal Vaccination OR (95% CI)	Colorectal Cancer Screening OR (95% CI)	Breast Cancer Screening OR (95% CI)	Cervical Cancer Screening OR (95% CI)
Age					
18-40 years	Ref.	N/A	N/A	N/A	Ref.
40 > years	1.5 (1.2-2.0)***				2.3 (1.5-3.7)***
Sex					
Male	Ref.	Ref.	Ref.	N/A	N/A
Female	0.6 (0.5-0.8)***	0.4 (0.2-1.2)	0.6 (0.4-0.9)**		
Ethnicity					
Non-Hispanic	Ref.	Ref.	Ref.	Ref.	Ref.
Hispanic	1.2 (0.8-1.6)	1.1 (0.2-5.3)	0.7 (0.4-1.2)	0.9 (0.4-2.5)	1.0 (0.6-1.8)
Race					
Caucasian	Ref.	Ref.	Ref.	Ref.	Ref.
Non-Caucasian	1.5 (1.1-1.9)**	0.9 (0.3-2.8)	1.6 (1.0-2.4)	1.3 (0.6-2.8)	1.3 (0.8-2.1)
Living Situation					
Non-Group Home	Ref.	Ref.	Ref.	Ref.	Ref.
Group Home	3.7 (2.7-5.1)***	7.0 (1.1-45.0)*	2.4 (1.1-5.6)*	4.9 (1.2-20.4)*	4.5 (2.6-7.7)***
Insurance					
Medicare and Medicaid	Ref.	Ref.	Ref.	Ref.	Ref.
Medicaid	1.3 (0.9-1.6)	dropped	1.0 (0.6-1.8)	1.3 (0.5-3.3)	0.8 (0.5-1.4)
Communication Ability					
Within Normal Limits	Ref.	Ref.	Ref.	Ref.	Ref.
Nonverbal	1.2 (0.8-1.7)	2.4 (0.4-13.3)	1.6 (0.9-2.9)	1.7 (0.7-4.1)	1.9 (1.0-3.9)
Intellectual Disability					
Mild/Moderate	Ref.	Ref.	Ref.	Ref.	Ref.
Severe/Profound	0.7 (0.5-0.9)*	0.3 (0.1-0.8)	0.6 (0.4-0.9)*	1.3 (0.7-2.7)	1.2 (0.7-2.0)
Annual Health Assessment					
No	Ref.	Ref.	Ref.	Ref.	Ref.
Yes	5.2 (3.9-6.8)***	4.9 (1.8-12.9)***	2.1 (1.4-3.2)***	1.7 (0.9-3.2)	1.4 (0.9-2.1)

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Table 4.5 below displays the results of a multivariate logistic regression for selected demographic, socioeconomic, and clinical characteristics on preventative service utilization. When incorporated into the model, significant characteristics associated with

influenza vaccination included age over 40 (aOR 2.1, 95% CI 1.2–3.5), Medicaid only insurance (aOR 1.8, 95% CI 1.1–3.2), living in a group home (aOR 3.4, 95% CI 1.8–6.1), and having had an annual health assessment (aOR 3.6, 95% CI 2.1–6.0). The only significant variable associated with colorectal cancer screening was having had an annual health assessment (aOR 2.3, 95% CI 1.0–5.3); when reducing the number of decimals and rounding, the confidence interval does include 1 for colorectal cancer. The significant characteristic associated with cervical cancer screening is living in a group home (aOR 3.8, 95% CI 1.3–11.2); however, the model was unable to identify characteristics associated with pneumococcal vaccination and breast cancer screening. Ethnicity, race, communication ability, level of intellectual disability, and number of medications were not associated with any type of preventative service utilization. This multivariate model was also run with fixed effect for the three initial insurance types (i.e., Medicaid only, Medicaid and Medicare, and private insurance), but no significant results were discovered.

Table 4.5
Multivariate Logistic Regression of Preventative Service Utilization (Preventative Care Study)

Independent Variables	Influenza Vaccination aOR (95% CI)	Pneumococcal Vaccination aOR (95% CI)	Colorectal Cancer Screening aOR (95% CI)	Breast Cancer Screening aOR (95% CI)	Cervical Cancer Screening aOR (95% CI)
Age					
18-40 years	Ref.	N/A	N/A	N/A	Ref.
40+ years	2.1 (1.2-3.5)**				1.9 (0.7-5.1)
Sex					
Female	Ref.	Ref.	Ref.	N/A	N/A
Male	1.6 (1.0-2.6)	1.1 (0.1-10.5)	1.5 (0.8-2.8)		
Ethnicity					
Non-Hispanic	Ref.	Ref.	Ref.	Ref.	Ref.
Hispanic	1.0 (0.6-1.9)	omitted	0.4 (0.2-1.2)	0.9 (0.2-5.1)	0.5 (0.2-1.4)
Race					
Caucasian	Ref.	Ref.	Ref.	Ref.	Ref.
Non-Caucasian	1.2 (0.7-2.1)	0.5 (0.0-5.9)	1.3 (0.6-3.0)	1.7 (0.4-7.5)	1.7 (0.6-4.7)
Insurance					
Medicare and Medicaid	Ref.	Ref.	Ref.	Ref.	Ref.
Medicaid	1.8 (1.1-3.2)*	omitted	1.6 (0.6-4.5)	1.8 (0.4-8.8)	1.4 (0.5-3.6)
Living Situation					
Non-Group Home	Ref.	Ref.	Ref.	Ref.	Ref.
Group Home	3.4 (1.8-6.1)***	omitted	3.1 (0.6-16.0)	5.4 (0.4-74.8)	3.8 (1.3-11.2)*
Level of Intellectual Disability					
Mild/Moderate	Ref.	Ref.	Ref.	Ref.	Ref.
Severe/Profound	1.5 (0.8-2.6)	omitted	1.1 (0.5-2.3)	2.6 (0.7-9.5)	2.0 (0.6-6.5)
Communication Ability					
Within Normal Limits	Ref.	Ref.	Ref.	Ref.	Ref.
Nonverbal	1.0 (0.6-1.7)	1.4 (0.1-20.0)	1.6 (0.8-3.1)	2.1 (0.7-6.4)	1.3 (0.5-3.1)
Medications					
0-14	Ref.	Ref.	Ref.	Ref.	Ref.
15+	1.1 (0.7-1.7)	2.0 (0.2-20.8)	1.2 (0.6-2.2)	0.9 (0.3-2.6)	0.8 (0.3-2.0)
Annual Health Assessment					
No	Ref.	Ref.	Ref.	Ref.	Ref.
Yes	3.6 (2.1-6.0)***	1.8 (0.1-28.0)	2.3 (1.0-5.3)*	2.5 (0.7-8.9)	2.2 (0.8-5.7)

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

**Study #2 Results - Characteristics Associated with Primary Care Follow-Up and
Discharge Summary Receipt Post-Hospitalization in Adults with Intellectual and/or
Developmental Disabilities**

Descriptive Statistics

A total of 341 unique individuals with 788 hospital admissions were included in the study. Demographic characteristics of the 341 unique individuals are shown in Table 4.6. The sample showed a normal age distribution with the highest portion of the study population in the 51-60 year-old strata. Both the median and mean age of the sample was 58 years old. Sex of the sample was predominantly male (54.3%) and ethnicity was predominantly non-Hispanic or Latino (87.4%). Race is 62.2% Caucasian, 28.4% African American, and 9.4% Other. The majority of patients live in group homes (81.2%) as opposed to non-group home settings (18.8%). The distribution of level of intellectual disability of the sample is 46.9% Mild, 28.4% Moderate, 14.4% Severe, and 10.3% Profound.

Table 4.6
Demographic Characteristics and Level of Intellectual Disability of the
Study Sample (Hospitalization Study)

	Frequency (%)
Total Unique Individuals	341
Age Strata	
18-30 years	9 (2.6%)
31-40 years	28 (8.2%)
41-50 years	54 (15.8%)
51-60 years	103 (30.2%)
61-70 years	90 (26.4%)
71-80 years	39 (11.4%)
80 > years	18 (5.3%)
Gender	
Male	182 (54.3%)
Female	156 (45.7%)
Ethnicity	
Non-Hispanic or Latino	298 (87.4%)
Hispanic or Latino	43 (12.6%)
Race	
Caucasian	212 (62.2%)
African American	97 (28.4%)
Other	32 (9.4%)
Living Situation	
Group Home	277 (81.2%)
Non-Group Home	64 (18.8%)
Level of Intellectual Disability	
Mild	160 (46.9%)
Moderate	97 (28.4%)
Severe	49 (14.4%)
Profound	35 (10.3%)

Table 4.7 below describes the 788 hospitalization admissions included in the study. The study used hospitalizations from 2012-2016 and their respective frequency can be seen with the most admissions (25.5%) occurring in 2016. The length of stay of each

admission is put into five day strata with the shortest 1-5 day strata representing the highest frequency of admissions (436; 55.3%). It is also important to note that the range of length of stay was 1-212 days. There were two significant admission outliers (i.e., 177 and 212 days) that resulted in stays over 100 days. The nine hospitals with the most admissions are listed with their corresponding frequencies; 44 different hospitals were included in the study.

Table 4.7
Frequency of Year of Admission, Length of Stay Strata, and
Hospital for all Encounters (Hospitalization Study)

	Frequency (%)
Total Admissions	788
Year of Admission	
2012	159 (20.2%)
2013	131 (16.6%)
2014	146 (18.5%)
2015	151 (19.2%)
2016	201 (25.5%)
Length of Stay Strata	
1 - 5 Days	436 (55.3%)
6 - 10 Days	200 (25.4%)
11 - 15 Days	68 (8.6%)
16 - 20 Days	34 (4.3%)
21 - 25 Days	12 (1.5%)
26 - 30 Days	14 (1.8%)
31 - 35 Days	9 (1.1%)
36 - 40 Days	4 (0.5%)
Greater than 40 Days	11 (1.4%)
Hospital	
White Plains Hospital	218 (27.7%)
Westchester Medical Center	138 (17.5%)
St. John's Riverside	55 (7.0%)
Northern Westchester Hospital	54 (6.7%)
Phelps Memorial Hospital	52 (6.6%)
Other (39 Hospitals)	271 (34.4%)

Table 4.8 below provides the admission count per patient, as well as the proportion each admission count category comprises of all of the admissions. Of note, 28 of the 341, or 8% of unique patients, had greater than five admissions during the study

period. This represented the largest total category of admissions. The range of number of admissions per unique patient was 1-28 admissions; nine unique patients had between 9-20 admissions, with one patient having 28 admissions.

Table 4.8
Admission Count by Unique Patient (Hospitalization Study)

	Unique Patient Count	Total Visits (%)
Total	341	788
Admission Count by Patient		
1 Admission	184	184 (23.3%)
2 Admissions	71	142 (18.0%)
3 Admissions	39	117 (14.8%)
4 Admissions	10	40 (5.1%)
5 Admissions	9	45 (5.7%)
Greater than 5 Admissions	28	260 (33.0%)

Table 4.9 below shows the mean length of days for the top five most frequently admitted hospitals. The mean length of stay for all hospitals is 8.0 (95% CI: 7.1–8.9). As mentioned above, there were some significant admission outliers including a 212-day admission at Westchester Medical Center.

Table 4.9
Top Five Hospitals Mean Length of Stay (Hospitalization Study)

Hospitals	Mean Length of Stay Days (95% CI)
White Plains Hospital	6.0 (CI: 5.4-6.7)
Westchester Medical Center	10.1 (CI: 7.0-13.3)
St. John's Riverside	8.4 (CI: 6.6-10.1)
Northern Westchester Hospital	7.7 (CI: 5.6-9.7)
Phelps Memorial Hospital	5.5 (4.1-7.0)

Table 4.10 on the next page reveals the principal diagnosis of the 525 admissions that were recorded using the ICD-9 format with both the Level 1 and 2 CCS Grouping schemes. All 16 unique Level 1 categories are listed in the table, but only the top 10 most frequent Level 2 categories were included.

Table 4.10
Frequency of Principal Diagnosis of Hospitalization Using Level 1 and 2
CCS Grouping (Hospitalization Study)

	Frequency (%)
Total CCS Grouped Admissions ^a	525
CCS Level 1 Grouping Diagnosis	
Infectious and Parasitic Diseases	96 (18.3%)
Diseases of the Respiratory System	82 (15.6%)
Mental Illness	73 (13.9%)
Diseases of the Digestive System	62 (11.8%)
Diseases of the Nervous System	56 (10.7%)
Diseases of the Genitourinary System	36 (6.9%)
Injury and Poisoning	29 (5.5%)
Diseases of the Circulatory System	21 (4.0%)
Diseases of the Skin and Subcutaneous Tissue	19 (3.6%)
Diseases of the Musculoskeletal System	15 (2.9%)
Endocrine, Nutritional and Metabolic Disorders	15 (2.9%)
Neoplasms	10 (1.9%)
Symptoms, Signs, Ill Defined Conditions	7 (1.3%)
Congenital Anomalies	2 (0.4%)
Diseases of the Blood	1 (0.2%)
Complications of Pregnancy	1 (0.2%)
CCS Level 2 Grouping Diagnosis	
Bacterial Infection	94 (17.9%)
Epilepsy	44 (8.4%)
Respiratory Infections	36 (6.9%)
Diseases of the Urinary System	35 (6.7%)
Mood Disorders	32 (6.1%)
Aspiration Pneumonitis	30 (3.8%)
Lower Gastrointestinal Disorders	20 (3.8%)
Schizophrenia and Other Psychosis	18 (3.4%)
Skin and Subcutaneous Infections	18 (3.4%)
Impulse Control Disorder	16 (3.1%)
Other	182 (34.7%)

^aThe 525 admissions analyzed is based off ICD-9 coding as described in the Methods section

Table 4.11 describes the discharge status from the 788 admissions. The vast majority of discharge statuses are home (74.4%), with very few patients leaving against medical advice.

Table 4.11
Frequency of Discharge Status from Hospital (Hospitalization Study)

	Frequency (%)
Total Admissions	788
Discharge Status	
Discharge Home	586 (74.4%)
Discharge to Skilled Nursing Facility	116 (14.7%)
Discharge to Home Health	41 (5.2%)
Expired	19 (2.4%)
Other	10 (1.3%)
Hospice	7 (0.9%)
Discharge to Psych	5 (0.6%)
Left AMA ^a	4 (0.5%)

^aAgainst medical advice

Table 4.12 provides the days of time strata for primary care follow-up and hospital discharge summary receipt. A large number of follow-up encounters with primary care occur in the first five days post-discharge (42.5%) and only a small proportion do not follow up within the expected 30-day time frame (5.2%). Receiving the discharge summary within the 30-day time frame is a little less reliable (16.5%). The mean days of follow-up for patients who did follow-up was 7.8 days (95% CI: 7.4–8.2)

and the mean discharge summary receipt for received discharge summaries was 7.9 days (95% CI: 7.5–8.3).

Table 4.12
Time Strata of Primary Care Follow Up and Hospital
Discharge Summary Receipt (Hospitalization Study)

	Frequency (%)
Total Admissions	788
Follow Up Days Strata	
1-5 Days	335 (42.5%)
6-10 Days	238 (30.2%)
11-15 Days	103 (13.1%)
16-20 Days	30 (3.8%)
21-25 Days	34 (4.3%)
26-30 Days	7 (1.0%)
Not Within 30 Days	41 (5.2%)
Discharge Summary Receipt	
1-5 Days	281 (35.7%)
6-10 Days	201 (25.5%)
11-15 Days	123 (15.6%)
16-20 Days	24 (3.1%)
21-25 Days	22 (2.8%)
26-30 Days	7 (1.0%)
Not Within 30 Days	130 (16.5%)

Figure 4.4 below compares primary care follow-up between individuals that live in a group home and those do not. As can be seen, individuals that live in group homes are much more likely to follow-up within 7 days (62% vs. 21%) and 14 days (89% vs. 56%).

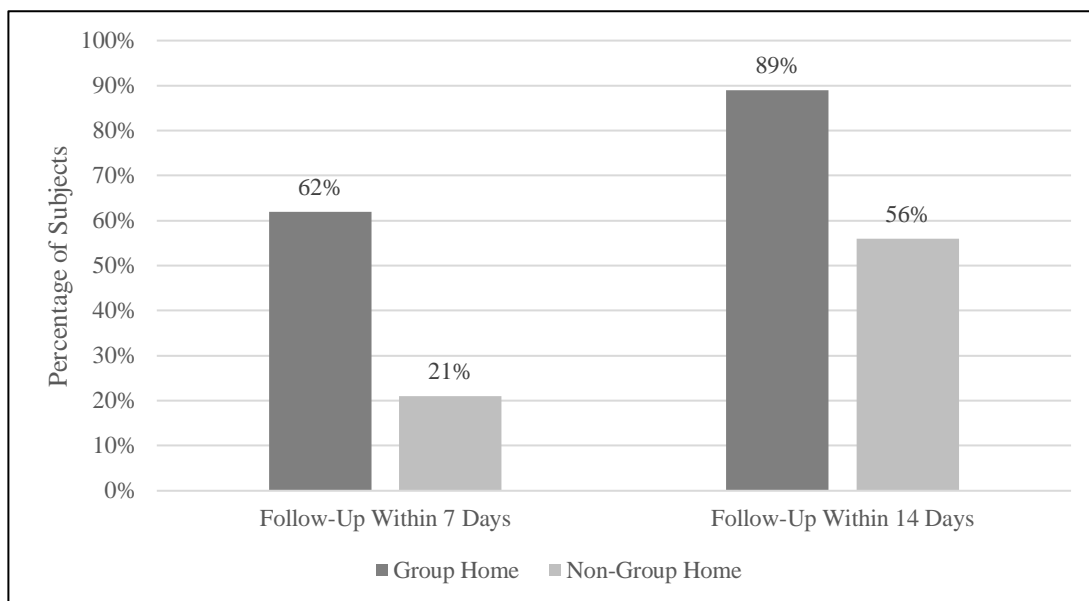


Figure 4.4 - Primary Care Follow-Up Within 7 and 14 Days Stratified by Living Situation

Figure 4.5 on the next page compares hospitalization discharge summary receipt between individuals that live in a group home and those do not. As can be seen, individuals that live in group homes are much more likely to have their discharge summary reach the primary care practice within 7 days (47% vs. 19%) and 14 days (81% vs. 42%).

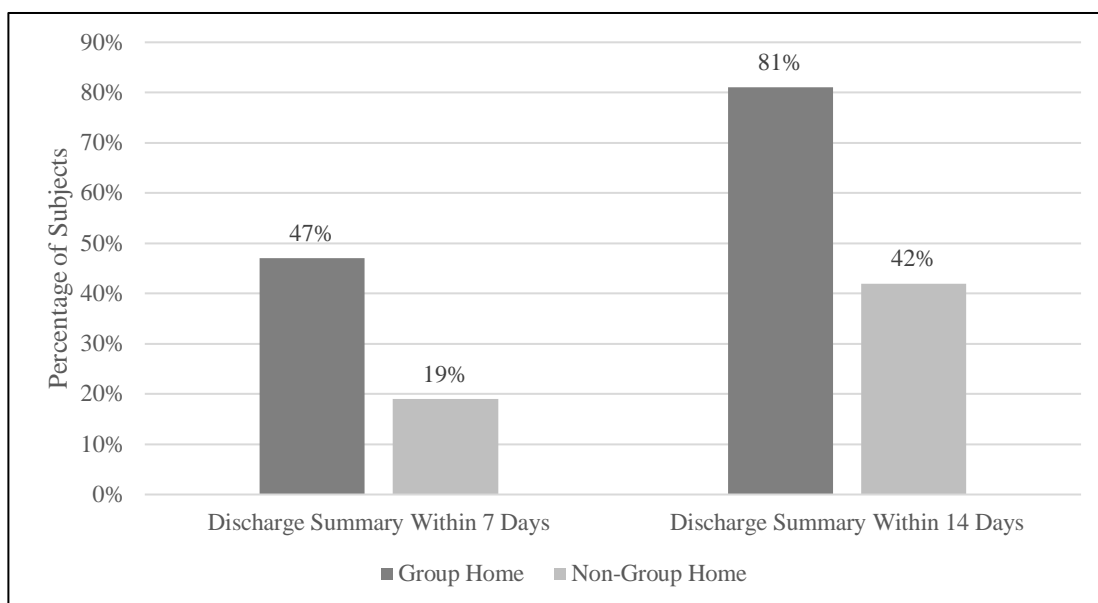


Figure 4.5 - Discharge Summary Receipt Within 7 and 14 Days Stratified by Living Situation

Analytic Statistics

Table 4.13 below is a bivariate regression analysis of primary care follow-up within 30 days or hospital discharge summary receipt within 30 days by the top five most frequently admitted hospitals. This analysis revealed a significant odds ratio for patients going to Westchester Medical Center and the practice not receiving the hospital discharge summary within the 30-day time period (n=138).

Table 4.13
Logistic Regression of Top Five Most Frequent Admitting Hospitals and
Primary Care Follow-Up and Hospital Discharge Summary Receipt
Within 30 Days (Hospitalization Study)

Hospital	Primary Care Follow-Up Within 30 Days OR (95% CI)	Hospital Discharge Summary Receipt Within 30 Days OR (95% CI)
White Plains Hospital	Ref.	Ref.
Westchester Medical Center	0.8 (CI: 0.3-2.2)	0.3 (CI: 0.2-0.5)***
St. John's Riverside	0.7 (CI: 0.2-2.9)	1.4 (CI: 0.5-3.7)
Northern Westchester Hospital	0.7 (CI: 0.2-2.8)	0.9 (CI: 0.4-2.2)
Phelps Memorial Hospital	1.1 (CI: 0.2-5.1)	1.3 (CI: 0.5-3.5)

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Table 4.14 below is the bivariate logistic regression of primary care follow-up and hospital discharge summary receipt within 7 and 14-day time frames by demographic, living situation, and level of intellectual disability variables. This bivariate analysis revealed odds ratios that were significant for both follow-up and discharge summary receipt for both 7 and 14-day time frames. The odds ratios suggest that individuals who live in non-group home settings are less likely to follow-up with primary care as opposed to individuals who live in group homes. The odds ratios also suggest that individuals who live in non-group home settings are less likely to have their discharge summary received by the practice within the specified time frame as opposed to individuals who live in group homes. There is no association between the demographic, living situation, and level of intellectual disability variables and the dependent variables.

Table 4.14
Bivariate Logistic Regression of Primary Care Follow-Up and Hospital Discharge Summary Receipt Within 7 and 14 Days (Hospitalization Study)

Independent Variables	Primary Care Follow-Up Within 7 Days OR (95% CI)	Primary Care Follow-Up Within 14 Days OR (95% CI)	Hospital Discharge Summary Receipt Within 7 Days OR (95% CI)	Hospital Discharge Summary Receipt Within 14 Days OR (95% CI)
Age				
18-40 years	Ref.	Ref.	Ref.	Ref.
40 > years	1.1 (0.7-1.6)	1.5 (0.9-2.5)	1.1 (0.7-1.8)	1.3 (0.8-2.2)
Gender				
Male	Ref.	Ref.	Ref.	Ref.
Female	0.9 (0.7-1.3)	0.7 (0.5-1.0)	1.1 (0.8-1.5)	1.0 (0.8-1.4)
Ethnicity				
Non-Hispanic	Ref.	Ref.	Ref.	Ref.
Hispanic	0.9 (0.6-1.6)	1.1 (0.5-2.2)	1.3 (0.8-2.1)	1.0 (0.6-1.8)
Race				
Caucasian	Ref.	Ref.	Ref.	Ref.
Non-Caucasian	1.1 (0.8-1.5)	1.1 (0.7-1.7)	1.2 (0.9-1.6)	1.0 (0.7-1.4)
Living Situation				
Non-Group Home	Ref.	Ref.	Ref.	Ref.
Group Home	6.1 (3.9-9.6)***	6.7 (4.3-10.2)***	3.8 (2.4-6.2)***	6.0 (4.1-9.0)***
Level of Intellectual Disability				
Mild/Moderate	Ref.	Ref.	Ref.	Ref.
Severe/Profound	1.2 (0.9-1.7)	1.1 (0.7-1.8)	1.1 (0.8-1.6)	1.3 (0.8-1.9)

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Table 4.15 below is the multivariate logistic regression of primary care follow-up and hospital discharge summary receipt within 7 and 14-day time frames by demographic, living situation, and level of intellectual disability variables. This

multivariate analysis revealed adjusted odds ratios that were significant for living situation and both follow up and discharge summary receipt for all time frames. This similar result to the bivariate analysis (in Table 4.15) suggests that demographic and level of intellectual disability variables are not confounding the association between living situation and primary care follow-up and hospital discharge summary receipt.

Table 4.15
Multivariate Logistic Regression of Primary Care Follow-Up and Hospital Discharge Summary Receipt Within 7 and 14 Days (Hospitalization Study)

Independent Variables	Primary Care Follow-Up Within 7 Days aOR (95% CI)	Primary Care Follow-Up Within 14 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 7 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 14 Days aOR (95% CI)
Age				
18-40 years	Ref.	Ref.	Ref.	Ref.
40 > years	0.7 (0.4-1.1)	0.9 (0.5-1.7)	0.9 (0.6-1.4)	0.9 (0.5-1.5)
Sex				
Male	Ref.	Ref.	Ref.	Ref.
Female	1.0 (0.7-1.4)	0.8 (0.5-1.2)	1.2 (0.9-1.6)	1.2 (0.8-1.7)
Ethnicity				
Non-Hispanic	Ref.	Ref.	Ref.	Ref.
Hispanic	1.0 (0.5-1.7)	1.3 (0.6-2.8)	1.3 (0.8-2.3)	1.2 (0.6-2.4)
Race				
Caucasian	Ref.	Ref.	Ref.	Ref.
Non-Caucasian	1.2 (0.9-1.7)	1.2 (0.7-1.9)	1.2 (0.8-1.7)	1.0 (0.7-1.4)
Living Situation				
Non-Group Home	Ref.	Ref.	Ref.	Ref.
Group Home	6.6 (4.1-10.5)***	7.0 (4.5-10.9)***	4.1 (2.5-6.7)***	6.4 (4.2-9.7)***
Level of Intellectual Disability				
Mild/Moderate	Ref.	Ref.	Ref.	Ref.
Severe/Profound	1.0 (0.7-1.5)	0.8 (0.5-1.3)	1.0 (0.7-1.4)	1.0 (0.6-1.5)

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Table 4.16 below is the multivariate logistic regression of primary care follow-up and hospital discharge summary receipt within 7 and 14-day time frames by demographic, living situation, level of intellectual disability, and the top 5 most frequently admitted hospital variables. This multivariate analysis also revealed adjusted odds ratios that were significant for living situation for both follow-up and discharge summary receipt for all time frames. However, this regression model observed that individuals who were admitted to Westchester Medical Center were also less likely to have their discharge summary receipt reach the primary care practice within both 7 and 14-day time frames. This multivariate regression also identified a significant association between being discharged from Phelps Memorial Hospital and not having a primary care visit within the 7 day time period.

Table 4.16
Multivariate Logistic Regression of Primary Care Follow-Up and Hospital Discharge Summary Receipt Within 7 and 14 Days with Hospital Variable (Hospitalization Study)

Independent Variables	Primary Care Follow-Up Within 7 Days aOR (95% CI)	Primary Care Follow-Up Within 14 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 7 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 14 Days aOR (95% CI)
Age				
18-40 years	Ref.	Ref.	Ref.	Ref.
40 > years	0.5 (0.2-1.2)	0.5 (0.2-1.7)	0.8 (0.4-1.7)	0.8 (0.4-2.0)
Sex				
Male	Ref.	Ref.	Ref.	Ref.
Female	0.9 (0.6-1.4)	0.9 (0.5-1.6)	1.2 (0.8-1.7)	1.1 (0.7-1.7)
Ethnicity				
Non-Hispanic	Ref.	Ref.	Ref.	Ref.
Hispanic	0.8 (0.4-1.7)	0.6 (0.2-1.6)	1.2 (0.6-2.6)	1.0 (0.4-2.3)
Race				
Caucasian	Ref.	Ref.	Ref.	Ref.
Non-Caucasian	1.5 (1.0-2.3)	1.7 (0.9-3.4)	1.5 (1.0-2.2)	1.1 (0.7-1.9)
Living Situation				
Non-Group Home	Ref.	Ref.	Ref.	Ref.
Group Home	9.9 (5.0-20.0)***	8.3 (4.4-15.5)***	5.1 (2.6-10.0)***	7.4 (4.1-13.2)***
Level of Intellectual Disability				
Mild/Moderate	Ref.	Ref.	Ref.	Ref.
Severe/Profound	0.9 (0.6-1.5)	1.1 (0.5-2.3)	0.9 (0.6-1.5)	1.0 (0.6-1.8)
Hospital				
White Plains Hospital	Ref.	Ref.	Ref.	Ref.
Westchester Medical Center	1.2 (0.7-1.9)	1.2 (0.6-2.3)	0.6 (0.4-0.9)*	0.5 (0.3-0.8)**
St. John's Riverside	0.6 (0.3-1.1)	1.9 (0.6-6.0)	0.6 (0.3-1.1)	1.3 (0.6-2.9)
Northern Westchester Hospital	0.9 (0.5-1.7)	1.0 (0.4-2.5)	1.0 (0.5-1.9)	1.1 (0.5-2.3)
Phelps Memorial Hospital	0.5 (0.3-1.0)*	1.2 (0.5-3.3)	0.8 (0.4-1.5)	1.4 (0.6-3.3)

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Table 4.17 on the next page is the multivariate logistic regression of primary care follow-up and hospital discharge summary receipt within 7 and 14-day time frames by demographic, living situation, level of intellectual disability, and the 16 unique Level 1 CCS Diagnostic Grouping categories. This multivariate analysis also revealed adjusted odds ratios that were significant for living situation for both follow-up and discharge summary receipt for all time frames. However, this regression model discovered that individuals who were admitted to Westchester Medical Center were also less likely to have their discharge summary receipt reach the primary care practice within both 7 and 14-day time frames.

Table 4.17

Multivariate Logistic Regression of Primary Care Follow-Up and Hospital Discharge Summary Receipt Within 7 and 14 Days with Level 1 CCS Grouper Diagnosis Variable (Hospitalization Study)

Independent Variables	Primary Care Follow-Up Within 7 Days aOR (95% CI)	Primary Care Follow-Up Within 14 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 7 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 14 Days aOR (95% CI)
Age				
18-40 years	Ref.	Ref.	Ref.	Ref.
40 > years	0.7 (0.3-1.3)	0.9 (0.4-2.0)	1.2 (0.6-2.3)	1.1 (0.6-2.3)
Sex				
Male	Ref.	Ref.	Ref.	Ref.
Female	0.8 (0.5-1.2)	0.6 (0.4-1.0)	1.0 (0.7-1.4)	1.0 (0.6-1.5)
Ethnicity				
Non-Hispanic	Ref.	Ref.	Ref.	Ref.
Hispanic	0.8 (0.4-1.6)	1.0 (0.4-2.8)	1.0 (0.5-2.1)	0.8 (0.4-1.8)
Race				
Caucasian	Ref.	Ref.	Ref.	Ref.
Non-Caucasian	1.3 (0.9-2.1)	1.6 (0.9-2.8)	1.3 (0.8-2.0)	1.2 (0.7-1.9)
Living Situation				
Non-Group Home	Ref.	Ref.	Ref.	Ref.
Group Home	7.6 (4.1-14.4)***	7.5 (4.2-13.3)***	4.1 (2.2-7.7)***	6.7 (3.9-11.6)***
Level of Intellectual Disability				
Mild/Moderate	Ref.	Ref.	Ref.	Ref.
Severe/Profound	1.0 (0.6-1.6)	1.1 (0.6-2.0)	1.0 (0.7-1.6)	1.2 (0.7-2.1)
CCS Level 1 Grouping Diagnosis				
16 Unique Diagnosis	See Note ^a	See Note ^a	See Note ^a	See Note ^a

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

^aAll 16 unique level 1 Grouping Diagnosis (as listed in Table 4.10) were not significant

Table 4.18 below is the multivariate logistic regression of primary care follow-up and hospital discharge summary receipt within 7 and 14-day time frames by

demographic, living situation, level of intellectual disability, and the top 5 most frequently admitted hospitals, and the 16 unique Level 1 CCS Diagnostic Grouping categories. Living situation was relatively stable throughout each of the regression iterations and across models. This multivariate analysis also revealed adjusted odds ratios that were significant for living situation for both follow-up and discharge summary receipt for all time frames. This regression model identified that individuals who were admitted to Westchester Medical Center were also less likely to have their discharge summary receipt reach the primary care practice within both 7 and 14-day time frames. This multivariate regression also detected a statistically significant coefficient for being over the age of 40 and not following up within 7 days ($p=0.021$), being discharged from Phelps Memorial Hospital and not having a primary care visit within the 7-day time period ($p=0.048$), and being in the non-Caucasian category and following up within the 14-day time period ($p=0.041$).

Table 4.18
Multivariate Logistic Regression of Primary Care Follow-Up and Hospital Discharge Summary Receipt Within 7 and 14 Days with Hospital and Level 1 CCS Grouper Diagnosis Variables (Hospitalization Study)

Independent Variables	Primary Care Follow-Up Within 7 Days aOR (95% CI)	Primary Care Follow-Up Within 14 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 7 Days aOR (95% CI)	Hospital Discharge Summary Receipt Within 14 Days aOR (95% CI)
Age				
18-40 years	Ref.	Ref.	Ref.	Ref.
40 > years	0.2 (0.1-0.8)*	0.4 (0.1-1.5)	0.8 (0.3-2.3)	1.0 (0.3-3.0)
Sex				
Male	Ref.	Ref.	Ref.	Ref.
Female	0.7 (0.4-1.2)	0.7 (0.4-1.4)	1.1 (0.7-1.7)	0.9 (0.5-1.6)
Ethnicity				
Non-Hispanic	Ref.	Ref.	Ref.	Ref.
Hispanic	0.6 (0.2-1.4)	0.4 (0.1-1.3)	1.0 (0.4-2.4)	0.5 (0.2-1.5)
Race				
Caucasian	Ref.	Ref.	Ref.	Ref.
Non-Caucasian	1.6 (0.9-2.7)	2.3 (1.0-5.3)*	1.5 (0.9-2.6)	1.3 (0.7-2.4)
Living Situation				
Non-Group Home	Ref.	Ref.	Ref.	Ref.
Group Home	12.8 (4.8-34.0)***	8.0 (3.5-18.2)***	5.8 (2.3-14.4)***	7.3 (3.3-16.0)***
Level of Intellectual Disability				
Mild/Moderate	Ref.	Ref.	Ref.	Ref.
Severe/Profound	1.0 (0.6-1.9)	1.4 (0.6-3.3)	1.0 (0.6-1.8)	1.4 (0.7-2.9)
Hospital				
White Plains Hospital	Ref.	Ref.	Ref.	Ref.
Westchester Medical Center	1.0 (0.5-2.0)	0.9 (0.4-2.2)	0.4 (0.2-0.8)**	0.3 (0.2-0.7)***
St. John's Riverside	0.6 (0.3-1.2)	1.9 (0.5-7.2)	0.5 (0.3-1.1)	1.2 (0.5-3.2)
Northern Westchester Hospital	0.7 (0.2-1.8)	0.9 (0.3-2.7)	0.7 (0.3-1.7)	0.7 (0.3-2.0)
Phelps Memorial Hospital	0.4 (0.2-1.0)*	1.1 (0.3-3.6)	0.8 (0.4-1.8)	1.4 (0.5-3.9)
CCS Level 1 Grouping Diagnosis				
16 Unique Diagnosis	See Note ^a	See Note ^a	See Note ^a	See Note ^a

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

^aAll 16 unique level 1 Grouping Diagnosis (as listed in Table 4.10) were not significant

Chapter 5: Discussion

Introduction

In 2002, the General Surgeon released its report, “Closing the Gap,” which identified improving health disparities in adults with mental retardation (now sensitively renamed to intellectual and/or developmental disabilities) as a national priority (U.S. Department of Health and Human Services, 2002). This report is often cited as the launch-pad for innovative research and targeted interventions to improve the quality and quantity of the lives of individuals with IDD. Since then, research and programmatic progress has progressed, albeit slowly.

As discussed above, adults with IDD represent a small, vulnerable and often overlooked and underrepresented proportion of the population in the United States, but account for a disproportionate amount of federal and state healthcare funding. The driver of cost in this population is fueled by the need for long term services and support, prescription medications, and the high prevalence of mental illness and secondary chronic health conditions (Fujiura et al., 2018). Although the IDD population represents a well-defined area of interest, the sheer number of investigative projects and governmental and private financial support are not tantamount to the total cost in both healthcare dollars and morbidity and mortality of this segment of the United States population.

Preventative and transitional healthcare service is a vitally important component of the quality of care an individual receives and the concomitant cost on the healthcare

system. However, research is lacking in this population, especially in the United States. In New York State, we anecdotally believe that agency-run group homes are providing a high level of care for adults with IDD when compared to adults with IDD who live in the community. However, the quantitative impact that agency-run group homes have on adults with IDD in New York has not been evaluated. This lack of focus in the literature represents an opportunity to identify adults with IDD who would benefit from enhanced care management strategies.

Preventative Care Study Findings

The preventative care study reveals some findings that are consistent with the IDD literature and some that have not been previously reported. The sample of 1,162 adults with IDD, although not all qualifying for each preventative service, is a large sample and brings power to this study. Although not larger than some of the studies in the literature, the record review using data from a comprehensive ambulatory center (WIHD) allowed for a more precise method of identification of adults with IDD than the more commonly used state and federal billing data repositories (Lin E., et al 2013). The sample, coming from a suburb of New York City, had large enough proportions of demographic and socioeconomic variables (e.g., 46.6% Caucasian vs. 53.4% Non-Caucasian), allowing for a generalizable analysis in the multivariate regression (Table 4.5). Of note, this study had a preponderance of male subjects (58.6%), which is also consistent with the IDD literature (Zablotsky et al., 2017).

The catchment area of the study is made of mostly Westchester (72.6%) and Bronx (23.0%) counties. No similar studies have been conducted in this region and only a few preventative care studies have occurred in the United States overall (Xingling et al., 2017; Deroche et al. 2017; Horner-Johnson et al., 2014; Lewis et al., 2002). This is important because national, state, and regional regulations often strongly influence the expectation and requirements of care for adults with IDD.

This study's ability to use an electronic medical record to review clinical characteristic variables (Table 4.3) also adds to the literature. Communication ability, number of medications, and having had an annual health assessment were all novel variables not captured in previous investigations. Although we know that adults with IDD as a population have a lower level of health literacy and, in many situations, a decreased capacity to communicate the signs and symptoms of a disease process, this study determined that communication ability (i.e., within normal limits vs nonverbal) is not associated with preventative service utilization (Table 4.5) (Sullivan et al. 2018). This allows us to confidently reject hypothesis 2 (Table 1.1), especially since the study had a high number of subjects who were within normal limits (309) and nonverbal (264). This result points to the significance of the caregiver or proxy and not the individual's ability to communicate and navigate the healthcare system.

The number of medications an individual is on, which took a standard bell-shaped distribution in this study (Figure 4.1), is not associated with preventative care utilization (Table 4.5). This is a novel negative finding that will add to the IDD literature. As

expected from hypothesis 3 (Table 1.1), this study did find that having had an annual health assessment was associated with a higher likelihood of influenza vaccination and colorectal cancer screening (Table 4.5). Although this variable is whether or not an individual had a specific appointment type (i.e., annual health assessment), the result corroborates previous research that discovered that the level of continuity (high, moderate, or low) of care with a primary care provider was related to the uptake of certain preventative services (breast and cervical cancer screening) in adults with IDD (Cobigo et al., 2018).

It is important to note that having had an annual health assessment is not associated with an increase in cervical or breast cancer screening in this study. This might be due to the lower sample size and concomitant confidence interval bands of those outcomes' variables, as eligible breast (n=189) and cervical cancer screening subjects (n=405) are lower than eligible colon cancer screening (n=464) and influenza vaccination subjects (n=1,162).

The level of intellectual disability variable is distributed in a rightward skewed distribution with mild (54.7%) representing the largest category and profound (11.5%) representing the smallest category. This distribution reflects what is most commonly seen in the literature (Sullivan et al., 2003; Shin et al., 2018; Lewis et al., 2003). This study's multivariate regression identified that level of intellectual disability was not associated with preventative care utilization (Table 4.5), so hypothesis 4 can be rejected (Table 1.1). This result is especially strong due to the large category size of mild/moderate (871) and

severe/profound (291) variables. A non-association between level of intellectual disability and communication ability suggests that the clinical condition of the adult with IDD is much less important than their medical care and their socioeconomic status or the quality of the long term services and support (LTSS) they are receiving.

It is important to note that the literature has mixed results in terms of level of intellectual disability and its association with preventative care utilization. Our results agree with Sullivan et al.'s 2018 finding of no association between level of intellectual disability and breast cancer screening, but disagree with Shin et al.'s 2018 result that found that severe disability was associated with a lower likelihood of cervical cancer screening. There are some potential reasons that could explain the discrepancy between Shin et al. (2018) and the results presented in this dissertation. Shin et al.'s (2018) primary independent variable was type of disability and not intellectual disability level, which resulted in different subpopulations (e.g., hearing, visual, hearing, intellectual, speech and language disability vs. IDD only). Another more obvious reason is the fact that Shin et al. (2018) conducted their study in South Korea, which has a much different surveillance and treatment system for adults with disability (Shin et al., 2018).

The major finding that supports hypothesis 1 (Table 1.1) is that living in a group home, as compared to a non-group home setting, is associated with preventative service utilization. In the bivariate regression model (Table 4.4), we found group home to be significantly associated with a higher likelihood of the utilization of all preventative services. This difference of preventative service utilization between group home and non-

group home individuals can be seen best in Figure 4.3. However, when we control for other variables in the multivariate logistic model, we find that only influenza vaccination and cervical cancer screening remain significant (Table 4.5). We compare these results to other group home/institutional setting studies below in Table 5.1.

Table 5.1
Preventative Care Studies in Adults with Intellectual and/or Developmental Disabilities that Report Adjusted Odds Ratios which Compare Living Situation and Preventative Service Utilization

Study	Influenza Vaccination aOR (CI) (n)	Colon Cancer Screening aOR (CI) (n)	Breast Cancer Screening aOR (CI) (n)	Cervical Cancer Screening aOR (CI) (n)
Xenakis et al., 2019	3.4 (1.8-6.1) (n=1,162)	3.1 (0.6-16.0) (n=464)	5.4 (0.4-74.8) (n=189)	3.8 (1.3-11.2) (n=405)
Xingling et al., 2017	N/A	N/A	7.52 (2.24-25.25) (n=2912)	6.27 (1.95-20.16) (n=5490)
Sullivan et al., 2003	N/A	N/A	Non-Significant (n=380)	N/A
Lewis et al., 2002	0.16 ^a (0.08-0.36) (n=325)	N/A	N/A	N/A

^aThe reported aOR is the inverse

These results are consistent with Xingling et al.'s 2017 research that observed that women with IDD who live in a group home are more likely to undergo breast and cervical cancer screenings. These findings also corroborate Lewis et al.'s 2002 finding out of California that adults with IDD living in a group home were more likely than those living at home or without assistance to receive their influenza vaccination. In light of

these results, it is important to note that Sullivan et al. (2003) did not find institutional care to be associated with breast cancer screening. This breast cancer screening result is consistent with our finding in the multivariate analysis; however, we believe that a larger sample size of women eligible for breast cancer screening may have produced contradictory results, as discussed above.

Furthermore, it is important to discuss the actual adherence rate of the different preventative services in the population. The dissertation detected very high documented preventative services adherence rates across the board for influenza vaccination (68%), pneumococcal vaccination (80%), colorectal cancer screening (62%), breast cancer screening (69%), and cervical cancer screening (72%) (Figure 4.1). These rates are higher than all rates documented in the IDD preventative care studies presented in the literature review (Table 2.2) and are more in line with screening in the general United States populations (CDC, 2012). Since this study took place at a single ambulatory center, the Westchester Institute for Human Development, the results must be evaluated through the lens of the operations of that site. As both a limitation and strength of the study, this suggests that this multi-specialty site, which focuses only on adults with IDD, may play a causal role in the end results of this study and that care setting is an important factor to consider in the treatment of adults with IDD.

In summary, the major findings from this study support the theory that care setting and caregivers are the most vital component effecting the quality of care that an adult with IDD receives. Our findings support previous studies from the United States

and abroad that living in a group home is associated with increased preventative service utilization. Although this dissertation agrees with previous studies, it evaluated a different population of adults with IDD in a novel catchment area during a more recent time period. This continues to add to the dearth of research that exists regarding the characteristics of adults with IDD who receive preventative service utilization. In addition, we evaluated novel variables, and discovered, to our surprise, that number of medications, communication ability, and level of intellectual disability were not associated with preventative service utilization in the multivariate analysis. This adds to a knowledge gap in the IDD literature that has not been previously documented. More importantly, it is consistent with our finding that an individual's caregiver or care setting is more important than their level or type of disability.

Post-Hospitalization Primary Care Follow-Up Study Findings

This second study added to existing IDD literature by describing variation in hospital and demographic impacts on post-acute care of the IDD population, as well as filling a knowledge gap by also describing the discharge statuses of adults with IDD who are hospitalized. However, the main objective of this study was to evaluate post-hospitalization primary care follow-up in adults with IDD, something that had never been formally investigated.

The sample of 788 hospital admissions by 341 unique adults with IDD over a 5-year study period, as well as the distribution and frequency of all the variables (Table 3.8), allowed for a robust analysis. The top 3 principal diagnosis using level two CCS grouped categories includes bacterial infections (17.9%), epilepsy (8.4%), and respiratory infections (6.9%) (Table 4.10). These results follow the same trend presented in previous studies that is specific and separate to the IDD population, namely the increased proportion of admissions for epilepsy, aspiration, mental illness diagnosis, and sepsis (Hosking et al., 2017; Ailey et. al., 2014). These findings support the hypothesis that IDD admission reasons in New York are similar to elsewhere in the United States.

A novel aspect of this dissertation's research is the descriptive presentation of the frequency of discharge status (where the individuals went after they left the hospital) (Table 4.11). Discharge status tabulation is not presented for adults with IDD anywhere in published literature. That said, this study detected a low against medical advice (AMA) discharge status rate of 0.5% (Table 4.11). When compared to the literature, studies have a range of between 1% and 8% of AMA discharge status depending on admission reason (Fiscella, et al., 2007; Karimi et al., 2014). Research has also determined that discharge against medical advice is associated with a significantly higher odds of readmission (risk adjusted OR: 2.06, 95% CI: 2.03-2.09) (Kumar, 2019). As such, this study suggests that being an adult with IDD may result in a reduction of leaving against medical advice. This could be attributed to a decreased capacity for medical decision making or autonomy in general, but nonetheless might be a protective factor.

Another major contribution of this dissertation to the literature was the results of post-hospitalization primary care follow-up and hospital discharge summary receipt for adults with IDD (Table 4.12). As stated above, this has not been explored previously. This dissertation found the overall post-hospitalization primary care follow-up rate to be high. In fact, 42.5% of individuals followed up within 5 days of discharge and 94.8% followed up within 30 days of discharge (Table 4.12). The 30-day primary care follow-up rate in the general population was identified to be approximately 50% depending on location, insurance type, and admission reason in two previous studies (Jencks et al., 2009; Misky et al., 2010). In addition, the rate of discharge summary receipt by the primary care practice amounted to 35.7% within 1-5 days post-discharge and 83.5% within 30 days. There is no comparison research for these time discharge summary frames; nonetheless, the rate of successful transitions of hospital records to the primary care office speaks to the effectiveness of the process currently in place.

The high rate of post-hospitalization primary care follow-up and timely discharge summary receipt could be associated with a number of organizations involved in the transition process. The most notable being the caretakers and group home agencies of this adult Medicare IDD population. The influencing governing bodies and their concomitant regulations that guide the policies and procedures of caretakers and group homes will be discussed in the next section.

Nonetheless, it is important to mention that the primary care practice and the hospital are also a large part of this transition. As discussed above, this study took place

at a single ambulatory center, the Westchester Institute for Human Development. The level of communication and operational relationships between primary care practices in the community and hospitals is an important factor that should have a direct effect on the post-hospitalization primary care follow-up and discharge summary receipt. Many innovative mechanisms of communication exist between practices and hospitals including shared electronic medical records, automatic faxing of hospital courses, discharge team care coordination processes, electronic alerts to the primary care practice through shared health information exchanges, and others. WIHD has a relatively robust communication strategy with surrounding hospitals through a health information exchange that provides automatic alerts when an individual is admitted. This allows for proactive communication by the primary care practice in scheduling timely follow-up and discharge summary receipt. These processes have not been well studied in the general population and not at all in the IDD population, but most likely impact transitions of care and play a causative role in the reassuring results presented in this investigation.

To examine this relationship between practices and hospitals further, this dissertation compared the odds of 30-day follow-up and discharge summary receipt between the top five most frequented hospitals (Table 4.13). This analysis detected no difference in primary care follow-up between the hospitals, suggesting that hospital was not a strong predictor of primary care follow-up. However, this study did find that one of the hospitals, Westchester Medical Center, was associated with a lower odds of the primary care practice receiving a discharge summary within 30 days (OR: 0.3, 95% CI:

0.2-0.5). This finding suggests that there could be a communicative or workflow deficiency originating either at the hospital or WIHD that is limiting the transition of patient information (e.g., poor relationship between the primary care practice and hospital discharge team). Again, this highlights the significance of the care settings and their processes in determining the quality of healthcare an adult with IDD receives.

Lastly, this study used the 7 and 14-day primary care follow-up and hospital discharge summary receipt time cut-offs as the dependent variables in numerous iterations of multivariate logistic regression models in order to evaluate characteristics that could predict the success of the outcomes. The final model controlled for age, sex, ethnicity, race, living situation, level of intellectual disability, as well as both the top 5 most admitted hospitals and the 16 unique level 1 principal admission diagnoses using fixed effect and clustering to account for subjects with multiple admissions (Table 4.18).

One of the most notable findings is the highly significant association between living situation and all four outcome variables. Adults with IDD who lived in a non-group home setting were less likely to follow up in 7 days (aOR: 0.1, 95% CI: 0.0-0.2) and 14 days (aOR: 0.1, 95% CI: 0.1-0.3) when compared to adults with IDD who lived in group homes. In addition, adults with IDD who lived in a non-group home setting were less likely to have their discharge summary reach WIHD within 7 days (aOR: 0.2, 95% CI: 0.1-0.4) and 14 days (aOR: 0.1, 95% CI: 0.1-0.3) when compared to adults with IDD who lived in group homes. . The magnitude and concomitant explanatory power of living in a group home cannot be understated here. That said, both hypothesis 5 and 6 (Table

1.1) can be accepted. Group homes and their success in both preventative care and post-hospitalization follow-up will be discussed further in the next section.

The final multivariate model (Table 4.18), which controlled for confounders, also determined that individuals discharged from Westchester Medical Center were less likely to have their discharge summary reach the primary care practice within the 7 (aOR: 0.4, 95% CI: 0.3-0.8) and 14 day time period (aOR: 0.3, 95% CI: 0.2-0.6) when compared to the other top 4 most frequented hospitals. Again, the magnitude of these results speaks to the significance and variation of the care settings that work together to transfer vital patient information.

Policy and Practice Implications and Future Research

This study has discovered evidence that both the medical provider and setting of adults with IDD have a stronger impact on their healthcare than their clinical status. Family members who care for individuals with IDD are often put in the difficult situation of making complex medical decisions, such as determining the importance of preventative care screening versus the comfort of their loved one (Greenwood et al., 2014). The policies and procedures that run group homes in New York State are based off the Office for People with Developmental Disabilities (OPWDD) guidelines. OPWDD is an independent cabinet-level New York State agency responsible for coordinating services such as Medicaid funded long term services and support (LTSS), medical care,

and residence requirements for approximately 140,000 individuals with developmental disabilities (which includes intellectual disabilities) (OPWDD, 2019a).

The OPWDD sets forth regulatory requirements of the group homes and their Division of Quality Improvement is charged with maintaining compliance with these requirements in order to operate (OPWDD, 2019b). Ensuring group home agency compliance requires staff members from the Division of Quality Improvement to interview group home staff members and review their documentation, as well as state-mandated incident reports (OPWDD, 2019b). One component of being in compliance with OPWDD regulations includes the proper documentation of medical care rendered and appropriate carrying out of a physician's orders (whether administering a medication as prescribed or transporting an individual to a primary care provider upon discharge from the hospital within a certain time frame). It is these regulations that drive the agencies to be in compliance with medical recommendations and most likely the strongest factor as to why New York State group homes in this study have high rates of preventative care, as well as post-hospitalization primary care follow-up, when compared to adults with IDD who live at home.

In addition to the regulatory aspects set forth by OPWDD, another state agency that has an impact on adults with IDD is the Justice Center for the Protection of People with Special Needs. Also known as the "Justice Center," the agency was established in 2013 by the Protection of People with Special Needs Act and accepts allegations and reports of either abuse or neglect of people with special needs (Justice Center for the

Protection of People with Special Needs, 2019). The Justice Center then investigates these allegations, issues recommendations and/or prosecutes criminally liable organizations and individuals if applicable. It is important to note that the Justice Center can be contacted anonymously by anyone, including agency staff or healthcare providers. This additional state-run surveillance agency instills an additional level of compliance and care for New York State's most vulnerable population.

This dissertation serves as direct evidence of the success of New York State regulations. Studies evaluating the trickle-down effect policy has on an individual's healthcare is important. That said, each state has similar, but different agencies and concomitant regulations that govern the organizations that take care of adults with IDD. Other states should learn from the success of New York State and implement positive change. Whenever future research can describe or even compare the effectiveness that state level policy has on its population, it should undoubtedly be conducted with support. Future investigation should use a larger statewide database, such as New York's all-payer Statewide Planning and Research Cooperative System (SPARCS) dataset using Lin et al.'s 2013 methodology for identifying individuals with intellectual and/or developmental disabilities (Lin et al., 2013). This would allow New York State to evaluate all adults with IDD and not be limited to those who receive their care from a single ambulatory center. With much of the previous research evaluating preventative care, forthcoming studies should assess chronic and acute disease outcome variables, such as diabetic control (i.e., HgbA1C levels), hypertensive control (i.e., blood pressure measurements),

schizophrenic antipsychotic medication adherence, and other similar endpoints that are used in the general population.

In addition to state level data, many researchers have called for the assessment of emerging models of care that have the potential to improve preventative service utilization along with other healthcare outcomes in the IDD population (Cobigo et al., 2013). As we know, there exists a system's level issue with IDD healthcare services. Many providers cite low reimbursement rate for non-private insurance compounded by the additional complexity and time required to treat an individual with IDD, and heavier than average administrative paperwork (Havercamp et al., 2004). This calls for a system's based solution in implementing models of care that will be successful in the IDD population.

One such emerging model of care is the patient centered medical home (PCMH). The PCMH is a primary care model that provides a framework for clinicians to reorganize their practice in order to address health system deficits. The core themes of the PCMH include enhanced access, team-based coordinated care, population health management with individualized care plans, and continuous quality improvement (National Committee for Quality Insurance [NCQA] 2019). This primary care model acts as an evidence-based road map shown to increase the quality of care, improve patient outcomes, and reduce costs on the system (Buel et al., 2016; Bazemane et al., 2017). Its success has resulted in widespread adoption in New York State (accounting for about 20% of all primary care practices), as well as financial support by many payers (Burke et

al., 2017). This model has incentivized physicians and practices with financial remuneration for delivering higher quality care.

The PCMH model of care's success in the general population within the United States, and specifically New York, should be evaluated in the IDD population. We believe the PCMH delivery model provides the organizational framework to combat IDD-specific population challenges by focusing on individualized care that follows an increasingly integrated strategy in order to provide better value for these high-need beneficiaries who often deal with fragmented uncoordinated care. In addition, the per capita opportunities for savings are greater because the health needs of the population are higher.

The ambulatory center used in this dissertation, the Westchester Institute for Human Development, became recognized as a New York State National Committee for Quality Assurance PCMH in January 2019. This is the first known IDD-specific ambulatory center that has gained this recognition, and thus, a great population to evaluate within this new model of care. Future investigations could utilize a matched sample that is pre- and post- PCMH recognition to see if preventative service utilization increases after model implementation, as seen in some general population PCMH studies (Markovitz et al., 2015; Alexander et al., 2015). Of course, additional endpoints could also be examined through the lens of the PCMH framework including acute and chronic disease care, care coordination, delivery of care, and patient or provider satisfaction metrics.

Conclusion

Adults with IDD represent 7% of the United States' population and have complex health needs requiring specialized medical care and broader social supportive services. When it comes to previous preventative care studies, adults with IDD are less likely to receive preventative services as recommended by the United States Preventative Service Task Force (USPSTF) and Centers for Disease Control and Prevention (CDC), including but not limited to, colon, breast, and cervical cancer screenings, as well as pneumococcal and influenza vaccinations.

For the preventative care study within this dissertation, medical records from an IDD-specific ambulatory center were used to explore demographic, socioeconomic, and clinical characteristics associated with whether an adult with IDD would receive appropriate preventive services from their primary care provider. This investigation identified that demographic and socioeconomic variables, especially living situation, were associated with some preventative service utilization, whereas clinical characteristics, such as level of intellectual disability, communication ability, and number of medications, were not. These findings added to existing IDD preventative care studies by providing an investigation in a novel location and by identifying non-significant associations with clinical characteristic variables and preventative service utilization.

This study also evaluated post-hospitalization primary care follow-up in the IDD population. Research in the general population finds that poor post-hospitalization primary care follow-up results in higher rates of readmissions. The post-hospitalization

primary care follow-up component of this dissertation used Medicare data and medical records from the same IDD-specific ambulatory center to explore associations between demographic, socioeconomic, and clinical variables, and whether an adult with IDD will achieve timely post-hospitalization primary care follow-up. This study determined that although adults with IDD have a high rate of post-hospitalization primary care follow-up and discharge summary receipt when compared to the general population, the major associated characteristic variable of primary care follow-up and discharge summary receipt in adults with IDD was living situation, namely living in a group home.

The results from this dissertation highlight the achievements that group homes are attaining in terms of preventative care and post-hospitalization primary care follow-up. These gains can be attributed to the regulations set forth by the Office for People with Developmental Disabilities (OPWDD) and should be shared with other state level agencies that create policies for adults with IDD. Further research should continue to evaluate the success that group homes have had directed by state level policy and by emerging models of care, such as the Patient Centered Medical Home, and how these innovations can impact the quality of care individuals with IDD receive.

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