

ADULT MEDICAID BENEFICIARIES WITH
DEVELOPMENTAL DISABILITIES AND EPILEPSY:
PROFILES OF SERVICE USE AND COSTS

by

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ABSTRACT OF THE DISSERTATION

ADULT MEDICAID BENEFICIARIES WITH DEVELOPMENTAL DISABILITIES AND EPILEPSY: PROFILES OF SERVICE USE AND COSTS

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Stephen Crystal, Ph.D.

Adults with developmental disabilities – serious chronic impairments that begin in childhood and continue through the lifespan – are a vulnerable population whose disabilities significantly affect their lives and who typically require lifelong supports (Aday, 1993; Developmental Disabilities Assistance and Bill of Rights Act of 2000, P.L. 106-402). This research analyzed eligibility and claims files of 9,303 community-dwelling adult Medicaid beneficiaries ages 21-64 that were enrolled with the NJ Division of Developmental Disabilities. Using an adapted Behavioral Model for Vulnerable Populations (Gelberg, Andersen, & Leake, 2000) as a conceptual framework, the study identified characteristics associated with epilepsy and addressed the impact of epilepsy on health service use and expenditures. It also identified patterns of epilepsy-related generalist and specialist physician care and examined the association of individual characteristics and patterns of physician care with health care use and expenditures.

Adult Medicaid beneficiaries with developmental disabilities and epilepsy were more likely than those without epilepsy to have one or more developmental disability diagnoses other than epilepsy, psychiatric comorbidity, and physical comorbidity. Individuals with epilepsy were more likely than those without epilepsy to have an inpatient admission and to have an emergency room visit. Epilepsy also was associated

with higher annual expenditures. Among those with epilepsy, African Americans were less likely than whites to have an epilepsy-related specialist visit. Individuals with Medicare and Medicaid coverage were much less likely to have an epilepsy-related emergency room visit than individuals with Medicaid only.

Study results can inform policy makers and practitioners in state developmental disabilities and Medicaid agencies as well as other professionals who assist people with developmental disabilities and their families in accessing medical care. Access to an appropriate health provider should be a priority of developmental disability case managers, care givers, and residential providers as well as state health care policy makers. The apparent disparity in access to epilepsy-related specialist care also underscores the need for state initiatives to ensure equitable access to care. Moreover, findings regarding comorbidities and increased hospital use by those with epilepsy suggest a need to explore approaches for better management of epilepsy, including coordination between generalist and specialist care.

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CHAPTER I

STATEMENT OF THE PROBLEM AND CONCEPTUAL FRAMEWORK

Introduction

Adults with developmental disabilities – serious chronic impairments that begin in childhood and continue through the lifespan – are a vulnerable population whose disabilities significantly affect their lives and who typically require lifelong supports (Aday, 1993; Developmental Disabilities Assistance and Bill of Rights Act of 2000, P.L. 106-402). Those who have epilepsy in addition to intellectual disability (previously mental retardation) or other developmental disabilities are especially vulnerable and have more complex medical needs (Devinsky, 2002; Branford, Bhaumik, & Duncan, 1998; Branford, Bhaumik, Collacott & Duncan, 1998). There is evidence from the United Kingdom that people with developmental disabilities and epilepsy use more intensive and more costly forms of health services, such as inpatient hospital care and emergency departments, than their counterparts without epilepsy (Currie, Morgan & Peters, 1998; Morgan, Baxter, & Kerr, 2003). Despite the frequency of epilepsy among individuals with developmental disabilities (Bowley & Kerr, 2000) and the complexity of their medical management (Alvarez, Kern, Cain, Coulter, Iivanainen, & Plummer, 1998; Working Group of the International Association of the Scientific Study of Intellectual Disability, 2001), their health service use and associated costs in the United States have not been well documented.

This study addresses impact of epilepsy on health service use and expenditures for adult Medicaid beneficiaries with developmental disabilities, patterns of epilepsy-related generalist and specialist physician care, and association of individual characteristics and

patterns of physician care with health care utilization and expenditures. Based on the small body of literature and limitations of the knowledge base about health care for adults with developmental disabilities and epilepsy, the study addressed the following research questions regarding Medicaid beneficiaries with both conditions:

1. What are the predisposing (age, gender, race/ethnicity, number of developmental disability diagnoses other than epilepsy, psychiatric comorbidity, substance abuse), enabling (Medicare and Medicaid, Medicaid only), and need (physical comorbidity) characteristics associated with this dual diagnosis?
2. In relation to having versus not having epilepsy, is there a difference in inpatient hospital admissions, length of stay, emergency room use, and expenditures among beneficiaries with developmental disabilities?
3. What is the profile of anticonvulsant medication use?
4. What are patterns of epilepsy-related generalist and specialist physician care for adult Medicaid beneficiaries with developmental disabilities and epilepsy? Do patterns differ by the aforementioned predisposing, enabling, and need characteristics?
5. What is the association of predisposing, enabling, and need characteristics with inpatient hospital admissions, emergency room use, and expenditures?

Study results can inform policy makers and practitioners in State developmental disabilities and Medicaid agencies as well as other professionals (e.g., case managers, health care providers) who assist people with developmental disabilities and their families. A better understanding of factors that contribute to use of the most expensive modes of treatment can promote better use of resources in order to improve patient outcomes. The study's findings can also inform the state policies and reimbursement mechanisms that promote access to appropriate specialist care and coordination between generalist and specialist care.

Definition and Prevalence of Developmental Disabilities and Epilepsy

Developmental disabilities are severe, chronic disabilities that occur during the developmental period, are likely to last throughout the lifespan, and are attributable to a single mental or physical impairment or a combination of mental or physical impairments (Developmental Disabilities Assistance and Bill of Rights Act of 2000, P. L. 106-402). They involve substantial functional limitations in major life activities such as learning, self-care, and mobility. While the most prevalent condition associated with developmental disability is intellectual disability, others include autism, cerebral palsy, and spina bifida. An analysis of the 1994-95 National Health Interview Survey Disability Supplement estimated the prevalence of intellectual disability and other developmental disabilities among non-institutionalized adults to be 6.8 per 1,000 (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001).

Characterized by recurrent, intermittent seizures, epilepsy is a common, serious condition among people with developmental disabilities (Alvarez, Kern, Cain, Coulter, Iivanainen, & Plummer, 1998; Bowley & Kerr, 2000; Coulter, 2005; Hannah & Brodie, 1998). Prevalence estimates of epilepsy among children and adults with developmental disabilities range from 14% to 44% (Beange, McElduff, & Baker, 1995; Bowley & Kerr, 2000; Branford, Bhaumik & Duncan, 1998; McDermott, Moran, Platt, Wood, Isaac, & Dasari, 2005; McGrother, Bhaumik, Thorp, Hauck, Branford, & Watson; Minihan, 1986; Minihan & Dean, 1990; Morgan, Baxter, & Kerr, 2003). Even the lowest estimates far exceed the range of 4.7 per 1000 in the general population (Centers for Disease Control, 1994). While in some cases the impact of epilepsy alone may result in disability severe enough to qualify as a developmental disability, epilepsy frequently occurs together with

developmental disabilities such as intellectual disability, cerebral palsy, and autism (Bowley & Kerr, 2000; Devinsky, 2002, McDermott, Moran, Platt, Wood, Isaac, & Dasari, 2005).

Epilepsy classification has been an evolving system that has undergone substantial revision over the past few decades. Terminology and classification of epileptic seizures and syndromes have been established by The International League Against Epilepsy (ILAE), an association of physicians and other health professionals (Engel, 2001). The ILAE adopted the current taxonomies in the 1980's, but classification of epilepsy types is a continuing process. The most recent recommendations of the ILAE Task Force on Classification and Terminology proposed a broad, flexible diagnostic scheme rather than a new fixed classification system (Engel, 2005). The scheme allowed for classifying seizures and syndromes in several different ways, recognizing the diverse opinions and multiple clinical and research applications any new system would be expected to address in order to gain acceptance in the field.

The variation in professional approaches to epilepsy diagnosis and the complexity of diagnosing and treating epilepsy in people with developmental disabilities (Bowley & Kerr, 2000; Coulter, 2005) present a substantial challenge to provision of quality care for people with developmental disabilities and epilepsy. A precise diagnosis improves the chance of effective epilepsy treatment (Coulter, 2005). However, diagnostic precision is difficult in this population, complicating selection of the most appropriate anticonvulsant medication(s) for an individual with developmental disabilities (Coulter, 2005). Despite this challenge, principles guiding epilepsy treatment for people with developmental disabilities are the same as those for the general population (Coulter, 1997).

People with epilepsy and another developmental disability are at higher risk for multiple disabling conditions (Devinsky, 2002; McDermott, Moran, Platt, Wood, Isaac, & Dasari, 2005). They also have more fractures (Lohiya, Crinella, Tan-Figueroa, Caires, and Lohiya, 1999), perhaps from seizures or loss of bone density resulting from anticonvulsant drug use (Wagemans, Fiolet, van der Linden, & Menheere, 1998). Finally, mortality risk is heightened (Forsgren, Edvinsson, Nystrom & Blomquist, 1996; Lerman, Apgar, & Jordan, 2003).

Significance and Implications for Social Work and Public Policy

The limited body of literature about this relatively small but vulnerable population has insufficiently described their health-related characteristics (apart from studies that cannot be generalized because of non-probability samples), health service utilization and costs (apart from a limited number of U.K. studies), and factors that may improve or impede access to medical care (apart from insurance). The current study is the first comprehensive analysis of health service utilization and expenditures for a statewide population of adult Medicaid beneficiaries with developmental disabilities and epilepsy. It compared the health care utilization and expenditures of adults with developmental disabilities and epilepsy to counterparts without epilepsy. It also identified the characteristics of individuals with both conditions, patterns of epilepsy-related generalist and specialist physician care, and factors associated with hospital care (admissions, emergency room use, costs).

Study findings have implications for state policy and practice regarding medical care and related services for this population. As first recognized in the U.K (Morgan,

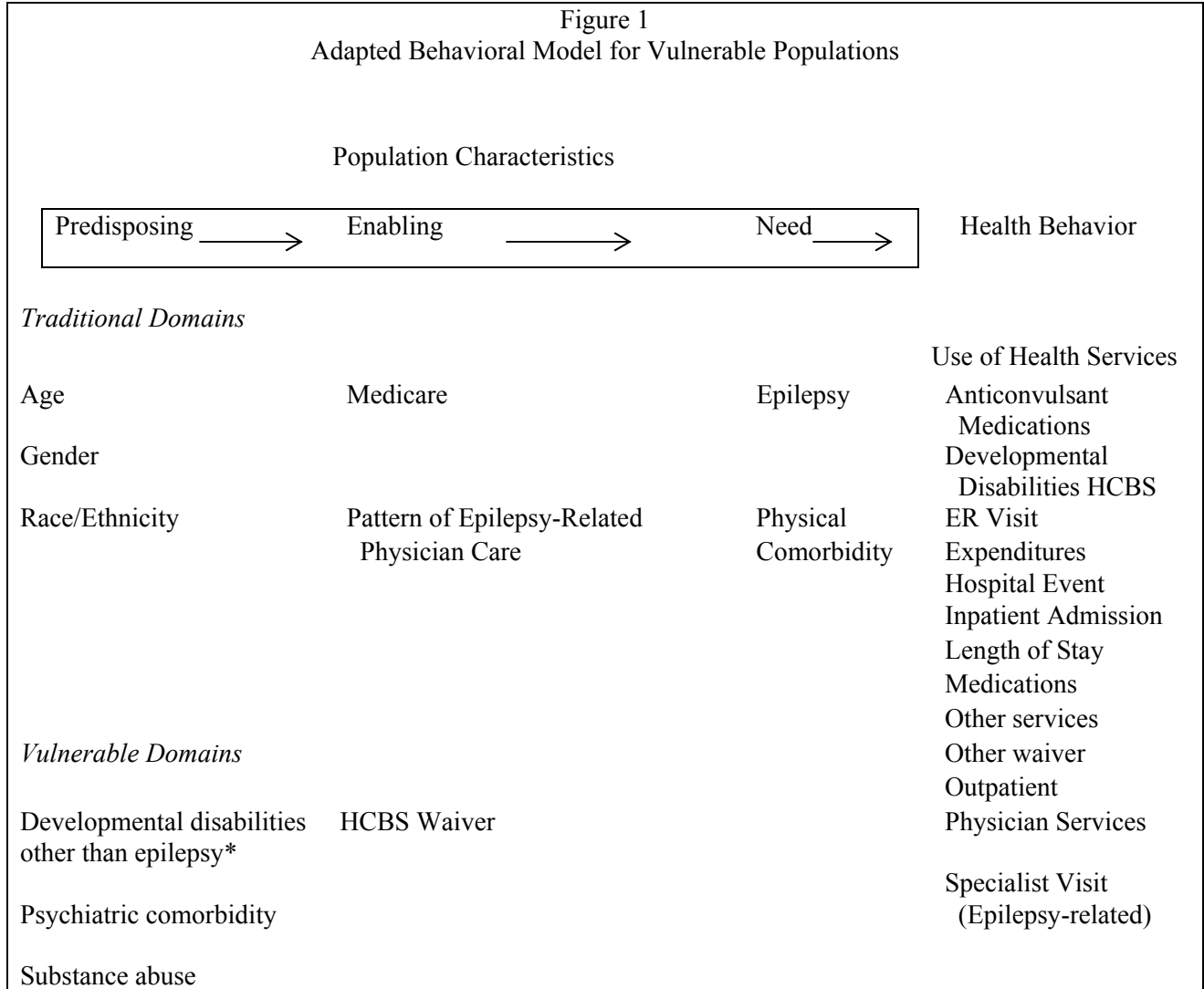
Baxter, & Kerr, 2003), adults with developmental disabilities and epilepsy use more intensive and costly forms of care. The current research substantiated these findings for the Medicaid population in a major urban state, suggesting it may be useful to explore more cost-effective ways of addressing the needs of this population. Further, the two-year hospitalization rate among adults with developmental disabilities and epilepsy in this study was 20%, compared with an 8 % annual admission rate for epilepsy in the general U.S. population with this condition (Centers for Disease Control, 1995). This apparent disparity warrants further examination to determine whether it is the result of differences in epilepsy severity, inequities in treatment, or other factors.

The current study also documented the advantage of dual eligibility for Medicare and Medicaid compared with Medicaid coverage alone. Controlling for other factors, the odds of an epilepsy-related emergency room visit for dual eligibles were only one-fifth of those with Medicaid only. Finally, this analysis of fee-for-service health care use and expenditures will provide a baseline for comparison with use and expenditure patterns in managed care plans, as states continue to turn to managed care approaches to improve patient outcomes and control Medicaid costs for people with developmental disabilities (Center for Health Care Strategies, 2000; Kastner & Walsh, 2006; The Pacific Health Policy Group, 2005).

Conceptual Framework: The Behavioral Model for Vulnerable Populations

The predominant model for studying health services utilization over the past thirty years is the Behavioral Model of Health Services Use (Aday & Awe, 1997; Andersen & Newman, 1973; Andersen, 1995). The central premise of the model is that health service

utilization is a function of characteristics that may predispose an individual to use health services, factors that enable or present barriers to accessing care, and the individual's or a health professional's assessment of the need for care. In order to improve the model's ability to explain the health care utilization and health status of vulnerable groups, the most recent revision of the model adds characteristics that make a population vulnerable and that may also affect their health care use and health outcomes (Gelberg, Andersen, & Leake, 2000). In addition to the "traditional" factors included in the behavioral model such as age, race/ethnicity, and insurance, the model includes "vulnerable domains," or characteristics of salience for vulnerable populations. For example, Gelberg et al. (2000) added mental illness and residential history as independent variables affecting the health care use and health outcomes of homeless adults. The model also allows for tailoring its categories to different vulnerable populations, such as individuals with disabilities (Aday, 1993; Millman, 1993; Pope & Tarlov, 1991). The Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) was adapted for this study (Figure 1).



*Classified as a need factor in relation to HCBS waiver.

Three sets of factors, classified as predisposing, enabling, and need characteristics, are considered to influence health services utilization. A predisposing characteristic affects the propensity to use medical care, but does not in itself constitute an illness or immediate need for medical care (Aday & Awe, 1997). The traditional domain of predisposing characteristics in this adapted Andersen-Gelberg model includes age, gender, and race/ethnicity. Developmental disabilities other than epilepsy,

psychiatric comorbidity, and substance abuse were added to the model as vulnerable domain predisposing characteristics.

Enabling factors refer to the means available to facilitate access to care as well as barriers to care. Traditional enabling resources in the original Andersen model include factors such as region, insurance and income. Pattern of epilepsy-related physician care was included as a traditional domain enabling factor and Developmental Disabilities Home and Community Based Services (HCBS) Waiver participation was added as a vulnerable domain factor.

Need factors relate to the immediate reasons for seeking care and commonly include health status, severity of illness, and comorbid conditions. In addition to epilepsy, physical comorbidity, defined as the presence of any chronic condition included in the Charlson Comorbidity Index, (Charlson, Pompei, Ales, & McKenzie 1987), was included in the adapted Gelberg model.

As noted in the description of predisposing characteristics, developmental disability other than epilepsy was considered a predisposing factor in this study of health care use and expenditures. Since developmental disabilities are related to problems in neurodevelopment and involve impairments that require intervention, initially they might be considered as need factors in the adapted Andersen-Gelberg model. However, the conditions associated with developmental disability (e.g., intellectual disability) may not require medical intervention, but individuals with developmental disabilities are more likely to have other health conditions that require medical care. Andersen's (1995) reflection on the evolution of the behavioral model supports the idea of developmental disability as a predisposing characteristic, suggesting that genetic factors might be added

to the model as a predisposing factor. Similarly, Gelberg et al. (2000) included "cognitive ability" and "developmental delay" as examples of vulnerable domain predisposing factors that might be added to the model.

While the focus of this study was on medical (e.g., physician, inpatient, and emergency room) services, it also analyzed predictors of use of and expenditures for developmental disabilities home and community based waiver services. In New Jersey, these services include case management, habilitation (day programs and supported employment), individual supports (residential habilitation in group homes, skill development homes, own homes, and self-determination), personal emergency response services, environmental/vehicle modifications, and Community Professional Support and Training (occupational therapy, physical therapy, psychology, and psychiatry). For the analysis of home and community based service interventions that address social and developmental aspects of disability, number of developmental disabilities was classified as a need factor. This conceptualization is congruent with Gelberg et al.'s (2000) labeling substance abuse as a predisposing characteristic in a study of medical care use, while noting that the condition would be considered a need factor in an analysis of substance abuse services.

Health behavior, including the use of health services, may be considered an outcome associated with independent influences of predisposing, enabling and need characteristics, or it may be considered to be a determinant of health outcomes. In this study, health service use was the outcome of interest. It included use and costs of: 1) home and community based waiver services; 2) hospital care (emergency room, inpatient

admissions; 3) medications; 4) outpatient care other than physician services; 5) physician services, and other services (e.g. durable medical equipment, medical transportation).

In general, if need factors are the most significant determinants of utilization, the evidence exists for equitable access to care. However, if predisposing factors (e.g., race/ethnicity) or enabling factors (e.g., insurance, income) are stronger determinants of service utilization, then there is evidence of inequitable access to care (Aday & Awe, 1997).

Summary of Chapter I

This chapter introduced the research problem and gaps in the literature regarding the health service use of adults with developmental disabilities and epilepsy. It also presented the research questions, highlighted the study's implications for social work practice and public policy, and described the conceptual framework used in the study.

CHAPTER II

LITERATURE REVIEW

Research Applications of the Behavioral Model for Vulnerable Populations

Studies applying the Behavioral Model for Vulnerable Populations were identified through a computer search of the Medline and CINAHL databases from the model's publication in 2000 to 2007 with appropriate descriptors (e.g. behavioral model, vulnerable populations, access, and utilization). None of the studies applying the Behavioral Model for Vulnerable Populations had a focus on adults with developmental disabilities. They analyzed access to substance abuse treatment for individuals with disabilities (Krahn, Farrell, Gabriel, & Deck, 2006) and health service use and outcomes for homeless adults (Desai et al., 2003; Gelberg et al., 2000; Lim, Anderson, Leake, Cunningham, & Gelberg, 2002, & Swanson et al., 2003), newly homeless youth (Solorio, Milburn, Weiss, & Batterham, 2006), minority and immigrant women receiving care at a safety-net healthcare system in Texas (Owusu, Eve, Cready, Koellin, Trevino, Urrutia-Rojas, & Baumer, 2005), residents of urban public housing communities (Baker, Bazargan, Bazargan-Hegazi, & Calderon, 2005; Barzagan, Barzagan-Hejazi, & Baker, 2005; Bazargan, Bazargan, Farooq, & Baker, 2004; Bazargan, Norris, Bazargan-Hegazi, Akhanjee, Calderon, Safvarti, & Baker, 2005), individuals with panic attacks (Katernahl & Parchman, 2002), and children of Latino migratory workers (Weathers et al., 2004).

Predisposing factors associated with use of health services included: 1) older age (Bazargan, Bazargan-Hegazi, & Baker, 2005; Gelberg et al., 2000 & Desai et al., 2003); 2) Hispanic race/ethnicity (Bazargan, Bazargan, Farooq, & Baker, 2004; Owusu, Eve, Cready, Koellin, Trevino, Urrutia-Rojas, & Baumer, 2005); 3) difficulty speaking

English (Baker, Bazargan, Bazargan-Hegazi, & Calderon, 2005); 4) mental illness (Desai et al., 2003; Gelberg et al., 2000; & Lim et al., 2002); 5) substance abuse (Gelberg et al., 2000; Desai et al., 2003; & Solorio, Milburn, Weiss, & Batterham, 2006); 6) a history of victimization or physical assault (Gelberg et al., 2000 & Lim et al., 2002), 7) placement in residential treatment for homeless veterans (Desai et al., 2003), 8) disability among African American and Hispanic public housing residents (Bazargan, Bazargan-Hegazi, & Baker, 2005), and 9) stigmatization/victimization of people with disabilities (Krahn, Farrell, Gabriel, & Deck, 2006).

Continuity of care was an important enabling factor for three types of medical care by public housing residents: antidepressant use by adults with depression (Bazargan, Bazargan-Hegazi, & Baker, 2005); vision care (Baker, Bazargan, Bazargan-Hegazi, & Calderon, 2005); and Pap smears (Bazargan, Norris, Bazargan-Hegazi, Akhanjee, Calderon, Safvarti, & Baker, 2005). Having a usual source of care was a significant factor in obtaining a Pap smear for low-income women (Owusu, Eve, Cready, Koellin, Trevino, Urrutia-Rojas, & Baumer, 2005). Similarly, homeless women who had a single place where they regularly obtained medical care had more outpatient visits and preventive health screens such as mammograms (Lim et al., 2002). There were inconsistent results concerning the effect of provider characteristics. Homeless women with a community clinic or a private physician as a usual source of care had better outcomes (Gelberg et al., 2000) and homeless women who saw private physicians were consistently more satisfied than those who visited clinics or other sites (Swanson et al., 2003). Facility characteristics, however, were not a significant factor in ambulatory visits by homeless veterans (Desai et al., 2003). People with disabilities identified inaccessibility of

programs and facilities, as well as negative attitudes on the part of treatment providers, as barriers to substance abuse services (Krahn et al., 2006). The results of the studies to date suggest the value of applying the model with other vulnerable populations, such as those with developmental disabilities.

Most of the studies employed similar statistical methods: linear and logistic regressions were used to analyze the associations between the predictor and outcome variables (Baker, Bazargan, Bazargan-Hegazi, & Calderon, 2005; ; Barzagan, Barzagan-Hejazi, & Baker, 2005; Bazargan, Bazargan, Farooq, & Baker, 2004; Bazargan, Norris, Bazargan-Hegazi, Akhanjee, Calderon, Safvarti, & Baker, 2005; Gelberg et al., 2000; Katernahl & Parchman, 2002; Lim et al., 2002; Owusu, Eve, Cready, Koellin, Trevino, Urrutia-Rojas, & Baumer, 2005; & Swanson et al., 2003). Desai et al. (2003) used generalized estimating techniques to account for clustering of patients within program sites. Limitations of the studies applying the Behavioral Model for Vulnerable Populations included: potential selection bias limiting generalizability to other populations (Desai et al., 2003; Gelberg et al. 2000; Katernahl & Parchman, 2002; Owusu, Eve, Cready, Koellin, Trevino, Urrutia-Rojas, & Baumer, 2005; Swanson et al., 2003 & Weathers et al., 2004); potential reporting bias from self-reports and subject recall (Baker, Bazargan, Bazargan-Hegazi, & Calderon, 2005; Barzagan, Barzagan-Hejazi, & Baker, 2005; Bazargan, Bazargan, Farooq, & Baker, 2004; Bazargan, Norris, Bazargan-Hegazi, Akhanjee, Calderon, Safvarti, & Baker, 2005; Gelberg et al. 2000; Katernahl & Parchman, 2002 & Weathers et al., 2004); limited power due to small sample size (Gelberg et al. 2000; Katernahl & Parchman, 2002); potential measurement error due to questionable content validity (Baker, Bazargan, Bazargan-Hegazi, &

Calderon, 2005; Barzagan, Barzagan-Hejazi, & Baker, 2005) or the collection of clinical data by lay interviewers rather than clinicians (Gelberg et al., 2000).

This research showed that predictors of service use and outcomes can vary with different services (Baker, Bazargan, Bazargan-Hegazi, & Calderon, 2005; Barzagan, Barzagan-Hejazi, & Baker, 2005; Bazargan, Bazargan, Farooq, & Baker, 2004; Gelberg et al., 2000; Lim et al., 2002). Moreover, the nature of the relationship between predictors and outcomes may not conform to expectations. For example, longer periods of homelessness were associated with better health outcomes (Gelberg et al., 2000)

The Behavioral Model for Vulnerable Populations was found to be useful for analyzing unmet need (Weathers et al., 2004) and patient satisfaction (Swanson et al., 2003), as well as service use (Baker, Bazargan, Bazargan-Hegazi, & Calderon, 2005; Barzagan, Barzagan-Hejazi, & Baker, 2005; Bazargan, Bazargan, Farooq, & Baker, 2004; Bazargan, Norris, Bazargan-Hegazi, Akhanjee, Calderon, Safvarti, & Baker, 2005; Desai et al., 2003; Gelberg et al., 2000; Katernahl & Parchman, 2002; Lim et al., 2002; Owusu, Eve, Cready, Koellin, Trevino, Urrutia-Rojas, & Baumer, 2005; Solorio, Milburn, Weiss, & Batterham, 2006) and health outcomes (Gelberg et al., 2000). This research also confirmed the value of adding vulnerable domain variables to the traditional behavioral model.

Application of the Andersen Behavioral Model to Individuals with Developmental Disabilities

Although the Behavioral Model for Vulnerable Populations has not been applied in prior studies of individuals with developmental disabilities, several studies have utilized the traditional Andersen behavioral model (Andersen & Newman, 1973;

Andersen, 1995) with the developmental disabilities population. Lin, Wu, & Lee (2004) identified predictors of inpatient care among children and youth with intellectual disabilities attending day care programs in Taiwan. Weller and colleagues (2003) analyzed utilization of health, mental health, and social services by school-age children and adolescents with special health care needs, a population that substantially overlaps with the population of children with developmental disabilities. Howard (1990) examined health characteristics, ambulatory care utilization, and associated expenditures among community-dwelling adults with intellectual disability in Massachusetts, and two studies (Pruchno & McMullen, 2004; Smith, 1997), examined service use and unmet needs for services among adults with developmental disabilities.

Predisposing factors predicting health and health-related (social) service use included age (Howard, 1990; Lin, Wu, & Lee, 2004; Smith, 1997), gender (Smith, 1997), education (Lin, Wu, & Lee, 2004; Weller et al., 2003), race/ethnicity (Lin, Wu, & Lee, 2004; Pruchno & McMullen, 2004), mobility impairment (Howard, 1990), and a history of institutionalization (Howard, 1990). Insurance was an important enabling factor for medical care use (Howard, 1990; Weller et al., 2003). Income (Smith, 1997) as well as public spending for community services and having activities outside the home (Pruchno & McMullen, 2004) were predictors of social service use by adults with developmental disabilities. Significant need factors included health status of the individual with a developmental disability (Howard, 1990; Lin, Wu, & Lee, 2004) and a caregiver (Smith, 1997), current use of prescription medications (Howard, 1990), and a pattern of violent behavior (Pruchno & McMullen, 2004).

A few themes emerged from the studies applying Andersen's (1973; 1995) behavioral model to individuals with developmental disabilities and special health care needs. The predisposing factor of race/ethnicity was associated with social service use (Pruchno & McMullen, 2004, & Weller et al., 2003) and unmet service needs (Pruchno & McMullen, 2004): African Americans were less likely to use health-related services and more likely to report unmet service need. This finding is consistent with the literature concerning racial disparities in health care (Smedley, Stith & Nelson, 2002). A history of institutionalization and mobility impairment were significant predisposing factors in several measures of ambulatory care utilization and expenditures by adults with developmental disabilities (Howard, 1990). Uninsured children were less likely to visit a doctor (Weller et al., 2003). Children with public and private insurance were more likely to have a hospitalization than those with private insurance only, and those with public insurance alone or together with private insurance were more likely to have an emergency room visit (Weller et al., 2003). Poor health status was associated with emergency room use by children (Weller et al., 2003) and adults (Howard, 1990). Existing illness and a need for rehabilitation were associated with a greater likelihood of hospitalization (Lin, Wu, & Lee, 2004), while need for rehabilitative services also was associated with ambulatory care expenditures (Howard, 1990). Adults with developmental disabilities using prescription drugs were more likely to visit the emergency room.

Limitations of the studies applying the behavioral model to the developmental disabilities population included use of a non-probability sample with a risk of selection bias (Howard, 1990; Pruchno & McMullen, 2004; & Smith, 1997), self-reports of service

use, with potential recall bias (Lin, Wu, & Lee, 2004; Pruchno & McMullen, 2004; & Smith, 1997), lack of demographic factors such as race/ethnicity (Smith, 1997), and a lack of system-level variables that may influence service accessibility (Howard, 1990; Lin, Wu, & Lee, 2004; Pruchno & McMullen, 2004; Smith, 1997 & Weller et al., 2003). Finally, although Smith (1997) and Pruchno & McMullen (2004) addressed the issue of correlation between the outcome measures, they did not address the potential problem of multicollinearity between independent variables. Several of the need factors, such as offspring disability and extent of caregiving by the parent, may be overlapping constructs.

Two studies with the adult developmental disabilities population (Pruchno & McMullen, 2004 & Smith, 1997) used the family or parent as the unit of analysis and analyzed nonmedical services. Both discussed the ambiguity of the relationship between caregiver burden and unmet service needs, with the possibility of a reciprocal relationship. The lack of a needed service, for example, could increase the mother's perception of her burden as a caregiver. The potential reciprocal relationship between the predictor variable of subjective burden and the outcome variable of unmet need makes it difficult to assess the direction of the relationship between the two factors (Pruchno & McMullen, 2004 & Smith, 1997). These two studies were limited by the lack of a discussion of potential multicollinearity between independent variables. Since multicollinearity was not examined, it is difficult to separate the effects of two variables that may be closely correlated, such as caregiver burden and future worry (Kachigan, 1991).

Developmental Disabilities and Epilepsy

In addition to the studies applying the Andersen model with the developmental disabilities population, other literature regarding health and health care for adults with developmental disabilities and epilepsy was identified through multiple strategies. A computer search of English language articles in the Medline and CINAHL databases from 1982 to 2007 was conducted with appropriate descriptors (e.g. developmental disabilities, mental retardation, intellectual disabilities, epilepsy, access, and utilization). In addition, a manual search of the journals *Intellectual and Developmental Disabilities (formerly Mental Retardation)* and *American Journal on Mental Retardation* from 1990 to 2007 was conducted. Additional studies were identified through the reference lists in the studies previously identified. Finally, health policy internet sites such as the Kaiser Family Foundation and the Center for Health Care Strategies were searched.

Past work specifically focusing on the health and health care of adults with developmental disabilities and epilepsy is even more limited than the work on adults with developmental disabilities and health conditions in general. There are, however, some findings that shed light on the health concerns of adults with developmental disabilities and epilepsy. This review is organized according to the theoretical framework of the behavioral model for vulnerable populations (Gelberg, Andersen, & Leake, 2000).

Analysis of Predisposing, Enabling and Need Characteristics of Adults with Developmental Disabilities and Epilepsy

Predisposing Factors - *Traditional Domain*

Estimates of epilepsy prevalence in adults with developmental disabilities have used a variety of age groupings with differing results (Bowley & Kerr, 2000; McDermott et al., McGrother et al., 2006; Morgan et al., 2003). Lower prevalence among older adults, however, has been a consistent finding, due to higher mortality of individuals with developmental disabilities and epilepsy (Forsgren, Edvinsson, Nystrom & Blomquist,

1996; Lerman, Apgar, & Jordan, 2003). Among individuals with Down syndrome, however, the risk of epilepsy increases with age (Johannsen, Christensen, Goldstein, Nielsen, & Mai, 1996; Menendez, 2004; McDermott, Moran, Platt, Wood, Isaac & Dasari, 2005). Further, epilepsy is associated with early development of dementia among adults with Down syndrome (Bush & Beail, 2004; Lott & Head, 2005; Menendez, 2005). McDermott et al. (2005) also found that prevalence of epilepsy increased with age for those with autism among adults in primary care settings.

Predisposing Factors - *Vulnerable Domain*

There have been conflicting results of studies regarding the association of psychiatric disorders with epilepsy among individuals with developmental disabilities. McGrother et al., (2006) found that epilepsy was associated with behavior problems and psychological symptoms. In contrast, Bowley & Kerr (2000) concluded that there is insufficient evidence to assert a definitive association between epilepsy and psychiatric disorders. There is, however, reason to continue to examine this question. A study of 1,135 individuals with intellectual disabilities referred for psychiatric assessment over a six-year period (Ryan & Sunada, 1997) found that epilepsy was the most common medical condition among the patients. Nearly half (45.8%) of the patients had under-treated or undiagnosed epilepsy. For many patients, appropriate treatment for the seizures was necessary in order to address the psychiatric issues.

Enabling Factors - *Traditional Domain*

Although no studies specifically addressing enabling factors in relation to adults with developmental disabilities and epilepsy were identified in the literature search, one study analyzed patterns of physician care for children with chronic conditions, including diagnoses related to developmental disabilities. The children were enrolled in fee-for-

service Medicaid in four states (Kuhlthau, Ferris, Beal, Gortmaker & Perrin, 2001). Among those whose Medicaid eligibility was based on SSI enrollment, the children who were younger, white, and who had higher scores on a measure of “illness burden” were more likely to see a subspecialist, compared with older children, nonwhites, and children with less severe illness. Epilepsy was the second most common condition among the study sample. Among the children with epilepsy receiving Supplemental Security Income (SSI), nearly three out of five (57%) saw a subspecialist (neurologist or psychiatrist) for the condition during a one-year period, with a mean of 14.1 visits. Eighty-seven percent saw a generalist physician (pediatricians, internists, family practitioners, or general practitioners) for the condition, with a mean of 7.4 visits. These findings suggest that nearly all of the children with seizure disorders were getting access to primary care, and that a substantial proportion were making intensive use of specialist care.

A second analysis of these data found that 45% of the children with epilepsy saw only generalists for the condition, 39% predominantly saw generalists (50% or more of their visits were to generalists), and 16% predominantly saw subspecialists (Perrin, Kuhlthau, Gortmaker, Beal, & Ferris, 2002). The children with epilepsy who received predominantly subspecialist care had lower Medicaid expenditures than their counterparts who received generalist only or predominantly generalist care. These two studies provide methodologies for analyzing patterns of care that can be applied to other Medicaid beneficiaries with chronic conditions, such as adults with developmental disabilities and epilepsy.

Need Factors - *Traditional Domain*

By definition, adults with developmental disabilities and epilepsy have at least one need factor, for epilepsy is a chronic condition that requires medical intervention. People with severe disabilities are at higher risk for epilepsy (Branford, Bhaumik & Duncan 1998; Bowley and Kerr, 2000; McGrother et al., 2006; & van Schrojenstein

Lantman-de Valk, Akker, Maaskant, Haveman, Urlings, Kessels, & Crebolder, 1997). Currie and colleagues (1998) found that intellectual disability was the most frequent additional co-occurring condition among adults with epilepsy age 19-55 admitted to the hospital in a large health district in Wales.

Diagnosis of epilepsy in the population with developmental disabilities is made more complex by the nature of the developmental disabilities as well as medication side effects (Bowley & Kerr, 2000; Coulter, 1997). Movement disorders, in some cases drug-related, can make diagnosis more difficult. In addition, there is evidence that this population has more complex needs than others with developmental disabilities. Multiple seizure types are common among adults with developmental disabilities, and epilepsy among adults with developmental disabilities is often resistant to intervention (Bowley & Kerr, 2000; Branford, Bhaumik, and Duncan 1998; McGrother et al., 2006; (“Special Groups of Patients: Mental Retardation,” 2003).

Need Factors - *Vulnerable Domain*

The presence of one or more developmental disabilities makes this population vulnerable. Further complicating the medical management of epilepsy among people with intellectual disabilities is the frequent presence of other disabling conditions, such as cerebral palsy or autism (Devinsky, 2002; McDermott et al., 2005; McGrother et al., 2006). Adults with intellectual disabilities have been found to have lower bone mass (Aspray, Francis, Thompson, Quillian, Rawlings, and Tyler, 1998). Moreover, those with developmental disabilities and epilepsy have a higher risk of fractures (Lohiya, Crinella, Tan-Figueroa, Caires, Cic, & Lohiya, 1999). This may be due to trauma such as falls caused by seizures as well as vitamin D deficiency related to the use of anti-seizure medications (Aspray, Francis, Thompson, Quillian, Rawlings, and Tyler, 1998). Not only can the additional conditions make diagnosis or treatment more difficult, the involvement of multiple medical specialists can make coordination of care more challenging.

Health Service Utilization

There is a scarcity of studies of the health service utilization of adults with developmental disabilities and epilepsy. In a population study in Wales, Morgan and colleagues (2003) found that people with intellectual disabilities and epilepsy had more inpatient admissions as well as outpatient and emergency room visits than those without epilepsy. The finding held even after excluding epilepsy-related admissions. This is consistent with other studies of hospital use by patients with epilepsy without intellectual disability (CDC, 1995, Currie et al., 1998), and individuals with developmental disabilities (Beange et al., 1995; Morgan, Ahmed, & Kerr 2000; Walsh, Kastner & Criscione, 1997). Among the U.S. general population, race/ethnicity has been identified as a factor in hospitalization rates for epilepsy, for admission rates are lower in whites than in other groups (CDC, 1995).

Patients with epilepsy in the UK have been found to have a longer length of stay than other patients, and the second most frequent primary diagnosis for the hospital admissions of adults with epilepsy was “other specified mental retardation.” This suggests that developmental disability is a factor in the increased length of stay for patients with epilepsy (Currie, et al., 1998). Higher hospitalization rates and a longer average length of stay are likely to result in higher expenditures for adults with developmental disabilities and epilepsy, for Morgan and Kerr (2004) found increased hospital costs for a population with epilepsy in the UK. Epilepsy related-expenditures for adults with developmental disabilities may be affected by patterns of physician care, if the results of Perrin et al’s (2002) finding that Medicaid expenditures are lower for children with epilepsy whose care was predominantly provided by a subspecialist also holds true for adults.

Quality of Care and Health Outcomes

There is evidence that the quality of health care for adults with developmental disabilities and epilepsy should be a significant concern for health care providers and the developmental disabilities service system. Several studies have found undiagnosed or under-treated epilepsy (Beange et al. 1995; Lewis, M., Lewis, C., Leake, King, & Lindeman, 2002; Ryan & Sunada, 1997). A follow-up study of adults with intellectual disabilities in the U.K. had discouraging results, for a higher percentage of the 138 individuals studied had more serious seizure problems in 1997 than they had in 1985 despite the introduction of new medicines and the use of more medicines (Branford, Bhaumik, Duncan, & Collacott, 1998). Since hospitalization for epilepsy is considered preventable with effective ambulatory care (Millman, 1993; CDC, 1995), Morgan et. al.'s (2003) finding of higher hospital use by adults with intellectual disabilities and epilepsy suggests less than optimal management of the condition.

Efforts to improve the management of epilepsy in this population include recommendations for the use of anticonvulsant medications in a consensus handbook on psychotropic medications distributed by the American Association on Mental Retardation (Alvarez, Kern, Cain, Coulter, Iivanainen, & Plummer, 1998) and the promulgation of clinical guidelines for the management of epilepsy in adults with an intellectual disability by the Working Group of the International Association of the Scientific Study of Intellectual Disabilities (IASSID)(2001). The impact of the Working Group's recommendations on physician practice in the U.S. may be limited by the absence of Americans on the panel, which is predominantly from the U.K., and almost exclusively European. However, significant work in the development of a standard of care for the management of epilepsy remains. The IASSID Working Group (2001) noted the scarcity of well-designed, randomized control trials on which to base their recommendations. An Evidence Report/Technology Assessment from the federal Agency for Healthcare Research and Quality on the management of newly diagnosed patients with epilepsy

found that “the best available evidence from the literature is not conclusive regarding the appropriate and necessary diagnostic, monitoring, and treatment services for patients with newly diagnosed epilepsy” (Ross, Estok, Chopra, & French, 2001).

Summary Review of Literature on Adults with Developmental Disabilities and Epilepsy

The small body of literature on the health and health care of adults with developmental disabilities and epilepsy has several limitations. First, prevalence estimates vary widely, in large part because of differences in the study populations (Bowley & Kerr). Differences in age groups and community vs. institutional populations are two factors on which there are differences. Since people with developmental disabilities remaining in institutional settings are more likely to have more severe disabilities (Beange et al., 1995; Bowley & Kerr, 2000), and severity is related to epilepsy (Bowley & Kerr, 2000; Branford, Bhaumik, & Duncan,; McGrother et al., 2006), studies of institutional populations are likely to find higher prevalence.

Difficulty in diagnosing epilepsy among people with disabilities may further confound study findings. Some studies were based on surveys of individuals with disabilities, family members or other caregivers (Branford, Bhaumik, & Duncan 1998; McGrother et al., 2006; Minihan & Dean, 1990), while others were based on registries or other medical records (Beange et al., 1995; Forsgren, 1996; McDermott et al.1997; McDermott et al., 2005; Morgan et al., 2003), and still others used a mixed approach of surveys and medical record reviews (Minihan, 1986; Branford, Bhaumik, Duncan & Collacott 1998. Further, most studies of the efficacy of treatment effectiveness are limited

by the lack of a control group (Bowley & Kerr, 2000; Coulter, 2005), a threat to internal validity (Black, 1999).

Despite these limitations, some important conclusions can be drawn, First, epilepsy is a serious chronic condition that disproportionately affects individuals with developmental disabilities (Bowley & Kerr, 2000; Branford, Bhaumik, & Duncan; McDermott et al., 2005). Second, diagnosis of epilepsy is more difficult in patients with developmental disabilities because of communication limitations and other characteristics of developmental disabilities (Bowley & Kerr, 2000; Hannah & Brodie, 1998; McGrother et al., 2006), and because of side effects from medications (Bowley & Kerr, 2000; Coulter, 2005). Third, a significant number people with developmental disabilities have multiple seizure types, making management of the epilepsy more complex (Branford, Bhaumik, & Duncan, 1998; Branford, Bhaumik, Collacott & Duncan, 1998). The complexity is often further compounded by the presence of other conditions such as cerebral palsy or autism (McDermott et al., 2005; McGrother et al., 2006; “Special Groups of Patients: Mental Retardation,” 2003). Moreover, epilepsy in people with developmental disabilities is frequently resistant to treatment, often despite the use of multiple medications with undesirable side effects (Bowley & Kerr, 2000; Branford, Bhaumik, & Collacott & Duncan, 1998; Branford, Bhaumik, & Duncan, 1998, Hannah & Brodie, 1998; McGrother et al., 2006). Lastly, management of the patient can be more difficult because of the frequent need for multiple specialists involved in their care (Bowley & Kerr, 2000). A study of health care use by adults with intellectual disabilities and epilepsy found that they used more outpatient and inpatient hospital care and had more emergency room visits than other adults with intellectual disabilities (Morgan et al.,

2003). As a result, patients with developmental disabilities and epilepsy present a major challenge to the developmental disabilities service system and providers of health care for this population.

Specific Hypotheses

Based on the findings and gaps in the previous applications of the Behavioral Model for Vulnerable Populations and the literature regarding health service use by adults with developmental disabilities and epilepsy, specific hypotheses were formulated. After controlling for other variables in the adapted Behavioral Model for Vulnerable Populations (Figure 1), it is hypothesized that:

Predisposing Characteristics

Traditional Domain

1. Adults ages 40-64 with developmental disabilities and epilepsy will have higher expenditures than those ages 21-39, even after controlling for gender, race/ethnicity, developmental disability diagnoses other than epilepsy, psychiatric comorbidity, insurance, and physical comorbidity, because older adults with developmental disabilities have been shown to have higher ambulatory care expenditures than younger adults (Howard, 1990).
2. There is no gender difference in annual expenditures among adult Medicaid beneficiaries with developmental disabilities and epilepsy, even after controlling for the same factors, for there is no evidence in the literature of a difference between men and women with epilepsy in regard to expenditures.
3. African American and adult Medicaid beneficiaries of other race/ethnicity with developmental disabilities and epilepsy are less likely to have an epilepsy-related specialist visit than whites after inclusion of control variables, because white Medicaid-enrolled children with chronic conditions (including

epilepsy) are more likely to have a specialist visit than counterparts from other racial/ethnic groups (Kuhlthau et al., 2001). The same is expected to hold true for adults.

4. African Americans and Medicaid beneficiaries of other race/ethnicity with developmental disabilities and epilepsy are more likely to have an epilepsy-related hospital admission than whites after inclusion of controlling variables, because African Americans between the ages 15 and 64 had a hospitalization rate for epilepsy 1.6 times the rate for all other groups in the same age group (CDC, 1995). It is expected that this difference also is true for the subpopulation with developmental disabilities and epilepsy.

Vulnerable Domain

5. Adult Medicaid beneficiaries with developmental disabilities and epilepsy and an additional co-occurring developmental disability diagnosis will be more likely, after adjusting for other influences, to have an inpatient hospital admission than those without additional co-occurring disabilities, because a study of hospitalizations of patients with epilepsy in the U.K. found that the second most frequent primary diagnosis for the hospital admissions of adults with epilepsy aged 19-55 years was “other specified mental retardation” (Currie et al., 1998). This suggests that developmental disability is a factor in hospitalizations for adults with epilepsy.
6. Adult Medicaid beneficiaries with developmental disabilities and epilepsy and an additional co-occurring developmental disability diagnosis will have higher expenditures than those without additional co-occurring disabilities, after controlling for age, gender, race/ethnicity, psychiatric comorbidity, insurance, and physical comorbidity, because it is expected that the longer average length of stay among adults with co-occurring epilepsy and another developmental disability diagnosis epilepsy will result in higher annual expenditures (Currie et al., 1998).

Enabling Characteristics – Traditional Domain

7. Adult Medicaid beneficiaries with developmental disabilities and epilepsy who receive epilepsy-related specialist care will have lower expenditures than those who receive generalist only or predominantly generalist care, because Medicaid-enrolled children with developmental disabilities and epilepsy who receive predominantly specialist care have been shown to have lower annual expenditures than those who received generalist only or predominantly generalist care (Perrin et al., 2002). It is expected that this difference will continue among adults with developmental disabilities and epilepsy.

8. Adult Medicaid beneficiaries with developmental disabilities and epilepsy who receive epilepsy-related specialist care will be less likely to have an inpatient hospital admission or emergency room visit than adults with developmental disabilities and epilepsy who receive generalist only or predominantly generalist care, because Medicaid-enrolled children with developmental disabilities and epilepsy who received predominantly specialist care have been shown to have lower annual expenditures than counterparts who received generalist only or predominantly generalist care (Perrin et al., 2002). Since inpatient hospital admissions and emergency room visits are resource-intensive services, it is expected that lower hospitalizations and emergency room visits contribute to lower annual expenditures.

Need Characteristics - *Traditional Domain*

9. Adult Medicaid beneficiaries with developmental disabilities and epilepsy are more likely to have an inpatient hospital admission or an emergency room visit than those without epilepsy, because adults with developmental disabilities and epilepsy in the U.K. have been shown to be more likely to have an inpatient hospital admission or an emergency room visit than counterparts without epilepsy (Morgan et al., 2003). It is expected that this difference will hold true for adult Medicaid beneficiaries in the United States.
10. Among Adult Medicaid beneficiaries with developmental disabilities and epilepsy with an inpatient hospital admission, the average length of stay will be longer for those with epilepsy compared to counterparts without epilepsy, because patients with epilepsy in the U.K. have been shown to have a longer length of stay than the general population without epilepsy (Currie et al., 1998). It is expected that this difference will hold true for adult Medicaid beneficiaries with developmental disabilities and epilepsy in the U.S.
11. Adult Medicaid beneficiaries with developmental disabilities and epilepsy will have higher expenditures than counterparts without epilepsy, because patients with epilepsy in the U.K. have been shown to have higher annual health expenditures than the general population without (Morgan & Kerr, 2004). Further, adults with developmental disabilities and epilepsy in the U.K. were more likely to have a hospital admission or emergency room visit than their counterparts without epilepsy (Morgan et al., 2003). Based on higher total expenditures for the population with epilepsy and the greater likelihood of using more resource intensive services among adults with developmental disabilities and epilepsy, it is expected that this group will have higher annual expenditures than their counterparts with developmental disabilities and no epilepsy.

Contributions of the Study

The current research addressed several gaps in the literature about adults with developmental disabilities and epilepsy. First, it applied the Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) to a new subpopulation. Second, it identified epilepsy and characteristics of adult Medicaid beneficiaries with developmental disabilities and epilepsy in a statewide population. Third, the research compared the health care use and expenditures of those with developmental disabilities and epilepsy to counterparts without epilepsy. The study also profiled the patterns of epilepsy-related physician care. Fourth, the current study documented the higher risk of hospitalization and emergency room use as well as higher expenditures associated with epilepsy in adults with developmental disabilities in the U.S. for the first time, while identifying predictors of inpatient care, emergency room use, and expenditures in this subpopulation. By examining these issues in regard to adult Medicaid beneficiaries with developmental disabilities, the study addressed a population that has received little attention in the health services research literature. The adaptation of a claims-based approach for analyzing patterns of care developed by Perrin et al. (2002) provides a method that can be used in future studies of this population using claims data. Finally, the study's findings have implications for policy and practice regarding medical care and related services for Medicaid-eligible adults with developmental disabilities and epilepsy, as discussed in Chapter V.

The current research did not have some of the limitations of previous studies, including use of non-probability samples (Howard, 1990; Pruchno & McMullen, 2004; &

Smith, 1997), potential recall bias (Lin, Wu, & Lee, 2004; Pruchno & McMullen, 2004; & Smith, 1997), the lack of demographic factors such as race/ethnicity (Smith, 1997), and a lack of provider or system-level variables that may influence service accessibility (Howard, 1990; Lin, Wu, & Lee, 2004; Pruchno & McMullen, 2004; Smith, 1997 & Weller et al., 2003).

Summary of Chapter II

This chapter reviewed the results of previous applications of the Behavioral Model for Vulnerable Populations and the literature regarding the health service utilization of adults with developmental disabilities and epilepsy. Based on the results and gaps in the literature, specific hypotheses were identified.

CHAPTER III

DATA AND METHODS

This research utilizes a statewide data set on adult Medicaid beneficiaries enrolled with the New Jersey Division of Developmental Disabilities (DDD). This chapter describes the data set, study population and measures, and operationalization of variables. The operational definitions are based on an adapted Behavioral Model for Vulnerable Populations (Gelberg et al., 2000). The chapter also presents the analytical procedures.

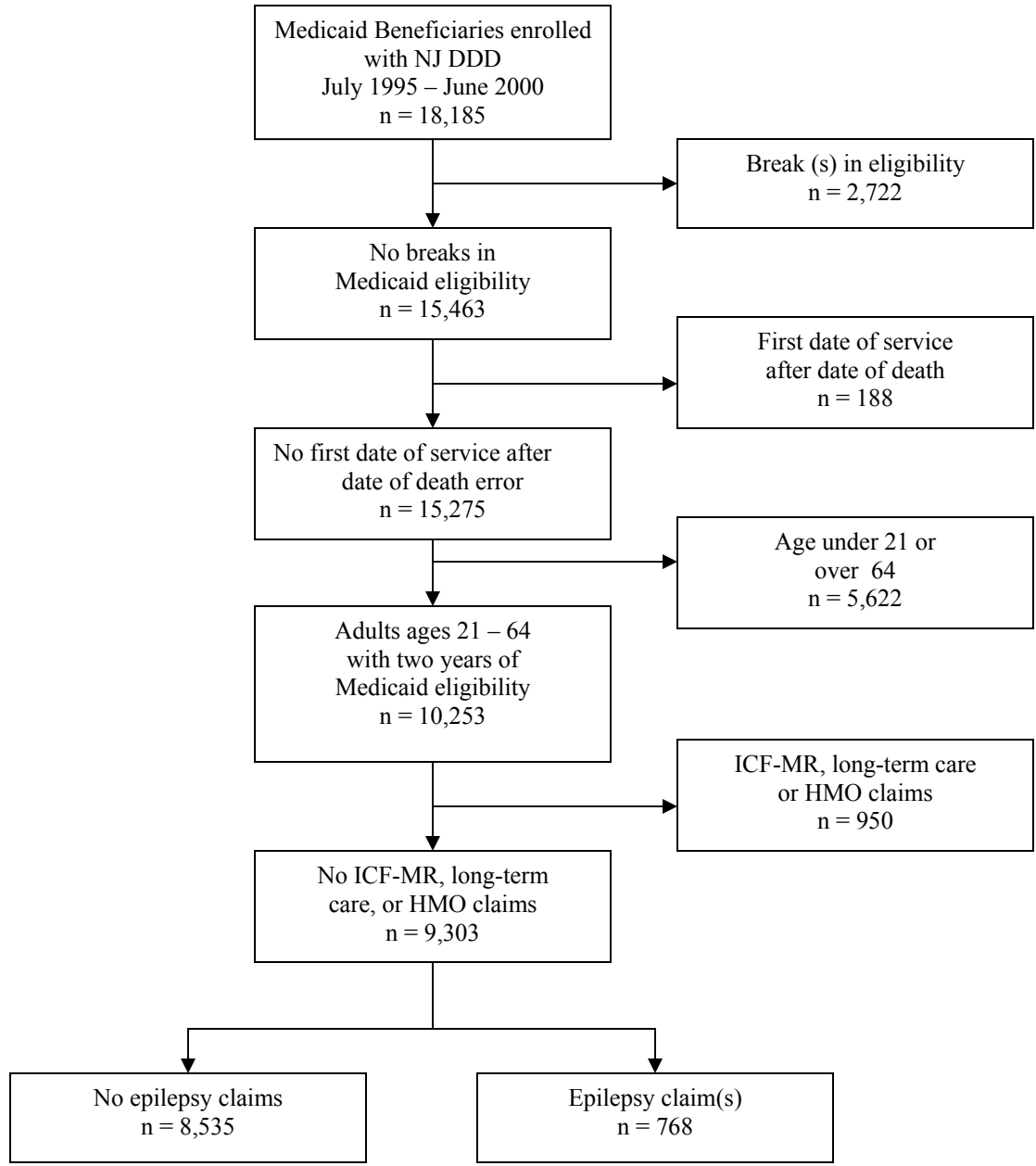
Information for this study is from a dataset developed from a cooperative agreement between the New Jersey Medicaid program and the University of Medicine and Dentistry of New Jersey. It was provided at the request of this author. The data set was constructed by UNISYS, the fiscal intermediary for the New Jersey Medicaid program. UNISYS performed a match of the community services file from the New Jersey Division of Developmental Disabilities (DDD) with Medicaid eligibility files for the period of January 1, 1995 – June 30, 2000. The community service database maintains information about children and adults enrolled with DDD and living in settings other than those in long-term placement in State or private large congregate facilities. It includes individuals placed in long-term care facilities and State developmental centers for “short-term” placements. These placements may be the result of a personal crisis or an event such as the death of the individual’s parent. Eligibility and claims files were provided in ASCII format in June 2003. Patient identifiers as well as provider identification numbers were scrambled to protect confidentiality.

Identification of the Study Sample

The study sample is composed of adults in community settings, enrolled with the New Jersey Division of Developmental Disabilities and the New Jersey Medicaid program during the period of July 1, 1995, through June 30, 2000. The inclusion criteria were: 1) adults in the age group 21 – 64; 2) continuous enrollment in Medicaid; 3) no managed care enrollment; and 4) alive as of the study period (please see definition below). Figure 2 presents a flow diagram of the identification of the sample. First, individuals enrolled with DDD with eligibility and Medicaid claims information observed during the study period of July 1, 1995 through June 2000 were identified. A total of 18,185 individuals had both eligibility and claims information during study period. Next, individuals with breaks in Medicaid enrollment were excluded to ensure that there were no gaps in the data during the study period; 15,463 individuals had no breaks in Medicaid eligibility. Since the Medicaid claims contain errors including a first service date that occurred after an individual's death, those with this error in the claims file were excluded, leaving 15,275 patients. From this group, 10,253 adults between the ages of 21 and 64 were identified. Adults between the ages of 21 and 64 as of the first date of service and who had two years of eligibility during the study period were included. Finally, adults with ICF-MR or long-term care claims and those enrolled in managed care were excluded because persons in ICF-MR or other long-term care facilities may receive medical care in those settings that would not generate claims (Morgan, Ahmed & Kerr, 2000), thereby resulting in an incomplete record of services received. Individuals enrolled in managed care plans, identified by capitation claims were excluded since their medical care does not generate encounter claims. Thus, in the final sample,

Figure 2

Identification of Study Sample



9,303 adult beneficiaries with developmental disabilities living in community settings and continuously enrolled with Medicaid were first observed in the Medicaid claims files during the period between July 1995 and June 1998. Identification of the sample ended with June 1998 in order to provide two years of claims for analyses. Year of observation was included in the analyses as a covariate to adjust for its influence of the year of observation on the dependent variables.

Study Design

This observational study utilized a dynamic retrospective design. Health service use and expenditures were calculated for each individual for a period of two years from the date of the first observed claim, beginning with July 1, 1995. This approach provides a uniform period of observation for each individual. It also avoids the problem of circular reasoning that would result from utilizing the same year, and therefore the same claims, for identification of an epilepsy diagnosis and for calculating the health service use and expenditures associated with the diagnosis.

Rationale for Use of Medicaid Claims Data

Administrative data such as Medicaid files have several characteristics that make them a powerful resource for studies concerning people with disabilities (Iezzoni, 2002). Although the primary use of these files is related to payment for services, they can be very useful for research. Administrative information systems can provide longitudinal

data about large groups such as a state population, that reflect care provided in natural settings, and they can be constructed in a way that protects confidentiality by shielding individuals' identities from researchers. Further, administrative data may be more accurate than survey data in capturing service provision, including hospitalizations and emergency room visits, because problems in recall are averted (Wallihan, Stump, & Callahan, 1999). Medicaid claims data, in particular, are a rich source of information about health care use and outcomes of vulnerable populations, and they can be used to examine disparities between racial and ethnicity groups as well as other differences in comorbidities and disability diagnoses, for example (Crystal, Akingicil, Bilder, & Walkup, in press).

Administrative data sets often consist of eligibility or enrollment files with information about individual participants and claims files about services provided. Eligibility files typically contain demographic characteristics and may contain other information such as insurance coverage and medical conditions. Claims files contain information about office visits and other health care encounters, procedures, and one or more codes for diagnoses associated with the services provided. In addition to health services research including analyses of patterns of ambulatory care (Kuhlthau et al., 2001; Turner et al. 1994) and the association of outpatient medical and substance abuse treatment and hospitalization (Laine, Hauck, Gourevitch, Rothman, & Turner, 2001), Medicaid and Medicare claims files have been used to examine the association between patterns of physician care and Medicaid expenditures (Perrin et al., 2002), determine

capitation payments (Kronick, Dreyfus, Lee & Zhou, 1996; Kronick, Gilmer, Dreyfus, & Lee, 2000) and to analyze medication use and outcomes (Crystal, Akingicil, Bilder, & Walkup, in press; Sambamoorthi, Olfson, Walkup, & Crystal, 2003; Walkup, Sambamoorthi, & Crystal, 2004).

Matching Medicaid files with other data sets has been used to identify other subpopulations of Medicaid beneficiaries, including dual Medicare and Medicaid eligibles (Sambamoorthi, Collins, & Crystal, 2001), individuals with HIV-AIDS and mental illness or mental retardation (Bagchi, Sambamoorthi, McSpiritt, Yanos, Walkup, & Crystal, 2004; Blank, Mandell, Aiken, & Hadley, 2002; Hoover, Sambamoorthi, Walkup, & Crystal, 2004; Rothbard, Metraux, & Blank, 2003; Walkup, Sambamoorthi, & Crystal, 1999). The matching of Medicaid files with a state agency roster has a distinct advantage over reliance on diagnosis codes in claims data to identify Medicaid beneficiaries with disabilities (Iezzoni, 2002). By starting with an administrative database from the State developmental disabilities agency, all of the individuals enrolled for developmental disability services are entered into the pool for matching with the Medicaid enrollment file. This method is preferable since claims for conditions such as intellectual disability are unstable – that is, the diagnosis may appear in the claims for one year and not the next, despite the fact that the individual continues to have the condition (Kronick, Gilmer, Dreyfus, & Lee, 2000). Unless a service is directly associated with the patient's disability, the Medicaid claim record is unlikely to include a disability-related diagnosis code (Perrin, Kuhlthau, Ettner, McLaughlin, & Gortmaker, 1998). As a result, data sets that depend on diagnosis codes to identify patients with developmental disabilities are likely to underidentify this population.

Measures

Values for the dependent variables were calculated for a two-year period following the first observed claim for each individual in the study population. This section identifies study variables, variable type (categorical or continuous), and associated code(s).

Anticonvulsant medication (Categorical) – Drug therapeutic class H4B.

Developmental Disabilities Home and Community Based Services (HCBS) Waiver (Categorical) – Category of service 90 (DDD). New Jersey’s Developmental Disabilities HCBS waiver includes: case management; habilitation (day programs and supported employment); individual supports (or residential habilitation in group homes, skill development homes, own homes, and self-determination); personal emergency response services; environmental/vehicle modifications; and Community Professional Support and Training (occupational therapy, physical therapy, psychology, and psychiatry).

Emergency Room Visit (Categorical) – Emergency indicator (Y/N).

Epilepsy-Related physician, inpatient, and emergency room use (Categorical) - *International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) code 345 (Public Health Service, 1980).*

Expenditures (Continuous) – Claim payment amount (U.S. dollars). Expenditures were converted to a logarithmic scale and adjusted to constant dollars with 2000 as the base year, utilizing the Consumer Price Index for Medical Services in the Northeast Urban region (Bureau of Labor Statistics, 2006). Medicaid claims include an indicator of

whether the claim was submitted via Medicare, but they do not include any Medicare payment information.

Inpatient Admission (Categorical) – Claim category of service code 01.

Length of Stay (Continuous) – Number of days calculated from date fields.

Medications (Categorical) – Claim category of service code 20.

Other Services (Categorical) – Claim category of service codes not classified as physician, inpatient, outpatient, medications, developmental disabilities waiver, or other waiver were classified as other services.

Other Waiver (Categorical) – Category of service codes 91 (CCPED), 92 (AACAP), and 93 (Model Waivers) were classified as Other Waiver.

Outpatient Services (Categorical) – Category of service code 04A.

Pattern of Epilepsy-Related Physician Care (Categorical) – Provider specialty codes 010 (General Practice), 080 (Family Practice), 110 (Internal Medicine), and 370 (Pediatrics) were classified as Generalist. Provider specialty codes 130 (Neurology), 260 (Psychiatry), and 270 (Psychiatry/Neurology) were classified as Specialist. Provider specialty codes 04B (Outpatient with Clinic Code), 08 (Clinic), 12 (Freestanding ASC), and 25 (Federally Qualified Health Center) were classified as Other.

Independent Variables

This information was extracted from the Medicaid eligibility file except where otherwise indicated.

Predisposing Characteristics – *Traditional Domain*

Age - Recipient Calculated Age field in the Medicaid claims files. Age was categorized in three groups: 1) young adults ages 21-39; 2) middle age adults ages 40-54; and 3) older adults ages 55-64.

Gender – Recipient Sex Code (M/F).

Race/ethnicity – Recipient Race Code 1 (White), 2 (African American), 3 (American Indian), 4 (Latin), 5 (Oriental), 6 (Other), 7 (Indo-Chinese Refugee/Cubans Admitted After 9/30/78), 8 (SSA Classification), and 9 (Cuban/Haitian Refugee Act of 1980). Creation of the data set preceded the release of the 2000 Census data and does not use the revised classifications promulgated by the Office of Management and Budget (1997). Analysis of the data showed a very low percentage in the categories other than White and African American. Therefore, race/ethnicity was classified as White, African American, and other.

Race/ethnicity information in the Medicaid eligibility file is extracted from the individual's application for Medicaid or Supplemental Security Income (SSI) eligibility. The identifying information on the application may be provided by the applicant, a family member, or other representative.

Predisposing Characteristics – *Vulnerable Domain*

Developmental Disability Diagnoses Other than Epilepsy - ICD-9-CM codes 299 (autism), 343 (cerebral palsy), 758 (Down syndrome), 317-319 (mental retardation, and 741 (spina bifida), identified in the claims records. New Jersey Medicaid physician claims identify up to two diagnoses and hospital claims identify up to five diagnoses,

using the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes in the claims records. Developmental Disability other than epilepsy was classified as: 1) None; 2) One; 3) Two/Three. It was treated as a continuous variable in the multivariate analyses. This method of measuring co-occurring developmental disabilities follows a method used in a study comparing a simple counting of unique diagnoses on hospital discharge summaries and two comorbidity indexes (Melfi, Holleman, Arthur & Katz, 1995).

Psychiatric Comorbidity - ICD-9-CM codes 295 (Schizophrenic Disorders), 296 (Affective Psychoses), 297 (Paranoid States), 298 (Other Nonorganic Psychoses), 299 (Psychoses with Origin Specific to Childhood), 300 (Neurotic Disorders), 301 (Personality Disorders), 302 (Sexual Deviations and Disorders), 307 (Special Symptoms or Syndromes, NEC), 308 (Acute Reaction to Stress), 309 (Adjustment Reaction), 310 (Specific Nonpsychotic Mental Disorders Due to Brain Damage), 311 (Depressive Disorder, NEC), 312 (Disturbance of Conduct, NEC), 313 (Disturbance of Emotions Specific to Childhood and Adolescence), 314 (Hyperkinetic Syndrome of Childhood), identified in claims records (Hoover, Sambamoorthi, Walkup, & Crystal, 2004). Psychiatric comorbidity was classified as “Yes” if of one or more claims had at least one of these diagnoses.

Substance Abuse - ICD-9-CM codes 291 (Alcoholic Psychoses), 292 (Drug Psychoses), 303 (Alcohol Dependence Syndrome), 304 (Drug Dependence), 305 (Nondependent Abuse of Drugs) in the claims records (Hoover, Sambamoorthi, Walkup, & Crystal, 2004). Substance abuse was classified as “Yes” if of one or more claims had at least one of these diagnoses.

Enabling Characteristics - *Traditional Domain*

Medicare - Claim Medicare Indicator (Y/N).

Pattern of Epilepsy-Related Physician Care – See description in Dependent Variables section (page 40). After bivariate analyses were conducted to identify the characteristics associated with each of the three patterns of epilepsy-related physician care (any specialist visit, generalist only, and other - outpatient and other clinics), pattern of care was included in the analyses of epilepsy-related care as an enabling factor.

Enabling Characteristics – *Vulnerable Domain*

Waiver Status. Participants in New Jersey's Home and Community Based Services program for individuals with developmental disabilities receive a broad range of social services such as personal care, habilitation, day programs, and case management. Waiver services can constitute a major proportion of the annual Medicaid expenditures for those with developmental disabilities. Accordingly, waiver status was identified for the study population. Waiver status was not included in the multivariate analyses because of collinearity with developmental disabilities (Kachigan, 1991) – 100% of waiver claims had a developmental disability diagnosis.

Need Characteristics - *Traditional Domain*

Epilepsy - ICD-9-CM code 345.

Physical Comorbidity - a history of one or more of the ICD-9-CM diagnosis codes for the 19 conditions in the Charlson Comorbidity Index (CCI) (Charlson et al., 1987; Deyo, Cherkin, & Ciol, 1992): myocardial infarction, congestive heart failure,

peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disease, ulcer disease, mild liver disease, diabetes, diabetes with end-organ damage, hemiplegia, moderate or severe renal disease, any tumor, leukemia; lymphoma, metastatic solid tumor, moderate or severe liver disease, and AIDS. (See Appendix A for a complete listing of CCI ICD-9 CM codes.) Physical comorbidity was classified as “Yes” if of one or more claims had at least one of these diagnoses.

Analytical Procedures

Bivariate tabulations were conducted to compare the proportion of the epilepsy group with the non-epilepsy group in regard to use of inpatient hospital care and emergency rooms, as well as inpatient length of stay and annual expenditures. Chi-square analyses were used for categorical outcome variables (inpatient hospital admission and emergency room use) and *t*-tests were used for continuous outcome variables (length of stay and annual expenditures).

All variables in the adapted Behavioral Model for Vulnerable Populations except substance abuse and waiver status were included in the multivariate analyses. Substance abuse was excluded due to insufficient cell size and waiver status was excluded because of multicollinearity with number of developmental disabilities diagnoses other than epilepsy. Factors associated with epilepsy were identified through logistic regression analyses. Logistic regression models were also conducted to test hypotheses concerning differences in the relative odds of inpatient hospital admission and emergency room use between those with epilepsy and those without epilepsy while controlling for other factors.

Interpreting parameter estimates produced by logistic regression is more difficult than interpreting the results of OLS regression, since they do not represent a direct estimate of the change in the value of the dependent variable for each unit change in the independent variable. Therefore, odds ratios and confidence intervals as well as parameter estimates are presented for the logistic regression results. The odds ratios represent the odds of the outcome occurring, controlling for all other variables in the model. In Table 3, for example, the odds of an inpatient admission for those with epilepsy are 1.93 times greater than the odds of an admission for those without epilepsy. Odds ratios of less than one indicate that outcome (e.g. inpatient admission) is less likely to occur for an individual with this characteristic compared to those in the reference category. If the 95% confidence interval contains a value of 1, the results are not statistically significant at the $p = .05$ level.

Ordinary Least Squares (OLS) regression was used to test hypotheses about differences in hospital length of stay and annual expenditures between those with epilepsy and those without. OLS regression calculates a regression equation that best fits the data by minimizing the sum of the squared deviations of the data from the regression line (Kachigan, 1991). OLS regression assumes that the relationship between the dependent variable means and the independent variables is linear, that the variances in the dependent variable for the same values of the independent variables are equal, and that the error terms have a normal distribution (Pedhazur, 1997). The regression equation can be expressed as:

$$Y = \alpha + \beta_1 X_1 + \beta_2 X_2 + \dots + \beta_k X_k + e$$

where α is the intercept, $\beta_1, \beta_2 \dots \beta_k$ are standardized regression coefficients associated with the independent variables $X_1, X_2, \dots X_k$, and e is the error (Pedhazur, 1997, p. 95). Two-tailed tests of statistical significance were used in order to detect any significant between or within group differences. Since there were multiple hospital admissions for some individuals in the analysis, length of stay was controlled for clustering of observations using SAS-Callable SUDAAN, a software program designed for analyzing correlated and weighted data. Expenditures were transformed to a logarithmic scale to reduce skewness.

Human Subject Research Review

A request for exemption from full Institutional Review Board (IRB) review was submitted to the Rutgers University IRB. The Rutgers Office of Research and Sponsored Programs determined that the study did not require review for exemption or approval, since it involves the analysis of existing data with patient identifiers scrambled, and therefore, did not meet the criteria for research involving human subjects.

Description of the Study Population

Table 1 presents the characteristics of the study population in terms of predisposing (age, gender, race/ethnicity, developmental disability diagnoses, psychiatric comorbidity, and substance abuse), enabling (Medicare and DDD waiver), and need (physical comorbidity) factors. As seen from the table, two-thirds (66.4%) of the study population were between the ages of 21 and 39; 27.8% were in the 40-54 year old age

group, and 5.4% were 55-64 years old. There were 5,049 men and 4,254 women. A majority of the study population were White (78.5%), followed by American Americans (13.8%) and other race/ethnicity (7.6%). Seventy percent had at least one claim with a diagnosis of developmental disability. More than one in five (22.9%) had a diagnosis of mental illness. Claims indicative of substance abuse were present among 1.4% of the study population. Half (49.6%) were enrolled in Medicare as well as Medicaid. Nearly sixteen percent (15.5%) had at least one chronic physical disease (as defined by the presence of one of the following conditions: a history of myocardial infarction; congestive heart failure; peripheral vascular disease; cerebrovascular disease; dementia; chronic pulmonary disease; connective tissue disease; ulcer disease; mild liver disease; moderate/severe liver disease; diabetes; diabetes with end-organ damage; hemiplegia; moderate or severe renal disease; any tumor; leukemia and lymphoma; metastatic solid tumor; and AIDS).

Summary of Chapter III

This chapter described the data set utilized in the study and how the study population was identified. It presented operational definitions for each of the independent and dependent variables in the adapted Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) used in the study. It also provided a profile of the study population and detailed the analytical methods used to test the hypotheses.

Table 1

<i>Characteristics of Study Population</i>		
	N	%
ALL	9,303	100.0
PREDISPOSING		
Age		
21-39	6,175	66.4
40-54	2,588	27.8
55-64	540	5.8
Gender		
Female	4,254	45.7
Male	5,049	54.3
Race/Ethnicity		
White	7,306	78.5
African American	1,288	13.8
Other	709	7.6
Number of Developmental Disability Diagnoses		
None	2,750	29.6
One	5,184	55.7
Two or Three	1,369	14.7
Psychiatric Comorbidity		
Yes	2,135	22.9
No	7,168	77.1
Substance Abuse		
Yes	126	1.4
No	9,177	98.6
ENABLING		
DDD Waiver		
Yes	5,216	56.1
No	4,034	43.4
Medicare		
Yes	4,612	49.6
No	4,691	50.4
NEED		
Physical Comorbidity		
Yes	1,438	15.5
No	7,865	84.5
Health System		
Year of Observation		
July 1995 – June 1996	8,402	90.3
July 1996 – June 1997	506	5.4
July 1997 – June 1998	395	4.2

CHAPTER IV

RESULTS

This chapter presents the results of the statistical analyses of group differences in health service use and expenditures between adults with developmental disabilities and epilepsy and those without epilepsy as well as other predisposing, enabling, and need characteristics, and examines subgroup differences within the population with epilepsy. It also presents the results of multivariate analyses testing the hypotheses and identifying factors associated with health service utilization and expenditures, using the conceptual framework introduced in Chapter 1.

Characteristics Associated with Epilepsy

Characteristics of the study population by the presence of epilepsy diagnosis are presented in Table 2. In addition to substance abuse and waiver status, number of developmental disabilities diagnoses other than epilepsy was excluded from the analysis because of concerns about the developmental disability and epilepsy having a common etiology, thus confounding the analysis. In the study group, 8.3% (n = 768) had at least one claim with an epilepsy diagnosis and 91.7% (n = 8,535) had no epilepsy diagnosis. The proportion of individuals with epilepsy was nearly 50% higher among those with one other developmental disability diagnosis and two-thirds higher among those with two or three other developmental disabilities compared to those without developmental disability diagnoses. Similarly, epilepsy was roughly 50% higher among adults with psychiatric comorbidity compared to those without psychiatric comorbidity. The epilepsy

rate among participants in the developmental disabilities community care waiver and dual eligibles was nearly one-fifth higher than non-participants in waiver services and those with Medicaid only. The percentage of individuals with physical comorbidity, defined as the presence of at least one chronic disease, was more than one-third higher than those without physical comorbidity.

Table 2 also presents characteristics associated with an epilepsy diagnosis identified using logistic regression. As seen from the table, controlling for other characteristics, psychiatric comorbidity, dual eligibility, and physical comorbidity were associated with greater odds of an epilepsy diagnosis. Age was associated with lower odds of epilepsy. The odds ratio for those with psychiatric comorbidity was 1.55 (95% CI = 1.32-1.82). Dual eligibles were more likely to have epilepsy than those with Medicaid only (OR = 1.27, 95% CI = 1.08-1.49). Those with physical comorbidity also were more likely to have an epilepsy diagnosis than those without chronic disease (OR = 1.32, 95% CI = 1.09-1.60). Adults age 40-54 and 55-64 were about 20 and 40 percent, respectively, less likely than those between 21 and 39 to have an epilepsy diagnosis.

Table 2

Characteristics of Study Population by Epilepsy Status

	No Epilepsy		With Epilepsy		Logistic Regression on Epilepsy	
	N	%	N	%	OR	95% CI
ALL	8,535	91.7	768	8.3		
PREDISPOSING						
Age						
21-39	5,644	91.4	531	8.6		
40-54	2,386	92.2	202	7.8	0.81*	(0.67-0.97)
55-64	505	93.5	35	6.5	0.63*	(0.44-0.90)
Gender						
Female	3,902	91.7	352	8.3	1.01	(0.87-1.17)
Male	4,633	91.8	416	8.2		
Race/Ethnicity						
White	6,703	91.7	603	8.3		
African American	1,185	92.0	103	8.0	0.94	(0.75-1.17)
Other	647	91.3	62	8.7	1.07	(0.81-1.41)
Developmental Disability Diagnoses ***						
None	2,581	93.9	169	6.1	Not Included	
One	4,723	91.1	461	8.9		
Two or Three	1,231	89.9	138	10.1		

Table 2 (continued)

	No Epilepsy		With Epilepsy		Logistic Regression on Epilepsy	
	N	%	N	%	OR	95% CI
Psychiatric Comorbidity ***						
Yes	1,895	88.8	240	11.1	1.55 ***	(1.32-1.82)
No	6,640	92.6	528	7.4		
Substance Abuse						
Yes	113	89.7	13	10.3	Not Included	
No	8,422	91.8	755	8.2		
ENABLING						
DDD Waiver						
Yes	4,755	91.2	461	8.8	Not Included	
No	3,780	92.5	307	7.5		
Medicare*						
Yes	4,200	91.1	412	8.9	1.27 **	(1.08-1.49)
No	4,335	92.4	356	7.6		
NEED						
Physical Comorbidity ***						
Yes	1,286	89.4	152	10.6	1.32 ***	(1.09-1.60)
No	7,249	92.2	616	7.8		

Table 2 (continued)

	No Epilepsy		With Epilepsy		Logistic Regression on Epilepsy	
	N	%	N	%	OR	95% CI
HEALTH SYSTEM						
Year of Observation **						
July 1995 – June 1996	7,687	91.5	715	8.5		
July 1996 – June 1997	485	95.8	21	4.2	0.49 **	(0.32-0.77)
July 1997 – June 1998	363	91.9	32	8.1	0.95	(0.65-1.37)

Significant group differences based on Chi-square statistics and significant differences relative to reference group denoted as * = $p \leq .05$, ** $p \leq .01$, and *** = $p \leq .001$.

Health Service Utilization by Epilepsy Status

Health service utilization consisted of use of inpatient services, length of stay among those with at least one inpatient admission, outpatient services other than physicians, physician services, medications, developmental disabilities home and community based waiver services, other services, and use of the emergency room.

Inpatient Use by Epilepsy Status: Bivariate Comparisons

Table 3 compares inpatient use by epilepsy status by various characteristics of the study population. A higher proportion of those with epilepsy had a hospital admission – 8.3% of the group without epilepsy had an admission, while nearly twice that percentage (16.3%) of those with epilepsy had an inpatient hospital stay ($p \leq .001$). This difference was significant for each subgroup, with the exception of those with chronic diseases.

Inpatient Use by Epilepsy Status: Logistic Regression

To test the hypothesis that adult Medicaid beneficiaries with developmental disabilities and epilepsy are more likely to have an inpatient hospital admission than those with developmental disabilities and no epilepsy after controlling for other factors, a logistic regression procedure was performed. Table 3 also presents the results of the logistic regression modeling inpatient admissions. The multivariate analysis substantiated the bivariate finding that patients with epilepsy were significantly more likely to have a hospital admission. Controlling for all of the other variables in the model, the odds of a hospital admission were nearly twice as great for those with epilepsy. The odds ratio was 1.93 (95% CI = 1.56 – 2.39).

Table 3

Inpatient Admission by Epilepsy Status

	No Epilepsy		With Epilepsy		Logistic Regression on Inpatient Admission	
	N	%	N	%	OR	95% CI
ALL	709	8.3	125	16.3 ***		
Epilepsy						
Yes					1.93 ***	(1.56-2.39)
No						
PREDISPOSING						
Age						
21-39	401	7.1	73	13.7 ***		
40-54	246	10.3	40	19.8 ***	1.39 ***	(1.18-1.65)
55-64	62	12.3	12	34.3 ***	1.64 ***	(1.24-2.17)
Gender						
Female	326	8.4	63	17.9 ***	1.00	(0.87-1.16)
Male	383	8.3	62	14.9 ***		
Race/Ethnicity						
White	529	7.9	92	15.3 ***		
African American	121	10.2	18	17.5 *	1.33 **	(1.08-1.62)
Other	59	9.1	15	24.2 ***	1.43 **	(1.10-1.86)

Table 3 (continued)

	No Epilepsy		With Epilepsy		Logistic Regression on Inpatient Admission	
	N	%	N	%	OR	95% CI
Developmental Disability Diagnoses					1.09 ¹	(0.97-1.22)
None	173	6.7	22	13.0*		
One	420	8.9	83	18.0 ***		
Two or Three	116	9.4	20	14.5 ***		
Psychiatric Comorbidity					2.13 ***	(1.83-2.48)
Yes	274	14.5	55	22.9 ***		
No	435	6.6	70	13.3 ***		
Substance Abuse						
Yes	36	31.9	8	61.5 *		Not Included
No	673	8.0	117	15.5 ***		
ENABLING						
DDD Waiver						
Yes	410	8.6	71	15.4 ***		Not Included
No	299	7.9	54	17.6 ***		
Medicare					1.16	(0.99-1.37)
Yes	401	9.5	73	17.7 ***		
No	308	7.1	52	14.6 ***		

Table 3 (continued)

	No Epilepsy		With Epilepsy		Logistic Regression on Inpatient Admission	
	N	%	N	%	OR	95% CI
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	222	17.3	34	22.4	2.29 ***	(1.94-2.70)
No	487	6.7	91	14.8 ***		
HEALTH SYSTEM						
Year of Observation						
July 1995 – June 1996	652	8.5	115	16.1 ***		
July 1996 – June 1997	30	6.2	2	9.5	0.80	(0.55-1.16)
July 1997 – June 1998	27	7.4	8	25.0 ***	0.91	(0.63-1.31)

Significant group differences based on Chi-square statistics and significant differences relative to reference group denoted as * = $p \leq .05$, ** $p \leq .01$, and *** = $p \leq .001$.

Length of Inpatient Stay by Epilepsy Status: Bivariate Comparisons

Table 4 compares inpatient length of stay by epilepsy status by predisposing, enabling and need characteristics of the study population. Overall, adult Medicaid beneficiaries with epilepsy had a mean length of stay of 7.0 days, 35% lower than the mean of 11.4 days for those without epilepsy ($p \leq .001$). Among subgroups, the difference in length of stay between those with epilepsy and those without epilepsy was not significant for younger adults age 40 and older, those of other race/ethnicity, those without developmental disability diagnoses other than epilepsy as well as those with two or three developmental disabilities, dual eligibles, and those with physical comorbidity.

Length of Inpatient Stay by Epilepsy Status: OLS Regression

To test the hypothesis that adult Medicaid beneficiaries with epilepsy would have a longer average length of stay than those without epilepsy after controlling other factors, an OLS regression procedure was performed (Table 4). (Regression coefficients presented in the table are unstandardized.) The multivariate analysis substantiated the bivariate results – length of stay for those with epilepsy was shorter than for those without epilepsy, after controlling for other variables in the model ($\beta = -0.369$, $p \leq .001$). The effect of dummy variables (e.g., epilepsy status) on length of stay cannot be interpreted as a percentage change for each unit of change, in contrast to continuous independent variables. Rather, the effect of a dummy variable can be estimated by exponentiating the regression coefficients of the dummy variable and subtracting one (i.e., percent change = $e^{\hat{\alpha}} - 1$) (Halvorsen & Palmquist, 1980). Estimating the difference in

Table 4

Length of Stay per Admission Among Hospitalized Patients¹

			OLS Regression on Length of Stay	
	No Epilepsy Mean	Epilepsy Mean	Beta	SE
ALL	11.4	7.0 **		
Epilepsy				
Yes			-0.369 ***	0.081
No				
PREDISPOSING				
Age				
21-39	13.4	7.2 ***		
40-54	8.4	6.8	-0.238 ***	0.069
55-64	6.8	6.3	-0.263 *	0.119
Gender				
Female	10.8	7.7 *	-0.057	0.058
Male	11.9	6.2 ***		
Race/Ethnicity				
White	11.4	7.3 ***		
African American	10.6	6.3 *	-0.130	0.076
Other	12.8	5.5	-0.235 *	0.103

Table 4 (continued)

	No Epilepsy	Epilepsy	OLS Regression on Length of Stay	
	Mean	Mean	Beta	SE
Developmental Disability Diagnoses			0.157 ²	0.047
None	8.8	6.1		
One	12.7	6.9 ***		
Two or Three	10.9	8.3		
Mental Comorbidity				
Yes	10.0	7.6 *	-0.046	0.059
No	12.3	6.4 ***		
Substance Abuse				
Yes	8.9	6.5 *		
No	11.5	7.1 ***		
ENABLING				
DDD Waiver				
Yes	9.8	7.3 *		
No	13.0	6.7 ***		
Medicare				
Yes	8.4	7.8	-0.251	0.064
No	14.0	6.4 ***		

Table 4 (continued)

	No Epilepsy	Epilepsy	OLS Regression on Length of Stay	
	Mean	Mean	Beta	SE
NEED				
Physical Comorbidity				
Any Chronic Disease				
Yes	10.2	7.0	-0.020	0.061
No	12.0	7.0		
Health System				
Yea of Observation				
July 1995 – June 1996	11.6	7.0		
July 1996 – June 1997	5.8	1.3	-0.344 *	0.167
July 1997 – June 1998	11.6	7.8	0.007	0.142

¹ Controlled for Clustering of Observations (SAS-Callable SUDAAN). Significant differences based on *t*-statistics and significant differences relative to reference group denoted by * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

length of stay from the beta coefficient of -0.369, the presence of an epilepsy diagnosis was associated with a 31% shorter length of stay compared to those without epilepsy.

Emergency Room Visit by Epilepsy Status: Bivariate Comparisons

Table 5 compares emergency room use by epilepsy status by predisposing, enabling and need characteristics of the study population. The rate of emergency room use was nearly twice as high for those with epilepsy (27.1%) compared to those without epilepsy (14.4%), ($p \leq .001$). The difference was significant for all subgroups except adults ages 55-64.

Emergency Room Visit by Epilepsy Status: Logistic Regression

To test the hypothesis that those with epilepsy were more likely to visit the emergency room than those without epilepsy after controlling for age, gender, race/ethnicity, additional co-occurring developmental disabilities, psychiatric comorbidity, Medicare eligibility, and physical comorbidity, a logistic regression procedure was performed. Table 5 presents the results of the adjusted logistic regression models predicting emergency room visits from presence versus absence of epilepsy. The multivariate analysis substantiated the bivariate comparisons between groups. The odds of an emergency room visit by those with epilepsy were more than twice greater than those without epilepsy (95% CI = 1.81 – 2.59)

Table 5

Emergency Room Visit by Epilepsy Status

	No Epilepsy		Epilepsy		Logistic Regression on Emergency Room Use	
	N	%	N	%	AOR	95% CI
ALL	1,225	14.4	208	27.1 ***		
Epilepsy						
Yes					2.16 ***	(1.81-2.59)
No						
PREDISPOSING						
Age						
21-39	874	15.5	153	28.8 ***		
40-54	293	12.3	49	24.3 ***	1.12	(0.97-1.30)
55-64	58	11.5	6	17.1	0.94	(0.71-1.25)
Gender						
Female	591	15.1	97	27.6 ***	1.13 *	(1.01-1.27)
Male	634	13.7	111	26.7 ***		
Race/Ethnicity						
White	897	13.4	160	26.5 ***		
African American	225	19.0	28	27.2 *	1.17 *	(1.00-1.38)
Other	1.03	15.9	20	32.3 **	1.04	(0.84-1.29)

Table 5 (continued)

	No Epilepsy		Epilepsy		Logistic Regression on Emergency Room Use	
	N	%	N	%	AOR	95% CI
Developmental Disability Diagnoses					1.14 ***	(1.07-1.21)
None	337	13.1	41	24.3 ***		
One	666	14.1	1228	27.8 ***		
Two or Three	222	18.0	39	28.3 **		
Psychiatric Comorbidity						
Yes	420	22.2	78	32.5 ***	1.88 ***	(1.65-2.13)
No	805	12.1	130	24.6 ***		
Substance Abuse						
Yes	29	25.7	6	46.2		
No	1,196	14.2	202	26.8 ***		Not Included
ENABLING						
DDD Waiver						
Yes	732	15.4	128	27.8 ***		Not Included
No	493	13.0	80	26.1 ***		
Medicare						
Yes	353	8.4	67	16.3 ***	0.31 ***	(0.27-0.36)
No	872	20.1	141	39.6 ***		

Table 5 (continued)

	No Epilepsy		Epilepsy		Logistic Regression on Emergency Room Use	
	N	%	N	%	AOR	95% CI
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	301	23.4	55	36.2 ***	2.15 ***	(1.86-2.48)
No	924	12.7	153	24.8 ***		
Health System						
year of Observation						
July 1995 – June 1996	1,121	14.6	194	27.1 ***		
July 1996 – June 1997	52	10.7	2	9.5	0.73 *	(0.54-0.98)
July 1997 – June 1998	52	14.3	12	37.5 ***	1.01	(0.76-1.35)

Significant differences based on Chi-squared statistics and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Annual Expenditures by Epilepsy Status

Annual expenditures per person were transformed to a logarithmic scale and standardized to constant dollars with 2000 as the base year to control for inflation in medical care costs (Bureau of Labor Statistics, 2006). All Medicaid expenditures, including home and community based Waiver services, were included in the analysis. Results are presented as constant dollars standardized to 2000 as the base year.

Annual Expenditures by Epilepsy Status: Bivariate Comparisons

Table 6 compares mean annual Medicaid expenditures (in 2000 constant dollars) by epilepsy status by predisposing, enabling and need characteristics. Annual expenditures include only amounts paid by Medicaid. (While the Medicaid claims include an indicator of whether the claim was submitted via Medicare, they do not include any Medicare payment information.) The overall mean annual expenditure was \$25,794. Mean expenditures were \$25,205 for those without epilepsy and \$32,352 for those with epilepsy ($p = .001$). The differences between group means were significant for all subgroups except those of Other race/ethnicity and those with more than one developmental disability diagnosis. Median expenditures were \$14,298 for those without epilepsy and \$22,020 for those with epilepsy (data not shown). As seen from Table 6, mean expenditures for those without epilepsy were six times greater for waiver participants than non-participants. Among those with epilepsy, mean expenditures for waiver participants were four times as high as the mean for non-participants.

Annual Expenditures by Epilepsy Status: OLS Regression

Ordinary Least Square regressions were conducted to test the hypothesis that adult Medicaid beneficiaries with developmental disabilities and epilepsy have higher expenditures than their counterparts without epilepsy (Table 6). (Regression coefficients presented in the table are unstandardized.) Controlling for the other variables in the model, mean annual expenditures were higher for the epilepsy group. Estimating the difference in expenditures from the (unstandardized) coefficient of 0.54, the presence of an epilepsy diagnosis was associated with expenditures 72% higher than those without epilepsy. The increase in expenditures associated with epilepsy was substantially smaller than the effect of number of developmental disability diagnoses, but similar to the effect of psychiatric comorbidity and older age (55-64 compared to younger adults ages 21-39).

Table 6

Annual Expenditures by Epilepsy Status

	No Epilepsy	Epilepsy	OLS Regression on Expenditures (Logged Values)	
	Mean	Mean	Beta	SE
ALL	25,205	32,352 ***		
Epilepsy				
Yes			0.536 ***	0.08
No				
PREDISPOSING				
Age				
21-39	22,146	29,391 ***		
40-54	31,096	38,884 ***	0.05 ***	0.06
55-64	31,558	39,579		
Gender				
Female	25,676	33,950 ***	0.108 *	0.05
Male	24,808	31,000 ***		
Race/Ethnicity				
White	26,599	33,432 ***		
African American	21,737	30,517 ***	-0.10	0.07
Other	17,114	24,903	-0.198 *	0.09

Table 6 (continued)

	No Epilepsy	Epilepsy	OLS Regression on Expenditures (Logged Values)	
	Mean	Mean	Beta	SE
Developmental Disability Diagnoses			1.76 ***	0.04
None	5,804	10,663 **		
One	31,306	37,466 ***		
Two or Three	42,473	41,830		
Mental Comorbidity				
Yes	32,700	40,132 ***	0.654 ***	0.06
No	23,066	28,816 ***		
Substance Abuse				
Yes	25,446	25,730	Not Included	
No	25,202	32,466 ***		
ENABLING				
DDD Waiver				
Yes	39,951	46,671 ***	Not Included	
No	6,655	10,850 ***		
Medicare				
Yes	28,974	33,610 **	0.325 ***	0.05
No	21,554	30,897 ***		

Table 6 (continued)

	No Epilepsy	Epilepsy	OLS Regression on Expenditures (Logged Values)	
	Mean	Mean	Beta	SE
NEED				
Physical Comorbidity				
Any Chronic Disease				
Yes	32,157	39,559 **	0.401 ***	0.06
No	23,971	30,574 ***		
Health System				
Yea of Observation				
July 1995 – June 1996	26,412	32,323 ***		
July 1996 – June 1997	12,687	23,073	-1.089 ***	0.10
July 1997 – June 1998	16,363	39,088 ***	-1.016 ***	0.11

Significant group differences based on *t*-statistic and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Health Service Expenditures and Use by Type of Service

Annual expenditures and use by type of service are shown in Tables 7-13.

Expenditures by Type of Service and Epilepsy Status: Bivariate Comparisons

Table 7 compares mean expenditures in 2000 constant dollars for the study population (users and nonusers) by type of service and epilepsy status. The mean expenditure for the epilepsy group was nearly 30% higher than the mean for those without epilepsy. Those with epilepsy had higher expenditures for five services: physician, medications, developmental disabilities waiver, other waiver, and other services. Taken together, the developmental disabilities waiver and medications made up 80% of the difference in mean expenditures between the epilepsy and no epilepsy groups.

Table 7

Annual Expenditures by Type and Epilepsy Status

	Inpatient		Outpatient		Physician		Medications		
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	
ALL	624	797	1,296	1,289	100	0179 ***	1,129	2,436 ***	
PREDISPOSING									
Age									
21-39	753	847	1,315	1,396	88	173 ***	1,067	2,539 ***	
40-54	389	664	1,271	1,120	123	178 **	1,239	2,539 ***	
55-64	294	797	1,205	644 *	125	261 *	1,312	3,039 ***	
Gender									
Female	692	1,048	1,373	1,306	102	187 ***	1,124	2,424 ***	
Male	568	584	1,232	1,275	97	172 ***	1,134	2,447 ***	
Race/Ethnicity									
White	545	787	1,219	1,289	98	174 ***	1,159	2,535 ***	
African American	917	812	1,939	1,454	113	146	1,038	2,001 ***	
Other	911	868	919	1,016	96	277 **	989	2,197 ***	
Developmental Disability Diagnoses ¹									
None	329	540	1,195	1,631	81	146 ***	986	2,395 ***	
One	748	876	1,349	1,128	104	186 ***	1,190	2,481 ***	
Two or Three	768	846	1,310	1,408	125	193 *	1,200	2,338 ***	

Table 7 (continued)

	Inpatient		Outpatient		Physician		Medications	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Psychiatric Comorbidity								
Yes	1,083	1,433	2,961	2,360	158	233 **	1,975	3,073 ***
No	494	508	821	802	83	154 ***	888	2,147 ***
Substance Abuse								
Yes	2,189	5,006	6,016	5,133	272	566	2,138	2,148
No	603	724	1,233	1,223	97	172 ***	1,116	2,441 ***
ENABLING								
DDD Waiver								
Yes	475	657	1,221	1,140	105	179 ***	1,220	2,529 ***
No	812	1,006	1,391	1,513	93	178 ***	1,016	2,297 ***
Medicare								
Yes	157	269	1,196	1,068	107	182 ***	1,241	2,464 ***
No	1,077	1,407	1,393	1,544	92	175 ***	1,022	2,405 ***
NEED								
Physical Comorbidity								
Any Chronic Disease								
Yes	1,281	1,299	1,757	1,820	210	221	1,824	2,785 ***
No	508	6783	1,215	1,158	80	168 ***	1,006	2,350 ***

Table 7 (continued)

	Inpatient		Outpatient		Physician		Medications	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Health System								
Year of Observation								
July 1995 – June 1996	660	761	1,327	1,187	106	184 ***	1,123	2,412 ***
July 1996 – June 1997	181	127	973	1,301	48	98	825	1,918 **
July 1997 – June 1998	471	2,027	1,088	3,569	29	112	1,672	3,330 **
	DDD Waiver		Other Waiver		Other		ER	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
ALL	19,553	23,984 ***	277	2 ***	2,214	3,649 ***	11	17
PREDISPOSING								
Age								
21-39	16,158	20,708 ***	394	2 ***	2,357	3,889 **	13	18
40-54	26,237	31,596 *	50	0 *	1,780	2,772	7	14 *
55-64	25,909	29,749	38	0	2,667	5,066	9	12
Gender								
Female	19,900	24,708 **	123	0 *	2,352	4,265 ***	11	13
Male	19,261	23,371 **	407	3 ***	2,098	3,128 *	11	21

Table 7 (continued)

	DDD Waiver		Other Waiver		Other		ER	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Race/Ethnicity								
White	21,131	25,599 ***	350	2 ***	2,088	3,028 **	9	18 *
African American	15,209	21,791 *	3	0	2,498	4,302	19	12
Other	11,157	11,915	21	0	3,004	8,606 *	17	26
Developmental Disability Diagnoses ¹								
None	1,020	1,695	636	7 ***	1,546	4,236 **	13	13
One	25,738	29,846 **	147	0 *	2,022	2,927 *	10	22 **
Two or Three	34,680	31,695	23	0	4,355	5,342	13	9
Psychiatric Comorbidity								
Yes	23,667	29,089 **	205	5	2,637	3,913	15	26
No	18,379	21,663 **	297	0 ***	2,094	3,529 ***	10	14
Substance Abuse								
Yes	13,231	6,561	0	0	1,558	6,233	42	85
No	19,638	24,284 ***	281	2 ***	2,223	3,604 ***	11	16
ENABLING								
DDD Waiver								
Yes	35,096	39,956 ***	2	0	1,824	2,200	9	12
No	0	0	623	4 ***	2,706	5,825 ***	14	26

Table 7 (continued)

	DDD Waiver		Other Waiver		Other		ER	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Medicare								
Yes	23,903	25,816	169	3 *	2,195	3,798 **	5	10
No	15,338	21,8653 ***	381	0 ***	2,233	3,476 *	17	27
NEED								
Physical Comorbidity								
Any Chronic Disease								
Yes	22,415	26,952	438	8 *	4,198	6,452	34	22
No	19,045	23,251 ***	248	0 ***	1,862	2,957 ***	7	16 **
Health System								
Year of Observation								
July 1995 – June 1996	20,574	24,045 **	302	2 ***	2,309	3,717 ***	12	17
July 1996 – June 1997	9,280	16,986	86	0	1,292	2,617	3	27
July 1997 – June 1998	11,658	27,219 **	0	0	1,439	2,809	6	24

¹ Classified as a need factor in relation to DDD waiver.

Significant differences based on *t*-distribution and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Health Services Use by Type of Service and Epilepsy Status: Bivariate Comparisons

As seen in Table 8, a higher proportion of individuals with epilepsy used every type of service, compared to those without epilepsy. Excluding the community long-term care developmental disabilities waiver category, a greater percentage of those with epilepsy used all services across all subgroups, except use of other services by dual eligibles and use of any service other than inpatient care by those with substance abuse. The percentage of individuals with an inpatient or emergency room visit was also greater for those with epilepsy compared to those without epilepsy ($p \leq .001$).

Table 8

Health Service Use by Type and Epilepsy Status

	Inpatient				Outpatient			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
ALL	714	8.4	127	16.5 ***	5,097	59.7	584	76.0 ***
Age								
21-39	400	7.1	74	13.9 ***	3,224	57.1	401	75.5 ***
40-54	20	10.5	41	20.3 ***	1,533	64.2	150	74.3 **
55-64	64	12.7	12	34.3 ***	340	67.3	33	94.3 ***
Gender								
Female	331	8.5	63	17.9 ***	2,448	62.7	267	75.9 ***
Male	383	8.3	64	15.4 ***	2,650	57.2	317	76.2 ***
Race/Ethnicity								
White	534	8.0	94	15.6 ***	3,947	58.9	457	75.8 ***
African American	121	10.2	18	17.5 *	777	65.6	74	71.8
Other	59	9.1	15	24.2 ***	373	57.7	53	85.5 ***
Developmental Disability Diagnoses								
None	177	6.9	23	13.6 **	1,210	46.9	116	68.6 ***
One	421	8.9	84	18.2 ***	3,022	64.0	356	77.2 ***
Two or Three	116	9.4	20	14.5	865	70.3	112	81.2 **

Table 8 (continued)

	Inpatient				Outpatient			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Psychiatric Comorbidity								
Yes	282	14.9	57	23.8 ***	1,554	82.0	215	89.6 **
No	432	6.5	70	13.3 ***	3,543	53.4	369	69.9 ***
Substance Abuse								
Yes	37	32.7	9	69.2 **	99	87.6	12	92.3
No	677	8.0	118	15.6 ***	4,998	59.3	572	75.8 ***
ENABLING								
DDD Waiver								
Yes	414	8.7	72	15.6 ***	3,206	67.4	367	79.6 ***
No	300	7.9	55	17.9 ***	1,891	50.0	217	70.7 ***
Medicare								
Yes	410	9.8	76	18.4 ***	2,720	64.8	310	75.2 ***
No	304	7.0	51	14.3 ***	2,377	54.8	274	77.0 ***
NEED								
Physical Comorbidity								
Any Chronic Disease								
Yes	222	17.3	35	23.0	954	74.2	129	84.9 **
No	492	6.8	92	14.9 ***	4,143	57.2	455	73.9 ***

Table 8 (continued)

	Inpatient				Outpatient			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Health System								
Year of Observation								
July 1995 – June 1996	656	8.5	117	16.4 ***	4,706	61.2	541	75.7 ***
July 1996 – June 1997	29	6.0	2	9.5	210	43.3	17	81.0 ***
July 1997 – June 1998	29	8.0	8	25.0 **	181	49.9	26	81.3 ***
	Physician				Medications			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
ALL	5,327	62.4	629	81.9 ***	7,059	82.7	736	95.8 ***
PREDISPOSING								
Age								
21-39	3,322	58.9	430	81.0 ***	4,523	80.1	506	95.3 ***
40-54	1,653	69.3	170	84.2 ***	2,084	87.3	195	96.5 ***
55-64	352	69.7	29	82.9	452	89.5	35	100.0 *
Gender								
Female	2,523	64.7	292	83.0 ***	3,302	84.6	339	96.3 ***
Male	2,804	60.5	337	81.0 ***	3,757	81.1	397	95.4 ***

Table 8 (continued)

	Physician				Medications			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Race/Ethnicity								
White	4,239	63.2	489	81.1 ***	5,584	83.3	572	94.9 ***
African American	715	60.3	87	84.5 ***	958	80.8	103	100.0 ***
Other	373	57.7	53	85.5 ***	517	79.9	61	98.4 ***
Developmental Disability Diagnoses								
None	1,265	49.0	130	76.9 ***	1,991	77.1	160	94.7 ***
One	3,164	67.0	382	82.9 ***	3,962	83.9	445	96.5 ***
Two or Three	898	72.9	117	84.8 **	1,106	89.8	131	94.9
Psychiatric Comorbidity								
Yes	1,400	73.9	208	86.7 ***	1,752	92.5	234	97.5 **
No	3,927	59.1	421	79.7 ***	5,307	79.9	502	95.1 ***
Substance Abuse								
Yes	85	75.2	12	92.3	105	92.9	12	92.3
No	5,242	62.2	617	81.7 ***	6,954	82.6	724	95.9 ***
ENABLING								
DDD Waiver								
Yes	3,287	69.1	389	84.4 ***	4,125	86.8	452	98.0 ***
No	2,040	54.0	240	78.2 ***	2,934	77.6	284	92.5 ***

Table 8 (continued)

	Physician				Medications			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Medicare								
Yes	3,015	71.8	356	86.4 ***	3,736	89.0	402	97.6 ***
No	2,312	53.3	273	76.7 ***	3,323	76.7	334	93.8 ***
NEED								
Physical Comorbidity								
Any Chronic Disease								
Yes	1,025	79.7	134	88.2 *	1,189	92.5	146	96.1
No	4,302	59.3	495	80.4 ***	5,870	81.0	590	95.8 ***
Health System								
Year of Observation								
July 1995 – June 1996	4,994	65.0	602	84.2 ***	6,512	84.7	690	96.5 ***
July 1996 – June 1997	208	42.9	12	57.1	299	61.6	19	90.5 **
July 1997 – June 1998	125	34.4	15	46.9	248	68.3	27	84.4
	DDD Wavier				Other Services			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
ALL	4,675	54.8	458	59.6 **	7,043	82.5	685	89.2 ***

Table 8 (continued)

	DDD Wavier				Other Services			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
PREDISPOSING								
Age								
21-39	2,740	48.5	296	55.7 **	4,515	80.0	463	87.2 ***
40-54	1,598	67.0	141	69.8	2,074	86.9	187	92.6 *
55-64	337	66.7	21	60.0	454	89.9	35	100.0 *
Gender								
Female	2,187	56.0	215	61.1	3,279	84.0	316	89.8 **
Male	2,488	53.7	243	58.4	3,764	81.2	369	88.7 ***
Race/Ethnicity								
White	3,826	57.1	371	61.5 *	5,543	82.7	538	89.2 ***
African American	600	50.6	63	61.2 *	995	84.0	94	91.3 *
Other	249	38.5	24	38.7	505	78.1	53	85.5
Developmental Disability Diagnoses¹								
None	206	8.0	15	8.9	1,764	68.3	132	78.1 **
One	3,429	72.6	342	74.2	4,122	87.3	422	91.5 **
Two or Three	1,040	84.5	101	73.2 ***	1,157	94.0	131	94.9

Table 8 (continued)

	DDD Wavier				Other Services			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Psychiatric Comorbidity								
Yes	1,065	56.2	151	62.9 *	1,686	89.0	230	95.8 ***
No	3,610	54.4	307	58.1	5,357	80.7	455	86.2 **
Substance Abuse								
Yes	41	36.3	4	30.8	101	89.4	13	100.0
No	4,634	55.0	454	60.1 **	6,942	82.4	672	89.0 ***
ENABLING								
DDD Waiver								
Yes	4,675	54.8	458	60.0	4,295	90.3	433	93.9 *
No					2,748	72.7	252	82.1 ***
Medicare								
Yes	2,627	62.5	264	64.1	3,680	87.6	372	90.3
No	2,048	47.2	194	54.5 **	3,363	77.6	313	87.9 ***
NEED								
Physical Comorbidity								
Any Chronic Disease								
Yes	710	55.2	87	57.2	1,173	91.2	146	96.1 *
No	3,965	54.7	371	60.2 **	5,870	81.0	539	87.5 ***

Table 8 (continued)

	DDD Wavier				Other Services			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Health System								
Year of Observation								
July 1995 – June 1996	4,329	56.3	432	60.4 *	6,516	84.8	642	89.8 ***
July 1996 – June 1997	210	43.3	9	42.9	311	64.1	15	71.4
July 1997 – June 1998	136	37.5	17	53.1	216	59.5	28	87.5 **
	ER				Inpatient/ER			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
ALL	1,216	14.2	207	27.0 ***	1,623	19.0	269	35.0 ***
PREDISPOSING								
Age								
21-39	870	15.4	153	28.8 ***	1,074	19.0	188	35.4 ***
40-54	288	12.1	48	23.8 ***	444	18.6	66	32.7 ***
55-64	58	11.5	6	17.1	105	20.8	15	42.9 **
Gender								
Female	586	15.0	96	27.3 ***	789	20.2	125	35.5 ***
Male	630	13.6	111	26.7 ***	834	18.0	144	34.6 ***

Table 8 (continued)

	ER				Inpatient/ER			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Race/Ethnicity								
White	892	13.3	159	26.4 ***	1,217	18.2	205	34.0 ***
African American	224	18.9	28	27.2 *	279	23.5	36	35.0 **
Other	100	15.5	20	32.3 ***	127	19.6	28	45.2 ***
Developmental Disability Diagnoses								
None	334	12.9	41	24.3 ***	423	16.4	50	29.6 ***
One	663	14.0	128	27.8 ***	911	19.3	168	36.4 ***
Two or Three	219	17.8	38	27.5 **	289	23.5	51	37.0 ***
Psychiatric Comorbidity								
Yes	417	22.0	78	32.5 ***	563	29.7	107	44.6 ***
No	799	12.0	129	24.4 ***	1,060	16.0	162	30.7 ***
Substance Abuse								
Yes	29	25.7	6	46.2	52	46.0	11	84.6 **
No	1,187	14.1	201	26.6 ***	1,571	18.7	258	34.2 ***
ENABLING								
DDD Waiver								
Yes	727	15.3	128	27.8 ***	969	20.4	166	36.0 ***
No	489	12.9	79	25.7 ***	654	17.3	103	33.6 ***

Table 8 (continued)

	ER				Inpatient/ER			
	No Epilepsy		Epilepsy		No Epilepsy		Epilepsy	
	N	%	N	%	N	%	N	%
Medicare								
Yes	345	8.2	66	16.0 ***	652	15.5	117	28.4 ***
No	871	20.1	141	39.6 ***	971	22.4	152	42.7 ***
NEED								
Physical Comorbidity								
Any Chronic Disease								
Yes	297	23.1	5	36.2 ***	417	32.4	72	47.4 ***
No	919	12.7	152	24.7 ***	1,206	16.6	197	32.0 ***
Health System								
Year of Observation								
July 1995 – June 1996	1,120	14.6	194	27.1 ***	1,489	19.4	250	35.0 ***
July 1996 – June 1997	49	10.1	2	9.5	68	14.0	4	19.0
July 1997 – June 1998	47	12.9	11	34.4 **	66	18.2	15	46.9 ***

Significant differences based on Chi-squared statistics denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Health Services Use by Type of Service and Epilepsy Status: Logistic Regression

Logistic regressions identifying characteristics associated with service use are shown in Table 9. In general, multivariate analysis substantiated the bivariate analyses. Individuals with epilepsy were more likely to use every type of service except the Developmental Disabilities HCBS waiver and they were much more likely to use medication. Controlling for other variables, those with epilepsy were twice as likely to use inpatient, outpatient, physician, and emergency care. The odds of those with epilepsy having any hospital event involving inpatient or emergency care were twice those of individuals without epilepsy. The presence of one or more developmental disability diagnoses other than epilepsy increased the odds of using all services except inpatient care. The strong association of developmental disability diagnoses and HCBS waiver participation (OR = 11.41, 95% CI = 10.2 – 12.7) reflects the requirement for a developmental disability diagnosis in order to receive developmental disabilities waiver services. Dual eligibles were more likely to use all acute medical care services except one; their odds of visiting the emergency room were less than one-third of those with Medicaid only. Dual eligibles' odds of having any hospital event were only half those of Medicaid only beneficiaries.

Table 9
Health Service Use by Type by Epilepsy Status – Logistic Regression

	Inpatient		Outpatient		Physician	
	OR	95% CI	OR	95% CI	OR	95% CI
Epilepsy						
Yes	1.95	[1.58,2.41] ***	1.89	[1.58, 2.27] ***	2.46	[2.02,2.99] ***
No						
PREDISPOSING						
Age						
21-39						
40-54	1.40	[1.18,1.66] ***	1.13	[1.02, 1.26] *	1.15	[1.02,1.28] *
55-64	1.67	[1.26,2.20] ***	1.32	[1.08, 1.61] **	1.05	[0.85,1.29]
Gender						
Female	1.01	[0.88,1.17]	1.22	[1.12, 1.34] ***	1.15	[1.05,1.26] **
Male						
Race/Ethnicity						
White						
African American	1.32	[1.08,1.61] **	1.31	[1.15, 1.50] ***	0.97	[0.85,1.11]
Other	1.42	[1.09,1.85] **	1.15	[0.97, 1.36]	1.03	[0.87,1.22]
Developmental Disability Diagnose	1.07	[0.95,1.20]	1.55	[1.44, 1.66] ***	1.54	[1.44,1.66] ***
Psychiatric Comorbidity						
Yes	2.23	[1.92,2.60] ***	3.71	[3.28, 4.21] ***	1.81	[1.61,2.04] ***
No						

Table 9 (continued)

	Inpatient		Outpatient		Physician	
	OR	95% CI	OR	95% CI	OR	95% CI
ENABLING						
Medicate						
Yes	1.22	[1.04,1.43] *	1.29	[1.17, 1.42] ***	1.94	[1.76,2.14] ***
No						
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	2.26	[1.91,2.66] ***	1.77	[1.55, 2.03] ***	2.26	[1.96,2.61] ***
No						
Health System						
Year of Observation						
July 1995 – June 1996						
July 1996 – June 1997	0.76	[0.52,1.11]	0.57	[0.47, 0.69] ***	0.45	[0.37,0.55] ***
July 1997 – June 1998	0.95	[0.67,1.36]	0.64	[0.51, 0.79] ***	0.25	[0.20,0.32] ***
	Medications		DDD Waiver		Other Services	
	OR	95% CI	OR	95% CI	OR	95% CI
Epilepsy						
Yes	4.14	[2.88,5.96] ***	1.00	[0.84, 1.21]	1.42	[1.11,1.82] **
No						

Table 9 (continued)

	Medications		DDD Waiver		Other Services	
	OR	95% CI	OR	95% CI	OR	95% CI
PREDISPOSING						
Age						
21.39						
40-54	1.24	[1.07,1.44] **	1.92	[1.70, 2.17] ***	1.27	[1.10,1.48] **
55-64	1.40	[1.03,1.90] *	1.90	[1.52, 2.38] ***	1.64	[1.20,2.24] **
Gender						
Female	1.23	[1.10,1.39] ***	1.05	[0.95, 1.16]	1.15	[1.02,1.29] *
Male						
Race/Ethnicity						
White						
African American	0.95	[0.80,1.12]	0.89	[0.77, 1.03]	1.21	[1.02,1.44] *
Other	1.04	[0.84,1.28]	0.57	[0.47, 0.70] ***	0.98	[0.80,1.20]
Developmental Disability Diagnose	1.29	[1.18,1.42] ***	11.41	[10.20,12.70] ***	2.58	[2.34,2.84] ***
Psychiatric Comorbidity						
Yes	2.88	[2,40,3.46] ***	0.81	[0.72, 0.91] ***	1.75	[1.49,2.05] ***
No						
ENABLING						
Medicate						
Yes	2.09	[1.83,2.38] ***	1.24	[1.11, 1.38] ***	1.54	[1.35,1.74] ***
No						

Table 9 (continued)

	Medications		DDD Waiver		Other Services	
	OR	95% CI	OR	95% CI	OR	95% CI
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	2.17	1.75,2.68] ***	0.72	[0.62, 0.83] ***	2.00	[1.63,2.45] ***
No						
Health System						
Year of Observation						
July 1995 – June 1996						
July 1996 – June 1997	0.32	[0.26,0.39] ***	0.70	[0.56, 0.88] **	0.38	[0.31,0.46] ***
July 1997 – June 1998	0.36	[0.29,0.46] ***	0.48	[0.37, 0.63] ***	0.28	[0.22,0.35] ***
	ER		Inpatient/ER			
	OR	95% CI	OR	95% CI		
Epilepsy						
Yes	2.16	[1.80,2.59] ***	2.16	[1.83, 2.55] ***		
No						
PREDISPOSING						
Age						
21-39						
40-54	1.11	[0.96,1.29]	1.14	[1.01, 1.30] *		
55-64	0.95	[0.71,1.26]	1.26	[1.00, 1.58] *		

Table 9 (continued)

	ER		Inpatient/ER	
	OR	95% CI	OR	95% CI
Gender				
Female	1.12	[1.00,1.26]	1.10	[1.02, 1.26] *
Male				
Race/Ethnicity				
White				
African American	1.17	1.00,1.38]	1.18	[1.02, 1.37} *
Other	1.01	[0.82,1.26]	1.10	[0.89, 1.32]
Developmental Disability Diagnose	1.21	[1.10,1.32] ***	1.20	[1.12, 1.31] ***
Psychiatric Comorbidity				
Yes	1.88	1.66,2.14] ***	2.00	[1.81, 2.27] ***
No				
ENABLING				
Medicate				
Yes	0.30	[0.26,0.35] ***	0.53	[0.48, 0.60] ***
No				
NEED				
Physical Comorbidity				
Any Chronic Disease				
Yes	2.13	[1.84,2.46] ***	2.30	[1.98, 2.56] ***
No				

Table 9 (continued)

	ER		Inpatient/ER	
	OR	95% CI	OR	95% CI
Health System				
Year of Observation				
July 1995 – June 1996				
July 1996 – June 1997	0.68	[0.50,0.92] *	0.70	[0.57, 0.97] *
July 1997 – June 1998	0.90	[0.67,1.21]	1.00	[0.74, 1.24]

Significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

User Expenditures by Type of Service and Epilepsy Status: Bivariate Comparisons

Service users were identified by at least one service claim with an amount greater than \$0.00. Among service users, those with epilepsy had higher annual expenditures (in 2000 constant dollars) for physician services, medications, developmental disabilities waiver, and other services compared to those without epilepsy (Table 10). (Other waiver expenditures are not shown because only one individual had claims for waiver services other than the developmental disabilities waiver.) Individuals without epilepsy had higher expenditures for inpatient care than those with epilepsy, reflecting their longer length of stay (Table 4). They also had higher outpatient care expenditures. The differences between subgroups were consistent, although in many cases they did not reach statistical significance.

Table 10

Annual Expenditures by Type and Epilepsy Status -- Users

	Inpatient		Outpatient		Physician		Medications	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
ALL	7,463	4,817 *	2,171	1,695	160	218 ***	1,366	2,542 ***
PREDISPOSING								
Age								
21-39	10,628	6,078 *	2,303	1,849	149	214 ***	1,331	2,474 ***
40-54	3,716	3,273	1,978	1,508	177	212	1,419	2,630 ***
55-64	2,317	2,324	1,789	683 ***	180	315 *	1,466	3,039 ***
Gender								
Female	8,153	5,856	2,189	1,721	158	225 **	1,328	2,517 ***
Male	6,866	3,795 *	2,154	1,673 *	161	212 **	1,389	2,564 ***
Race/Ethnicity								
White	6,839	5,047	2,071	1,701	155	215 ***	1,391	2,673 ***
African American	8,982	4,643	2,957	2,024	187	173	1,284	2,001 ***
Other	9,993	3,586	1,593	1,188	166	324 *	1,238	2,233 ***
Developmental Disability Diagnoses								
None	4,796	3,965	2,548	2,377	165	190	1,278	2,529 ***
One	8,395	4,808 *	2,108	1,461 ***	155	225 ***	1,418	2,570 ***
Two or Three	8,151	5,838	1,864	1,734	171	228	1,335	2,462 ***

Table 10 (continued)

	Inpatient		Outpatient		Physician		Medications	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Psychiatric Comorbidity								
Yes	7,276	6,033	3,610	2,634	214	268	2,136	3,162 ***
No	7,585	3,828 *	1,539	1,148 **	140	193 ***	1,111	2,258 ***
Substance Abuse								
Yes	6,686	7,230	6,867	5,560	362	614	2,301	2,327
No	7,505	4,633 *	2,078	1,614 *	156	210 ***	1,351	2,546 ***
ENABLING								
DDD Waiver								
Yes	5,455	4,206	1,811	1,432 *	152	212 **	1,406	2,579 ***
No	10,234	5,617 *	2,781	2,141	172	228 *	1,309	2,483 ***
Medicare								
Yes	1,608	1,460	1,847	1,420 *	150	211 ***	1,395	2,525 ***
No	15,360	9,821 *	2,541	2,007	173	228 *	1,333	2,563 ***
NEED								
Physical Comorbidity								
Any Chronic Disease								
Yes	7,419	5,642	2,369	2,145	263	250	1,973	2,900 ***
No	7,483	4,504 *	2,125	1,568 **	135	209 ***	1,243	2,454 ***

Table 10 (continued)

	Inpatient		Outpatient		Physician		Medications	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Health System								
Year of Observation								
July 1995 – June 1996	7,728	4,652 **	2,167	1,568 ***	164	218 ***	1,326	2,499 ***
July 1996 – June 1997	3,025	1,330	2,247	1,608	112	171	1,338	2,120 *
July 1997 – June 1998	5,893	8,106	2,181	4,392	85	239	2,447	3,946 *
	DDD Waiver		Other Services		ER			
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy		
ALL	35,697	40,217 ***	2,683	4,091 ***	78	65		
PREDISPOSING								
Age								
21-39	33,284	37,148 *	2,947	4,460 **	85	64		
40-54	39,175	45,265 **	2,048	2,995	60	59		
55-64	38,825	49,582 *	2,966	5,066	76	128		
Gender								
Female	35,504	40,452 *	2,799	4,750 ***	72	48		
Male	35,866	40,010 *	2,582	3,526	84	79		

Table 10 (continued)

	DDD Waiver		Other Services		ER	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Race/Ethnicity						
White	37,021	41,607 **	2,525	3,393 *	69	67
African American	30,038	35,626	2,975	4,714	101	43
Other	28,990	30,781	3,848	10,067	113	79
Developmental Disability Diagnoses						
None	12,776	19,093	2,261	5,424 *	100	55
One	35,450	40,231 **	2,317	3,197 *	70	78
Two or Three	41,050	43,306	4,633	5,627	71	31
Psychiatric Comorbidity						
Yes	42,111	46,235	2,964	4,083	70	80
No	33,805	37,257 *	2,595	4,095 **	83	55
Substance Abuse						
Yes	36,466	21,323	1,744	6,232	162	43
No	35,690	40,384 ***	2,697	4,050 **	76	61
ENABLING						
DDD Waiver						
Yes	35,697	40,217 ***	2,019	2,342	60	43
No	35,697	40,217	3,722	7,097 ***	105	99

Table 10 (continued)

	DDD Waiver		Other Services		ER	
	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
Medicare						
Yes	38,216	40,288	2,505	4,207 **	66	59
No	32,466	40,120 ***	2,879	3,954	83	67
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	40,600	47,089 *	4,602	6,717	149	60
No	34,819	38,606 **	2,300	3,380 **	56	66
Health System						
Year of Observation						
July 1995 – June 1996	36,533	39,796 *	2,724	4,139 **	82	62
July 1996 – June 1997	21,431	39,633	2,015	3,663	30	286
July 1997 – June 1998	31,117	51,235 **	2,418	3,210	48	68

¹ Other wavier data not shown due to insufficient cell size.

² Classified as need factor in relation to DDD waiver.

Significant differences based on *t*-distribution denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

User Expenditures by Type of Service and Epilepsy Status: OLS Regression

Controlling for other variables in the model, epilepsy was a significant predictor of users' annual expenditures (in 2000 constant dollars) for physician services ($\beta = 0.41$, $p \leq .001$), medications ($\beta = 0.98$, $p \leq .001$), developmental disabilities waiver ($\beta = 0.18$, $p \leq .01$), and other services ($\beta = 0.42$, $p \leq .001$) (Table 11). Physical comorbidity was the strongest predictor of physician ($\beta = 0.46$, $p \leq .001$), other ($\beta = 0.74$, $p \leq .001$), and emergency room ($\beta = 0.20$, $p \leq .01$) expenditures. Psychiatric comorbidity was the largest factor in inpatient ($\beta = 0.19$, $p \leq .01$), and outpatient ($\beta = 0.63$, $p \leq .001$) costs. Dual eligibles had lower Medicaid expenditures for inpatient ($\beta = -1.75$, $p \leq .001$), outpatient ($\beta = -0.65$, $p \leq .001$), and other ($\beta = -0.25$, $p \leq .001$) services. Developmental disabilities waiver costs were of interest because the difference in mean total expenditures between participants and non-participants (Table 6) was so large (\$39,951 annually for waiver participants without epilepsy compared to \$6,655 for non-participants, and \$46,671 per year for waiver participants with epilepsy compared to \$10,850 for non-participants). The number of developmental disabilities diagnoses predicted expenditures for the developmental disabilities home and community based services waiver ($\beta = 0.40$, $p \leq .001$) and other services ($\beta = 0.613$, $p \leq .001$).

Table 11

OLS Regression on Annual (Logged) Expenditures by Type - Users

	DDD Wavier		Other		ER	
	Beta	SE	Beta	SE	Beta	SE
Intercept	9.390	0.052 ***	4.899	0.055 ***	3.185	0.071 ***
Epilepsy						
Yes	0.183	0.057 **	0.415	0.080 ***	0.083	0.084
No						
PREDISPOSING						
Age						
21-39						
40-54	0.233	0.038 ***	-0.052	0.054	0.177	0.074 *
55-64	0.185	0.068 **	0.185	0.097	0.136	0.146
Gender						
Female	-0.022	0.033	0.255	0.045 ***	0.061	0.059
Male						
Race/Ethnicity						
White						
African American	-0.250	0.049 ***	0.224	0.066 ***	0.104	0.079
Other	-0.221	0.074 **	0.397	0.089 ***	0.189	0.108
Psychiatric Comorbidity						
Yes	0.236	0.039 ***	0.199	0.053 ***	0.071	0.062
No						
Developmental Disability Diagnoses ¹	0.395	0.034 ***	0.613	0.036 ***	-0.056	0.044

Table 11 (continued)

	DDD Waiver		ER		Inpatient/ER	
	Beta	SE	Beta	SE	Beta	SE
ENABLING						
Medicate						
Yes	0.109	0.036 **	-0.249	0.049 ***	-0.070	0.070
No						
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	0.090	0.046 *	0.743	0.061 ***	0.199	0.069 **
No						
Year of Observation						
July 1995 – June 1996						
July 1996 – June 1997	-0.528	0.081 ***	-0.297	0.113 **	-0.318	0.159 *
July 1997 – June 1998	-0.132	0.096	-0.264	0.130 *	0.056	0.150

¹Classified as a need factor in relation to developmental disabilities waiver

Significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Predictors of Health Service Use and Expenditures by Type of Service for Adult Medicaid Beneficiaries with Developmental Disabilities and Epilepsy

Health Services Use by Type of Service: Logistic Regression

Table 12 presents the results of a logistic regression modeling the epilepsy group's service use by type of service. Results for medications and other services are not shown due to insufficient cell size for the regression analysis. (The analyses in Tables 12 and 13 differ from those presented in Tables 18 and 19 in that Tables 12 and 13 include all service use, whereas Tables 18 and 19 include only epilepsy-related service use, and pattern of epilepsy-related physician care was added to the model as an enabling factor.) Adults ages 40-54 were more likely to have a hospital admission and to receive developmental disabilities waiver services than younger adults. Individuals aged 55-64 were more than twice as likely to have a hospital admission and more than four times as likely to have an outpatient visit as those ages 21-39. Those of other race/ethnicity were more likely to have an inpatient admission compared to whites. The presence of one or more developmental disability diagnoses other than epilepsy increased the odds of using outpatient care and the developmental disabilities waiver. Those with psychiatric comorbidity were more likely to have a physician visit, receive outpatient care, and to have a hospital event compared to those without psychiatric comorbidity. Dual eligibles were more likely to have a physician encounter and less likely to visit the emergency room or to have any hospital event than those with Medicaid only. Those with physical comorbidity were more likely to have an emergency visit and any hospital event but were less likely to be developmental disabilities waiver participants.

Table 12

Use of Services by Adults with Developmental Disabilities and Epilepsy

	Inpatient		Outpatient		Physicians	
	OR	95% CI	OR	95% CI	OR	95% CI
PREDISPOSING						
Age						
21-39						
40-54	1.60	[1.00,2.57] *	0.99	[0.65,1.51]	1.10	[0.66,1.84]
55-64	2.57	[1.16,5.69] *	4.59	[1.05,2.00] *	0.99	[0.35,2.76]
Gender						
Female	1.19	[0.80,1.76]	0.97	[0.68,1.37]	1.11	[0.75,1.65]
Male						
Race/Ethnicity						
White						
African American	1.21	[0.68,2.15]	0.77	[0.47,1.27]	1.23	[0.68,2.23]
Other	2.03	[1.06,3.90] *	2.04	[0.96,4.35]	1.61	[0.75,3.47]
Developmental Disability Diagnose ¹	0.96	[0.70,1.31]	1.33	[1.00,1.75] *	1.28	[0.94,1.74]
Psychiatric Comorbidity						
Yes	1.97	[1.31,2.95] **	3.30	[2.07,5.24] ***	1.63	[1.03,2.59] *
No						
ENABLING						
Medicare						
Yes	1.15	[0.74,1.77]	0.87	[0.60,1.26]	2.37	[1.53,3.66] ***
No						

Table 12 (continued)

	Inpatient		Outpatient		Physicians	
	OR	95% CI	OR	95% CI	OR	95% CI
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	1.44	[0.91,2.27]	1.61	[0.97,2.65]	1.56	[0.89,2.75]
No						
Health System						
Year of Observation						
July 1995 – June 1996						
July 1996 – June 1997	0.48	[0.10,2.19]	1.50	[0.48,4.70]	0.25	[0.10,0.65]**
July 1997 – June 1998	1.42	[0.60,3.36]	1.22	[0.47,3.18]	0.11	[0.05,0.24] ***

Table 12 (continued)

	DDD Waiver		ER		Inpatient/ER	
	OR	95% CI	OR	95% CI	OR	95% CI
PREDISPOSING						
Age						
21-39						
40-54	1.83	[1.21,2.77] **	1.30	[0.84,2.02]	1.18	[0.80,1.74]
55-64	1.47	[0.65,3.32]	0.70	[0.26,1.87]	1.51	[[0.71,3.19]
Gender						
Female	1.00	[0.72,1.40]	1.03	[0.73,1.45]	1.03	[0.75,1.40]
Male						
Race/Ethnicity						
White						
African American	1.13	[0.69,1.86]	0.82	[0.50,1.35]	0.91	[0.58,1.44]
Other	0.54	[0.29,1.00]	1.25	[0.68,2.29]	1.63	[0.94,2.82]
Developmental Disability Diagnose ¹	5.94	[4.31,8.19] ***	1.02	[0.78,1.33]	1.11	[0.87,1.41]
ENABLING						
Medicate						
Yes	1.34	[0.94,1.91]	0.25	[0.17,0.37] ***	0.47	[0.34,0.66] ***
No						
Psychiatric Comorbidity						
Yes	0.98	[0.68,1.42]	1.41	[0.98,2.02]	1.66	[1.20,2.31] **
No						

Table 12 (continued)

	DDD Waiver		ER		Inpatient/ER	
	OR	95% CI	OR	95% CI	OR	95% CI
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	0.60	[0.39,0.92] *	1.75	[1.16,2.65] **	1.76	[1.20,2.58] **
No						
Health System						
Year of Observation						
July 1995 – June 1996						
July 1996 – June 1997	0.47	[0.17,1.26]	0.26	[0.06,1.17]	0.43	[0.14,1.34]
July 1997 – June 1998	0.40	[0.17,0.93]	2.24	[1.00,5.04]	1.94	[0.92,4.10]

¹Classified as a need factor in relation to developmental disabilities waiver

Significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

User Expenditures by Type of Service: OLS Regression

Ordinary Least Squares regressions were used to isolate subgroup differences in the level of expenditures (in 2000 constant dollars) for each type of service (Table 13). Compared with 21-39 year olds, developmental disabilities waiver expenditures were 40% higher for those in the 40-54 year-old age group and more than 80% higher for those ages 55-64. Females' expenditures for other services were three-fourths higher than males. African Americans' medication expenditures were one-third lower than whites. Those of other race/ethnicity had roughly 40% lower waiver expenditures and their expenditures for other services were approximately half of whites'. Each developmental disability diagnosis other than epilepsy increased expenditures for other services by nearly 75% and reduced expenditures for emergency care by nearly 25%. Psychiatric comorbidity increased expenditures for every category except other services. In particular, expenditures for outpatient care and medications were 75% and 50% higher, respectively, compared with those without psychiatric comorbidity. Dual eligibility was associated with 83% higher inpatient costs, nearly 50% higher outpatient costs, and 22% higher waiver expenditures compared with Medicaid coverage only. Compared to individuals without physical comorbidity, expenditures for individuals with physical comorbidity were 49% higher for outpatient services, 27% higher for medications, and almost 90% higher for other services.

Table 13 (continued)

		OLS Regression on Logged Expenditures							
		Medications		DDD Waiver		Other		ER	
		No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy	No Epilepsy	Epilepsy
ENABLING									
Medicare									
Yes		-0.045	0.086	-0.247	0.113 *	-0.113	0.173	-0.357	0.187
No									
NEED									
Physical Comorbidity									
Any Chronic Disease									
Yes		0.237	0.102 *	0.188	0.134	0.628	0.199 **	-0.085	0.189
No									
Health System									
Year of Observation									
July 1995 – June 1996		-0.153	0.252	0.242	0.370	-0.656	0.546	0.881	0.869
July 1996 – June 1997		0.535	0.215 *	0.291	0.276	-0.719	0.408	0.304	0.359
July 1997 – June 1998									

¹Classified as a need factor in relation to developmental disabilities waiver

Significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Characteristics of Patients with Highest 10% of Expenditures

The characteristics of individuals with the highest 10% of expenditures were analyzed, as shown in Table 14. The bivariate analysis showed that a higher proportion (12.6%) of those with epilepsy were in the high-cost group, compared to 9.8% of those without epilepsy. However, there was no significant difference between those with epilepsy and those without epilepsy, however, for several subgroups, including: adults ages 40-64; men; African Americans and those of other race/ethnicity; each of the developmental disability diagnosis categories (no developmental disability diagnosis, one diagnosis, two or three diagnoses), dual eligibles; those without chronic disease; those without psychiatric comorbidity; Medicaid waiver participants; and those without substance abuse.

Table 14 also presents odds ratios from a logistic regression on high expenditures. The difference between those with epilepsy and those without epilepsy did not remain significant in a logistic regression controlling for age, gender, race/ethnicity, developmental disability diagnosis, psychiatric comorbidity, Medicare eligibility, and physical comorbidity. The logistic regression revealed significant differences in the odds of being in the high expenditure group by age, race/ethnicity, developmental disability diagnosis, psychiatric comorbidity, and physical comorbidity. Adults age 40 and older were more likely to have high expenditures than younger adults ages 21-39. The odds of being in the high-cost group increased nearly three times for each additional developmental disability diagnosis other than epilepsy compared to those without a developmental disability diagnosis. Those with physical or psychiatric comorbidity also were more likely to have high expenditures compared with those without physical or

psychiatric comorbidity. Those of other race/ethnicity were less likely to be in the high-cost category than whites, but there was no significant difference between African Americans and whites.

Table 14

High Annual Expenditures by Epilepsy Status

	No Epilepsy		Epilepsy		Logistic Regression on High Expenditures	
	N	%	N	%	OR	95% CI
ALL	835	9.8	97	12.6		
Epilepsy						
Yes					1.16	(0.92-1.46)
No						
PREDISPOSING						
Age						
21-39	461	8.2	60	11.3*		
40-54	309	13.0	31	15.3	1.58	(1.35-1.87) ***
55-64	65	12.9	6	17.1	1.63	(1.23-2.16) ***
Gender						
Female	392	10.0	56	15.9 ***	1.07	(0.93-1.24)
Male	443	9.6	41	9.9		
Race/Ethnicity						
White	706	10.5	80	13.3 *		
African American	96	8.1	12	11.7	0.81	(0.65-1.01)
Other	33	5.1	5	8.1	0.58	(0.41-0.81) **

Table 14 (continued)

	No Epilepsy		Epilepsy		Logistic Regression on High Expenditure	
	N	%	N	%	OR	95% CI
Developmental Disability Diagnoses					2.88	(2.57-3.22) ***
None	23	0.9	4	2.4		
One	563	11.9	65	14.1		
Two or Three	249	20.2	28	20.3		
Psychiatric comorbidity						
Yes	248	13.1	43	17.9 *	1.41	(1.20-1.64) ***
No	586	8.8	54	10.2		
Substance Abuse						
Yes	8	7.1	2	15.4		
No	827	9.8	95	12.6 *		Not Included
ENABLING						
DDD Waiver						
Yes	797	16.8	90	19.5		Not Included
No	38	1.0	7	2.3 *		
Medicare						
Yes	474	11.3	46	11.2	0.92	(0.78-1.07)
No	361	8.3	51	14.3 ***		

Table 14 (continued)

	No Epilepsy		Epilepsy		Logistic Regression on High Expenditure	
	N	%	N	%	OR	95% CI
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	170	13.2	31	20.4 *	1.31	(1.1-1.56) **
No	665	9.2	66	10.7		
Health System						
year of Observation						
July 1995 – June 1996	809	10.5	92	12.9		
July 1996 – June 1997	10	2.1	1	4.8	0.23	(0.12-0.42) ***
July 1997 – June 1998	16	4.4	4	12.5 *	0.44	(0.28-0.71) ***

Significant differences based on Chi-squared statistics and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, AND *** = $p \leq .001$.

Adults with Developmental Disabilities and Epilepsy: Anticonvulsant Medication Use, and Epilepsy-Related Specialist Use**Anticonvulsant Medication Use by Adults with Developmental Disabilities and Epilepsy**

Table 15 presents anticonvulsant medication use by adults with developmental disabilities and epilepsy. Eighty-nine percent of the 768 individuals in the study population had claims for anticonvulsants during the two-year follow-up period. There were no significant differences in anticonvulsant use between the subgroups of those with epilepsy. The lowest percentage of anticonvulsant medication use was 87.9% among individuals with Medicaid only, and the highest proportion was 100% by the thirteen individuals with substance abuse claims.

Table 15

Anticonvulsant Medication Use by Adults with Developmental Disabilities and Epilepsy

	N	%	Chi-Square	P-Value
ALL	687	89.5		
PREDISPOSING				
Age			0.61	0.7386
21-39	477	89.8		
40-54	178	88.1		
55-64	32	91.4		
Gender			0.83	0.3609
Female	311	88.4		
Male	376	90.4		
Race/Ethnicity			1.80	0.4066
White	535	88.7		
African American	94	91.3		
Other	58	93.5		
Developmental Disability Diagnoses			1.25	0.5360
None	149	88.2		
One	417	90.5		
Two or Three	121	87.7		
Psychiatric Comorbidity			0.70	0.4012
Yes	218	90.8		
No	469	88.8		
Substance Abuse			1.56	0.2118
Yes	13	100.00		
No	674	89.3		
ENABLING				
DDD Waiver			0.15	0.6974
Yes	414	89.8		
No	273	88.9		
Medicare			1.65	0.1989
Yes	374	90.8		
No	313	87.9		
NEED				
Physical Comorbidity			0.36	0.5492
Any Chronic Disease				
Yes	138	90.8		
No	549	89.1		
Health System				
Year of Observation			1.82	0.4017
July 1995 – June 1996	642	89.8		
July 1996 – June 1997	17	81.0		
July 1997 – June 1998	28	87.5		

Epilepsy-Related Specialist Visits by Adults with Developmental Disabilities: Bivariate Comparisons

Table 16 identifies the use of a specialist versus no specialist visit among adults with developmental disabilities and epilepsy. Of the 768 patients with epilepsy in the study population, 411 (48%) had an epilepsy-related physician contact during the 24-month follow-up period. Statistically significant group differences between those with a specialist visit and those who had not seen a specialist were observed in regard to gender, race/ethnicity and Medicare eligibility. More than two-thirds of women saw a specialist for epilepsy, while a little more than half of men saw a specialist. Similarly, about two-thirds of dual eligibles had a specialist visit, compared to about half of those with Medicaid only. Forty-four percent of African Americans and half of those of other race/ethnicity had specialist visits, compared to nearly two-thirds of whites ($p \leq .01$).

Epilepsy-Related Specialist Visits by Adults with Developmental Disabilities: Logistic Regression

To test the hypothesis that among adult Medicaid beneficiaries with developmental disabilities and epilepsy, African Americans and those of other race/ethnicity are less likely to have an epilepsy-related specialist visit than whites, a logistic regression procedure was performed (Table 16). Controlling for age, gender, developmental disability diagnoses, psychiatric comorbidity, Medicare eligibility, and physical comorbidity, African Americans were significantly less likely to see a specialist than whites (OR = 0.45, 95% CI = 0.24-0.84). The difference between other race/ethnicity and whites was not significant.

Table 16

Epilepsy-Related Specialist Visit among Adults with Developmental Disabilities

	No Specialist Visit		Specialist Visit		Logistic Regression on on Specialist Visit	
	N	%	N	%	AOR	95% CI
ALL	162	39.4	249	60.6		
PREDISPOSING						
Age						
21-39	118	42.3	161	57.7		
40-54	38	33.3	76	66.7	1.08	(0.65-180)
55-64	6	33.3	12	66.7	0.92	(0.32-2.63)
Gender						
Female	58	32.4	121	67.6	1.70 *	(1.11-2.59)
Male	104	44.8	128	55.2		
Race/Ethnicity **						
White	116	35.7	209	64.3		
African American	28	56.0	22	44.0	0.45 *	(0.24-0.84)
Other	14	50.0	18	50.0	0.63	(0.30-1.30)
Developmental Disability Diagnoses						
None	31	34.8	58	65.2	Not Included	
One	95	38.5	152	61.5		
Two or Three	36	48.0	39	52.0		

Table 16 (continued)

	No Specialist Visit		Specialist Visit		Logistic Regression on on Specialist Visit	
	N	%	N	%	AOR	95% CI
Psychiatric Comorbidity						
Yes	42	34.4	80	65.6	1.32	(0.83-2.09)
No	120	41.5	54	58.5		
Substance Abuse						
Yes	3	37.5	5	62.5	Not Included	
No	159	39.5	244	60.5		
Health System ENABLING DDD Waiver						
Yes	110	41.7	154	58.3	Not Included	
No	52	35.4	95	64.6		
Medicare **						
Yes	81	33.9	158	66.1	1.60 *	(1.03-2.48)
No	81	47.1	91	52.9		
NEED Physical Comorbidity Any Chronic Disease						
Yes	28	33.7	55	66.3	1.31	(0.77-2.22)
No	134	40.9	194	59.1		

Table 16 (continued)

	No Specialist Visit		Specialist Visit		Logistic Regression on on Specialist Visit	
	N	%	N	%	OR	95% CI
Year of Observation						
July 1995 – June 1996	149	38.5	238	61.5		
July 1996 – June 1997	6	75.0	2	25.0	0.19 *	(0.04-0.96)
July 1997 – June 1998	7	43.8	9	56.3	0.72	(0.26-2.03)

Significant group differences based on Chi-square statistics and significant differences relative to reference group denoted as * = $p \leq .05$, ** $p \leq .01$, and *** = $p \leq .001$.

The multivariate analysis also substantiated the bivariate results that women and dual eligibles were more likely to see a specialist than men and those with Medicaid only, after controlling for other characteristics.

Patterns of Epilepsy-Related Physician Care – Bivariate Comparisons

Patterns of care for epilepsy are presented in Table 17. Physician encounters with an epilepsy diagnosis code were grouped into three categories: 1) any specialist visit; 2) generalist only; and 3) other (outpatient and other clinics). Table 17 presents descriptive and bivariate statistics for epilepsy-related pattern of care. Sixty-one percent of the 411 patients with epilepsy-related physician visits during the follow-up period saw a specialist; 25.06% saw only generalists, and 14.36% received their care at outpatient clinics. Females had lower percentages that visited generalist physicians and clinics than males. The proportion of African Americans receiving care at clinics was twice as high for African Americans compared to the 12.6% for whites, and 16.7% of those in the other race/ethnicity group received care at outpatient clinics. Smaller percentages of those with dual eligibility visited generalists and clinics compared to those with Medicaid coverage only.

Table 17

Patterns of Epilepsy-Related Physician Care among Adults with Developmental Disabilities

	Specialist		Generalist Only		Other	
	N	%	N	%	N	%
ALL	249	60.6	103	25.1	59	14.4
PREDISPOSING						
Age						
21-39	161	57.7	69	24.7	49	17.6
40-54	76	66.7	30	26.3	8	7.0
55-64	12	66.7	4	22.2	2	11.1
Gender *						
Female	121	67.6	38	21.2	20	11.2
Male	128	55.2	65	28.0	39	16.8
Race/Ethnicity *						
White	209	64.3	75	23.1	41	12.6
African American	22	44.0	16	32.0	12	24.0
Other	18	50.0	12	33.3	6	16.7
Developmental Disability Diagnoses						
None	58	65.2	20	22.5	11	12.4
One	152	61.5	65	26.3	30	12.1
Two or Three	39	52.0	18	24.0	18	24.0
Psychiatric Comorbidity						
Yes	80	65.6	26	21.3	16	13.1
No	169	58.5	77	26.6	43	14.9

Table 17 (continued)

	Specialist		Generalist Only		Other	
	N	%	N	%	N	%
Substance Abuse						
Yes	5	62.5	2	25.0	1	12.5
No	244	60.5	101	25.1	58	14.4
ENABLING						
DDD Wavier						
Yes	154	58.3	70	26.5	40	15.2
No	95	64.6	33	22.4	19	12.9
Medicate*						
Yes	158	66.1	54	22.6	27	11.3
No	91	52.9	49	28.5	32	18.6
NEED						
Physical Comorbidity						
Any Chronic Disease						
Yes	55	66.3	21	25.3	7	8.4
No	194	59.1	82	25.0	52	15.9
Health System						
Year of Observation ***						
July 1995 – June 1996	238	61.5	101	26.1	48	12.4
July 1996 – June 1997	2	25.0	1	12.5	5	62.5
July 1997 – June 1998	9	56.3	1	6.3	6	37.5

Significant differences based on *t*-statistic and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Epilepsy-Related Health Service Use

Measures of health service utilization by adults with epilepsy included use of inpatient services and the emergency room. These analyses were conducted with the 411 patients with epilepsy-related physician visits. They differ from those presented in Tables 12 and 13 with the addition of pattern of epilepsy-related physician care to the model and using only epilepsy-related care in the analyses of health service use.

Epilepsy-Related Inpatient Hospital Admission of Adults with Developmental Disabilities and Epilepsy: Bivariate Comparisons

Table 18 presents inpatient use by predisposing, enabling, and need characteristics of adults with developmental disabilities and epilepsy. A fifth of the 411 patients with an identified pattern of epilepsy-related care had an epilepsy-related hospital admission. Significant bivariate differences were found in regard to age, psychiatric comorbidity and substance abuse. Nearly half of older adults ages 55-64, a quarter of those ages 40-54, and a sixth of young adults ages 21-39 had an inpatient admission. More than a quarter of those with a psychiatric diagnosis had a hospital admission, compared to only one-sixth of those without a psychiatric diagnosis. Three-quarters of those with substance abuse were hospitalized, while less than one-fifth of those without a substance abuse diagnosis had an inpatient admission.

Epilepsy-Related Inpatient Hospital Admission of Adults with Developmental Disabilities: Logistic Regression

A logistic regression procedure was performed to test the hypothesis that minority adult Medicaid beneficiaries with developmental disabilities and epilepsy are more likely

to have a hospital admission for an epilepsy diagnosis than whites (Table 18). After controlling for other characteristics, no significant difference was found between African Americans or those of other race/ethnicity compared to whites. A logistic regression modeling inpatient admissions also was conducted to test the hypothesis that adult Medicaid beneficiaries with developmental disabilities and epilepsy who receive specialist care are less likely to have an epilepsy-related inpatient hospital admission than those who receive generalist only or other care. No significant differences were found between patients with different patterns of care.

Age and psychiatric comorbidity remained significant in the logistic regression analysis. Adults 40-54 were more likely and those ages 55-64 were much more likely to have an inpatient admission. Those with psychiatric comorbidity also were more likely to have an admission, even after excluding psychiatric admission.

Table 18

Epilepsy-Related Inpatient Admission Among Adults with Developmental Disabilities

	N	%	Logistic Regression on Inpatient Admission	
			OR	95% CI
ALL	82	20.0		
PREDISPOSING				
Age **				
21-39	46	16.5		
40-54	28	24.6	1.84 *	(0.01- 3.32)
55-64	8	44.4	3.74 *	(1.30-10.72)
Gender				
Female	42	23.5	1.28	(0.77- 2.14)
Male	40	17.2		
Race/Ethnicity				
White	62	19.1		
African American	10	20.0	1.38	(0.63- 3.04)
Other	10	27.8	2.07	(0.89- 4.83)
Developmental Disability Diagnoses				
None	15	16.9	0.95	(0.63- 1.43)
One	53	21.5		
Two or Three	14	18.7		

Table 18 (continued)

	N	%	Logistic Regression on Inpatient Admission	
			OR	95% CI
Mental Comorbidity **				
Yes	34	27.9	2.01 *	(1.18- 3.41)
No	48	16.6		
Substance Abuse ***				
Yes	6	75.0	Not Included	
No	76	18.9		
ENABLING				
DDD Waiver				
Yes	46	17.4	Not Included	
No	36	24.5		
Medicare				
Yes	51	21.3	1.03	(0.59- 1.78)
No	31	18.0		
Patterns of Care				
Any Specialist	56	22.5		
Only Generalist	16	15.5	0.66	(0.35- 1.24)
Outpatient Only	10	16.9	0.80	(0.35- 1.79)

Table 18 (continued)

	N	%	Logistic Regression on Inpatient Admission	
			OR	95% CI
NEED				
Physical Comorbidity				
Any Chronic Disease				
Yes	20	24.1	1.16	(0.63- 2.13)
No	62	18.9		
Health System				
Year of Observation				
July 1995 – June 1996	76	19.6		
July 1996 – June 1997	2	25.0	1.75	(0.32- 9.63)
July 1997 – June 1998	4	25.0	1.21	(0.35- 4.15)

Significant differences based on Chi-squared statistics and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Epilepsy-Related Emergency Room Visit: Bivariate Comparisons

Table 19 compares epilepsy-related emergency room use by various characteristics of the study population. More than a third of individuals with epilepsy-related physician encounters had an epilepsy-related emergency room visit. The proportion of individuals with dual Medicare and Medicaid eligibility who had an epilepsy-related emergency room visit was less than half of the proportion of those with Medicaid only who visited the emergency room.

Epilepsy-Related Emergency Room Visit: Logistic Regression

To test the hypothesis that adult Medicaid beneficiaries with developmental disabilities and epilepsy who receive specialist care will be less likely to have an epilepsy-related emergency room visit than those who receive generalist only or other care, a logistic regression procedure was performed. As shown Table 19, pattern of care was not significant in the multivariate analysis. The difference between dual Medicare and Medicaid eligibles and those with Medicaid only remained significant – controlling for other characteristics, the odds of dual eligibles having an epilepsy-related emergency room visit were just 22% of those with Medicaid only.

Table 19

Epilepsy-Related Emergency Room Visit among Adults with Developmental Disabilities

	N	%	Logistic Regression on ER Visit	
			AOR	95% CI
ALL	139	33.8		
PREDISPOSING				
Age				
21-39	99	35.5		
40-54	35	30.7	1.15	(0.67- 1.99)
55-64	5	27.8	0.75	(0.23- 2.41)
Gender				
Female	67	37.4	1.40	(0.89- 2.20)
Male	72	31.0		
Race/Ethnicity				
White	109	33.5		
African American	18	36.0	0.91	(0.46- 1.79)
Other	12	33.3	0.81	(0.36- 1.79)
Developmental Disability Diagnoses				
None	25	28.1	1.07	(0.75- 1.54)
One	91	36.8		
Two or Three	23	30.7		

Table 19 (continued)

	N	%	Logistic Regression on ER Visit	
			AOR	95% CI
Psychiatric Comorbidity				
Yes	47	38.5	1.31	(0.80- 2.14)
No	92	31.8		
Substance Abuse				
Yes	3	37.5	Not Included	
No	136	33.7		
ENABLING				
DDD Waiver				
Yes	88	33.3	Not Included	
No	51	34.7		
Medicare***				
Yes	52	21.8	0.22 ***	(0.14- 0.36)
No	87	50.6		
Patterns of Care				
Any Specialist	89	35.7		
Only Generalist	31	30.1	0.70	(0.41- 1.20)
Outpatient Only	19	32.2	0.72	(0.36- 1.44)

Table 19 (continued)

	N	%	Logistic Regression on ER Visit	
			OR	95% CI
NEED				
Physical Comorbidity				
Any Chronic Disease				
Yes	34	41.0	1.39	(0.80- 2.40)
No	105	32.0		
Health System				
Year of Observation				
July 1995 – June 1996	130	33.6		
July 1996 – June 1997	0		0.00	0.00
July 1997 – June 1998	9	56.3	3.58 *	(1.13-11.36)

Significant differences based on Chi-squared statistics and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Annual Expenditures for Adults with Developmental Disabilities and Epilepsy:

Bivariate Comparisons

Table 20 presents mean annual Medicaid expenditures (in 2000 constant dollars) for 411 adults with developmental disabilities and epilepsy who had an epilepsy-related physician contact. Age, gender, race/ethnicity, number of developmental disability diagnoses, psychiatric comorbidity, and physical comorbidity showed significant differences in the bivariate analysis. Mean expenditures were higher for adults ages 40-54 and ages 55-64 compared to younger adults ages 21-39. Females had higher expenditures than males, and individuals with one or more developmental disability diagnoses had higher expenditures than those with no developmental disability diagnoses. Individuals with psychiatric comorbidity and waiver participants had higher expenditures than those without psychiatric comorbidity and non-participants in waiver services, respectively. Individuals with physical comorbidity had higher expenditures than those without physical comorbidity. The other race/ethnicity group had lower expenditures than whites. African Americans also had lower mean expenditures than whites, but the difference was not significant.

Annual Expenditures for Adults with Developmental Disabilities and Epilepsy: OLS Regression

Ordinary Least Squares regressions were used to isolate subgroup differences in level of expenditures (Table 20). The analysis tested the hypothesis that 1) those age 40 and older have higher expenditures than those ages 21-39, 2) there is no difference in expenditures between women and men, 3) those with developmental disability diagnoses other than epilepsy have higher expenditures than those without developmental disability

diagnoses, and 4) those who receive epilepsy-related specialist care than those with other patterns of care. Multivariate analysis substantiated the bivariate results that age, race/ethnicity, co-occurring developmental disability diagnosis, and psychiatric comorbidity were significant factors, after controlling for other characteristics. Those in the 40-54 age group had 44% higher expenditures and those ages 55-64 had 86% higher expenditures than younger adults. Other race/ethnicity was associated with a mean expenditure only half that of whites. Spending rose 103% for each additional developmental disability diagnosis other than epilepsy and psychiatric comorbidity increased annual expenditures by 53%.

Table 20

Annual Total Expenditures among Adults with Developmental Disabilities and Epilepsy

	Mean	OLS Regression on Logged Expenditures	
		Beta	SE
PREDISPOSING			
Age			
21-39			
40-54	9,242 **	0.366 *	0.149
55-64	16,522 *	0.624 *	0.311
Gender			
Female	6,664 *	0.187	0.126
Male			
Race/Ethnicity			
White			
African American	-4,863	-0.244	0.193
Other	-12,767 *	-0.518 *	0.224
Developmental Disability Diagnoses			
None	18,621 ***	1.028 ***	0.100
One			
Two or Three			
Mental Comorbidity			
Yes	12,715 ***	0.427 **	0.138
No			
Substance Abuse			
Yes	-11,301	Not Included	
No			
ENABLING			
DDD Waiver			
Yes	35,130 ***	Not Included	
No			

Table 20 (continued)

	Mean	OLS Regression on Logged Expenditures	
		Beta	SE
Medicare			
Yes	635	-0.242	0.133
No			
Patterns of Care			
Any Specialist			
Only Generalist	-2,434	-0.206	0.149
Other	945	0.151	0.192
NEED			
Physical Comorbidity			
Any Chronic Disease			
Yes	7,261 *	-0.003	0.156
No			
Health System			
Year of Observation			
July 1995 – June 1996			
July 1996 – June 1997	-5,987	-0.323	0.455
July 1997 – June 1998	16,952 *	-0.184	0.326

Significant differences based on *t*-statistic and significant differences relative to reference group denoted as * = $p \leq .05$, ** = $p \leq .01$, and *** = $p \leq .001$.

Summary of Chapter IV

This chapter presented the results of analyses of characteristics associated with epilepsy, health service use, and expenditures by adult Medicaid beneficiaries with developmental disabilities and epilepsy. Adult Medicaid beneficiaries with developmental disabilities and epilepsy were more likely to have one or more developmental disability diagnoses and mental illness than those without epilepsy. They were also more likely to have Medicare as well as Medicaid coverage and physical comorbidity.

Bivariate analyses showed a higher proportion of those with epilepsy were users of inpatient and emergency room services than those without epilepsy. Length of stay, however, was longer for those who did not have epilepsy. Multivariate results generally substantiated the bivariate results. The epilepsy group had higher mean expenditures than those without epilepsy, and a higher proportion of those with epilepsy had expenditures in the top ten percent. Those with epilepsy were more likely than their counterparts without epilepsy to use all services except the developmental disabilities waiver, and among service users they were more costly in regard to physician services, medications, the developmental disabilities waiver, and other services. Among those with epilepsy, nine out of ten had anticonvulsant drug claims, and there were no significant differences in anticonvulsant use between the subgroups. The only significant group difference in epilepsy-related emergency room visits was between the dually eligible group and those with Medicaid only – a lower percentage of those with Medicare and Medicaid coverage had an emergency room visit.

Multivariate analyses substantiated bivariate results that gender, race/ethnicity, and dual eligibility were associated with epilepsy-related specialist use. Women and dual eligibles had greater odds of seeing a specialist for epilepsy compared to men and those with Medicaid only, and African Americans were less likely than whites to have a specialist visit. Older adults and those with psychiatric comorbidity had higher odds of an inpatient admission, compared to adults ages 21-39 and those without psychiatric comorbidity. The odds of an epilepsy-related emergency room visit by dual eligibles were only one-fifth those of individuals with Medicaid only. Adults ages 40 and older, those with developmental disability diagnoses, and those with psychiatric comorbidity had higher expenditures than adults ages 21-39, those without developmental disability diagnoses other than epilepsy, and those without psychiatric diagnoses. Those of other race/ethnicity had lower expenditures than whites.

CHAPTER V

DISCUSSION

This chapter presents a review of the research questions and major findings, compares the results with prior research, describes the findings within the framework of the adapted Behavioral Model for Vulnerable Populations, and identifies the study's limitations. It also discusses implications for policy and practice as well as future research. The study identified characteristics associated with epilepsy, compared the health service use and expenditures of adult Medicaid beneficiaries with developmental disabilities and epilepsy and those without epilepsy, and identified other predictors of utilization and expenditures. Using an adapted Behavioral Model for Vulnerable Populations as a conceptual framework, the study analyzed Medicaid eligibility and claims data for a statewide population of individuals between 21 and 64 years of age, enrolled with the New Jersey Division of Developmental Disabilities and living in community settings.

Research Questions and Summary of Findings

This study addressed the following questions regarding adult Medicaid beneficiaries with developmental disabilities and epilepsy:

1. What are the predisposing (age, gender, race/ethnicity, number of developmental disability diagnoses, psychiatric comorbidity, substance abuse), enabling (Medicare and Medicaid, Medicaid only), and need (physical comorbidity) characteristics associated with this dual diagnosis?

Adult Medicaid beneficiaries with developmental disabilities and epilepsy were more likely than those without epilepsy to have one or more developmental disability

diagnoses other than epilepsy and psychiatric comorbidity (predisposing characteristics). They were also more likely to have Medicare as well as Medicaid coverage (enabling characteristic) and physical comorbidity (need characteristic). While those with epilepsy had better insurance coverage than those without epilepsy, the prevalence of multiple disabling conditions makes those with both conditions an especially vulnerable subgroup of adults with developmental disabilities.

2. In relation to having versus not having epilepsy, is there a difference in inpatient hospital admissions, length of stay, emergency room use, and expenditures among beneficiaries with developmental disabilities?

Adults with developmental disabilities and epilepsy were more likely than those without epilepsy to have at least one inpatient admission. Contrary to expectations, however, individuals with epilepsy had a shorter length of stay than those with developmental disabilities but no epilepsy. Those with epilepsy had greater odds of an emergency room visit and higher annual expenditures than those without epilepsy. The developmental disabilities home and community based services waiver was the single largest component of annual expenditures, representing 77% of spending for those without epilepsy and 74% of expenditures for those with epilepsy. Other services (including home health care, medical transportation, and durable medical equipment), medications, outpatient services other than physician care, and inpatient care were the largest spending categories after the developmental disabilities waiver for both groups.

Those with epilepsy were more likely than their counterparts without epilepsy to use all services except the developmental disabilities waiver, and among service users they were more costly in regard to physician services, medications, the developmental

disabilities waiver, and other services. Medication expenditures for those with epilepsy were two-thirds higher than those without epilepsy. Epilepsy followed the number of developmental disabilities diagnoses and psychiatric comorbidity as the strongest predictors of annual expenditures.

Although individuals with epilepsy had higher average expenditures than those without epilepsy, epilepsy did not increase the odds of being in the highest expenditure group. The odds of high expenditures were greater for adults 40 and older compared to younger adults ages 21-39, those with one or more developmental disability diagnoses compared to those without a developmental disability diagnosis, individuals with psychiatric comorbidity compared to those without psychiatric comorbidity, and individuals with physical comorbidity, compared to those without physical comorbidity. Those of other race/ethnicity were less likely to be in the high expenditure group compared with whites. This reflects their lower odds of using developmental disabilities waiver services. African Americans' odds of receiving developmental disabilities waiver services did not differ from whites', but African American waiver participants had lower waiver expenditures.

3. What is the profile of anticonvulsant medication use among adult Medicaid beneficiaries with developmental disabilities and epilepsy?

Anticonvulsant use by adults with developmental disabilities and epilepsy was approximately 90%, without significant differences in the proportion of medication users between subgroups.

4. What are patterns of epilepsy-related generalist and specialist physician care for adult Medicaid beneficiaries with developmental disabilities and epilepsy? Do patterns differ by the aforementioned predisposing, enabling, and need characteristics?

Three out of five (61%) of adults with developmental disabilities and epilepsy had one or more epilepsy-related visits to a specialist, one in four saw only generalists, and fewer than one in seven (14 %) received care at hospital-based outpatient or other clinics. Patterns of physician care varied by gender, race/ethnicity, and insurance. A higher proportion of women, whites, and dual eligibles saw a specialist for epilepsy, compared to men, African Americans and those of other race/ethnicity, and those with Medicaid coverage only.

5. What is the association of predisposing, enabling, and need characteristics with inpatient hospital admissions, emergency room use, and expenditures?

There were no factors associated with both inpatient hospital stays and emergency room visits with an epilepsy-related diagnosis. Adults age 40 and older and individuals with psychiatric comorbidity were more likely to have a hospital admission than adults ages 21-39. Individuals without psychiatric comorbidity and dual eligibles were less likely than to have an emergency room visit compared to those with psychiatric comorbidity and those with Medicaid only. Older adults age 40 and above and those with psychiatric comorbidity as well as individuals with developmental disability diagnoses had higher annual expenditures, compared with adults ages 21-39, those with no psychiatric comorbidity, and those with no developmental disability diagnoses, respectively. Annual expenditures for those of other race/ethnicity were approximately

half of mean expenditures for whites. Pattern of care was not significantly associated with epilepsy-related hospital admissions, emergency room use, or total expenditures.

The level of service use and Medicaid expenditures by adults with developmental disabilities in the present study reveals that they use substantially less acute medical care resources than other adult Medicaid beneficiaries with disabilities. Excluding long-term care costs, FY 2000 payments per eligible adult equaled \$5,875 for individuals with developmental disabilities compared to \$8,298 for all adult Medicaid beneficiaries with disabilities (CMS, 2005). Mean payments per eligible adult with developmental disabilities were lower than all adult beneficiaries with disabilities for medications as well as inpatient, emergency, physician, and other services. This finding supports the results of an analysis of health care access and use among adult Medicaid beneficiaries in New York (Long, Coughlin, & Kendall, 2002). Adults with developmental disabilities were in better health and used less inpatient and emergency care than Medicaid beneficiaries with physical disabilities and those with mental illness. The finding also supports the premise that developmental disability does not equal disease, and that health plans should not assume that all patients with developmental disabilities will be high consumers of medical care.

Comparison of Findings with Prior Research

1. Among adult Medicaid beneficiaries with developmental disabilities between the ages of 21 and 64, 8.3% had an epilepsy diagnosis. Adults ages 21-39, those with psychiatric comorbidity, dual eligibles, and those with physical

comorbidity were more likely to have an epilepsy diagnosis, compared to those age 40 and older, those with no psychiatric diagnoses, and those with no physical comorbidity. While the number of developmental disabilities diagnoses was not included in the multivariate analyses for methodological reasons, the proportion of those with epilepsy rose with the number of developmental disability diagnoses.

The 8.3% prevalence rate is much lower than previous studies of adults with developmental disabilities in community settings. Earlier estimates have ranged from 16.1% (Morgan, Baxter, & Kerr, 2003) to 27% (McGrother, Bhaumik, Thorp, Hauck, Branford, & Watson, 2006). The discrepancy may result from a difference in study populations. Morgan et al. (2003) included only adults with intellectual disabilities in their research, while McDermott et al. (2005) analyzed epilepsy prevalence in a sample of patients with a range of disabilities at two university-affiliated primary care practices.

The declining frequency of epilepsy with age contrasts with some previous research, but earlier studies' results are inconsistent. In a population-based study of adults with intellectual disabilities in Leicester, U.K., epilepsy was highest among young adults between 20 and 39 years, declined between 40 and 49 years, rose between ages 50 and 69, and then dropped sharply in adults age 70 and older (McGrother, Bhaumik, Thorp, Hauck, Branford, & Watson, 2006). Among adults with developmental disabilities at primary care centers in South Carolina, a slightly higher proportion of adults with developmental disabilities in the 40-49 year old age group had epilepsy compared to younger adults ages 20-39 (McDermott, Moran, Platt, Wood, Isaac, & Dasari, 2005).

Epilepsy prevalence, however, increased steadily with age in those with Down syndrome and rose in 50-59 year-olds among those with autism. Previous studies also had found an association between age and epilepsy in individuals with Down syndrome (Bowley & Kerr, 2000; Johannsen, Christensen, Goldstein, Nielsen, & Mai, 1996; Menendez, 2004).

The relationship between multiple developmental disabilities and epilepsy in this study is supported in the literature (Devinsky, 2002; McDermott et al., 2005; McGrother et al., 2006). Prior research on the association between epilepsy and psychiatric comorbidity in those with developmental disabilities, however, is inconclusive. In a review of the literature on epilepsy and intellectual disability, Bowley & Kerr (2000) concluded that there is insufficient evidence to support the hypothesis that psychiatric disorders are more common among those with epilepsy, but McGrother and colleagues (2006) found an association between epilepsy and psychological symptoms, notably mood swings. Results of this study support McGrother et al.'s (2006) finding of an association between epilepsy and psychiatric comorbidity among adults with developmental disabilities.

The rate of substance abuse identified in this analysis of claims data for a statewide population of adults with developmental disabilities was only 1.4%. This is below earlier estimates of drug abuse among people with developmental disabilities (Minihan, 2005), and dramatically below the rate of substance abuse among a subset of the developmental disability population with mental retardation and HIV/AIDS in New Jersey's Medicaid program (Walkup, Sambamoorthi, & Crystal, 1999). Substance abuse may be less prevalent among adults with developmental disabilities than other groups

with disabilities, but the low rate of substance abuse treatment in the present study suggests that substance abuse is under-recognized and under-treated in this population.

2. Adults with developmental disabilities and epilepsy were more likely to have an inpatient hospital admission and more likely to have an emergency room visit than those who did not have epilepsy.

This result is supported by Morgan et al.'s (2003) finding that adults with developmental disabilities and epilepsy in the U.K. were more likely to have an inpatient hospital admission and more likely to have an emergency room visit than those without epilepsy. It is consistent with a U.K. study that found that mental retardation was the second most frequent primary diagnosis for the hospital admissions of non-elderly adults with epilepsy (Currie et al., 1998).

3. Adults with developmental disabilities and epilepsy had higher annual expenditures than those who did not have epilepsy.

Previous literature supports these results; epilepsy has been found to be associated with higher health expenditures in the U.K. general population (Morgan & Kerr, 2004) and with use of resource intensive services such as inpatient hospital care among adults with developmental disabilities and epilepsy in the U.K (Morgan et al., 2003).

4. Adults with developmental disabilities and epilepsy had a shorter length of stay than those without epilepsy.

This surprising result differed from Morgan et al.'s (2003) finding of no significant difference in length of stay between adults with developmental disabilities and epilepsy and those without epilepsy. The discrepancy in length of stay may be due in part to unmeasured differences in severity of comorbid physical or mental conditions.

5. African Americans were more likely to have an inpatient or emergency hospital event and to use other services, compared to whites. Those of other race/ethnicity were more likely than whites to have an inpatient admission and less likely to use developmental disability waiver services.
6. African American and Other race/ethnicity service users had lower waiver expenditures and higher expenditures for other services compared with whites. African Americans also had lower medication expenditures than whites.

The finding of lower waiver spending for African Americans and those of other race/ethnicity is in accord with earlier studies documenting health and social service access issues for minority individuals with developmental disabilities. Weller et al. (2003) found that minority children and adolescents were less likely to use mental health/substance abuse treatment, non-Hispanic black children were less likely to use four out of seven health-related services, and Hispanic children were less likely to use medical

care coordination. Studies of health-related and social service use by adults with developmental disabilities also found race/ethnicity disparities. African Americans were less likely to use occupational therapy and psychological services, more likely to report unmet needs, and had lower expenditures for community services (Pruchno & McMullen, 2004). African Americans' lower medication expenditures may reflect less use of newer and more expensive drugs, similar to the lag time documented in use of newer HIV-AIDS medications (Crystal, Sambamoorthi & Merzel, 1995; Sambamoorthi, Moynihan, McSpiritt, & Crystal, 2001). The pattern of race/ethnicity differences in this study is complex – African Americans were more likely than whites to have an inpatient admission or emergency room visit, but they were also more likely than whites to use outpatient care and other services. While there is insufficient evidence to draw firm conclusions about racial disparities based on these findings, the combination of African Americans' lower expenditures for medication and waiver services and greater likelihood of hospital use require further examination.

7. The number of developmental disability diagnoses other than epilepsy was associated with increased odds of using every type of service except inpatient care. Number of developmental disability diagnoses also was associated with higher expenditures for waiver and other services, and for total annual expenditures.

Findings substantiate earlier research showing an association between multiple developmental disabilities and health service use. Howard's (1990) analysis of total ambulatory health expenditures for adults with developmental disabilities found that a

history of institutionalization, having a mobility impairment, and the number of recommendations for therapeutic services were significant predictors of health expenditures.

8. Adults with developmental disabilities and psychiatric comorbidity were less likely to receive developmental disabilities waiver services than their counterparts without psychiatric comorbidity. They also had higher expenditures than service users with no psychiatric comorbidity for all services except emergency care.

The finding of higher costs associated with services for adults with developmental disabilities and mental illness is consistent with a Taiwan study of individuals with intellectual disabilities and psychiatric disorders (Lin, Yen, Li, & Wu, 2007).

9. Adults with developmental disabilities and physical comorbidity were less likely to receive developmental disabilities waiver services than those with no physical comorbidity.

No published analyses of the waiver participation of individuals with developmental disabilities and physical comorbidity or other characteristics were identified in the literature search. This gap in the literature highlights an area for future research to assess equity in access to developmental disabilities home and community based services.

10. Dual eligibles were more likely to use every service except the emergency room; their odds of using emergency care were only one-third those with Medicaid only. They also had higher waiver and total expenditures compared to those with Medicaid coverage only.

The lower likelihood of an emergency room visit for dual eligibles supports Howard's (1990) finding that adults with developmental disabilities who had both Medicaid and Medicare coverage were less likely to have an emergency room visit than those with Medicaid alone. The finding of higher spending for dual eligibles is consistent with an analysis of Medicaid expenditures for dual eligibles (Lied, 2006). Dual eligibles were 14.7% of the national Medicaid population, but they accounted for 40.5% of expenditures in 2002.

11. Nine out of ten adults with developmental disabilities and epilepsy received anticonvulsant medication during the follow-up period; there were no significant differences between subgroups.

The literature regarding anticonvulsants and individuals with developmental disabilities is limited (Coulter, 2005). The apparently uniformly high use of anticonvulsant medication by adult Medicaid beneficiaries with developmental disabilities and epilepsy in this analysis supports the finding of one study and contrasts with another. All of the adults with developmental disabilities and epilepsy at primary care centers in South Carolina were taking anticonvulsant medication (McDermott et al.,

2005). On the other hand, only 13.2% of individuals with autism in a North Carolina study were taking anticonvulsant medications, while 19.2% were reported to have epilepsy (Aman, Van Bourgondien, Wolford, & Saphare, 1995).

12. Patterns of physician care for epilepsy varied by gender, race/ethnicity, and insurance. The odds of seeing a specialist for epilepsy were greater for women and dual eligibles, compared to men and those with Medicaid only. African Americans with epilepsy were less likely than whites to have an epilepsy-related specialist visit.

Fifty-four percent of the 768 adults with developmental disabilities and epilepsy in this statewide sample of Medicaid beneficiaries had at least one epilepsy-related physician encounter during the two-year follow-up period. This appears to be a low percentage, but it is difficult to evaluate since the claims data do not provide information about seizure frequency or any other indication of active epilepsy. A study in one U.K. health region found that 38% of adults with epilepsy had an epilepsy-related GP encounter (Jacoby, Buck, Baker, McNamee, Graham-Jones, & Chadwick, 1998) in the prior 12 months. The gender difference in specialist use contrasts with a study of Medicaid-enrolled children with chronic health conditions, including epilepsy (Kuhlthau et al., 2001). There was no difference in the odds of seeing a specialist between males and females among the children eligible for Medicaid on the basis of SSI. The greater likelihood of females visiting a specialist in this study of an adult population may be related to issues such as the effects of estrogen on seizure susceptibility (Morrell, Sarto,

Shafer, Borda, Herzog, & Callanan, 2000). Dual eligibles' greater likelihood of visiting a specialist supports the finding of a study of a different population (dual eligibles with HIV-AIDS (Sambamoorthi, Collins, & Crystal, 2001).

The race/ethnicity difference in specialist use in this study is consistent with the limited previous work examining disparities in epilepsy care. Nonwhite children receiving SSI were less likely to have a pediatric subspecialist visit than whites (Kuhlthau et al. 2001). A study of emergency room patients with seizures also found that African Americans had limited access to specialists (Szaflarski, Szaflarski, Privitera, Ficker, & Horner, 2006).

13. Older adults and those with psychiatric comorbidity were more likely to have an epilepsy-related hospital admission than those under age 40 and those with no psychiatric diagnosis.

Previous research concerning hospitalizations among adults with developmental disabilities and epilepsy (Morgan et al., 2003) did not include age or psychiatric variables. Among adult SSI beneficiaries with disabilities in New York City and Westchester County, age was associated with greater odds of hospitalization (Coughlin, Long, & Kendall, 2002). Mental illness, however, was not a significant predictor of hospitalization.

14. Dual eligibles were less likely to have an epilepsy-related emergency room visit than individuals with Medicaid only.

Although Howard (1990) did not analyze a subpopulation of adults with developmental disabilities and epilepsy, she found a lower likelihood of emergency room use for adults with developmental disabilities who had both Medicaid and Medicare coverage compared to those with Medicaid alone.

15. Among those with epilepsy, adults ages 40 and older, those with other developmental disability diagnoses, and those with psychiatric comorbidity had higher annual expenditures than younger adults, those with no developmental disability diagnoses, and those without psychiatric comorbidity.

The association of older age, developmental disability diagnoses, and psychiatric comorbidity with total annual Medicaid expenditures was inconsistent with an earlier study of ambulatory care costs of adults with developmental disabilities. Howard (1990) analyzed ambulatory care expenditures for adult Medicaid beneficiaries with mental retardation, including individuals with epilepsy. Neither age nor developmental disability diagnoses nor psychiatric diagnoses were significant predictors of expenditures. The conflicting findings could be a result of differences in the study populations, differences in determinants of ambulatory expenditures as opposed to total annual expenditures, or both.

16. Among individuals with epilepsy, those of other race/ethnicity had lower expenditures than whites.

This finding reflects lower odds of developmental disabilities waiver participation by those of other race/ethnicity and lower expenditures for waiver participants of Other race/ethnicity compared to whites. It supports Pruchno & McMullen's (2004) results documenting lower community services expenditures for African Americans with developmental disabilities.

Relationship of Findings to the Behavioral Model for Vulnerable Populations

This study represents the first application of an adapted Behavioral Model for Vulnerable populations (Gelberg et al., 2000) to adults with developmental disabilities. A recent review of the literature regarding the health and health care of people with intellectual disabilities noted the potential of the behavioral model for studying health service utilization and needs for people with disabilities (Krahn, Hammond, & Turner, 2006). Most of the previous research applying the traditional Andersen behavioral model (Andersen, 1968; Andersen, 1995) to analyze service utilization by individuals with disabilities or other special health care needs focused on children and adolescents or health-related services such as occupational therapy and assistive devices, rather than acute health care. One U.S. study (Howard, 1990) examined ambulatory and emergency room care by adults with intellectual disabilities, and a national study in Taiwan identified factors associated with hospitalization among children and young adults with intellectual disabilities (Lin, Wu, & Lee, 2004).

Traditional domain variables in the adapted behavioral model associated with having an epilepsy diagnosis in this study included age (predisposing characteristic), dual eligibility (enabling characteristic) and physical comorbidity (need characteristic). The vulnerable domain predisposing factor of psychiatric comorbidity also was associated with epilepsy.

In general, the traditional domain predisposing factors of older age and female gender were associated with greater service use and spending. Non-white race/ethnicity, another predisposing characteristic, was associated with lower use of some service types and lower expenditures, most notably for developmental disabilities waiver services. Dual eligibility, an enabling factor in the traditional domain, predicted greater use of most services and higher total expenditures. The presence of an epilepsy diagnosis, a traditional need factor, predicted greater use of more intensive and costly services as well as annual expenditures. Individuals with epilepsy had a shorter length of stay than those without epilepsy, but multivariate analysis showed no difference in expenditures between inpatients with epilepsy and those without.

Significant vulnerable domain factors included number of developmental disabilities other than epilepsy and psychiatric comorbidity. Developmental Disability diagnoses were associated with greater service use only for home and community based waiver and other services. This finding provides support for classifying developmental disabilities as a predisposing rather than a need factor in analyses of medical care access, use, and spending. Since waiver costs accounted for so much of total annual spending, individuals with developmental disability diagnoses had higher annual expenditures than

those without a developmental disability diagnosis. Psychiatric comorbidity predicted greater use of every service except waiver services, and higher spending for all services.

Among those with epilepsy, male gender and African Americans race/ethnicity were associated with lower odds of a specialist visit, and those of other race/ethnicity had lower annual expenditures than whites. The other significant traditional predisposing factor effect was the association of older age with a greater likelihood of an epilepsy-related inpatient admission and higher annual expenditures, compared with adults under age 40. The traditional enabling characteristic of dual eligibility was associated with greater odds of specialist use compared with those with Medicaid only. Psychiatric comorbidity, a predisposing characteristic in the vulnerable domain, was associated with greater likelihood of an inpatient admission and higher expenditures compared with those without psychiatric comorbidity. Annual expenditures also increased with the vulnerable domain factor of number of developmental disabilities diagnoses.

The Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) was well suited for use with Medicaid beneficiaries with developmental disabilities. For example, it allowed for developmental disability diagnoses to be considered predisposing characteristics in regard to medical care and need factors in regard to home and community based waiver services. The model provided an analytical framework for examining patterns of health care use and expenditures and illuminating non-economic as well as financial concerns about equity in access to care. Specifically, race/ethnicity differences in waiver participation, hospital events, epilepsy-related specialist use, and annual expenditures suggest disparities in service access. The addition of predisposing factors in the vulnerable domain, i.e., developmental disabilities other than epilepsy,

psychiatric diagnoses, and substance abuse also shed light on aspects of service use and spending. The finding that dual eligibility was associated with better access for epilepsy-related specialist care and lower odds of an emergency room visit underscores the importance of enabling factors in facilitating access to care. Finally, the model provided an analytical framework to test the premise that epilepsy is a powerful indicator of vulnerability and need for health care resources, even after controlling for other factors.

Implications for Policy and Practice

The low epilepsy rate compared with previous studies suggests that this condition may be under-diagnosed in New Jersey. While there is no clear reason why under-diagnosis would occur in this state more than others, the difficulty of diagnosing epilepsy in people with adults with developmental disabilities has been well established (Bowley & Kerr, 2000; Coulter, 2005). Further, practitioners have reported under-diagnosis and misdiagnosis of epilepsy in patients presenting with psychiatric or other medical issues (Ryan & Sunada, 1997; Ziring et al., 1988). High epilepsy prevalence, the complexity of diagnosing epilepsy in adults with developmental disabilities and the implications of missed or inaccurate diagnosis of this condition point to the need for educating practicing physicians as well as medical students, residents, and fellows about epilepsy among individuals with developmental disabilities. Since video monitoring has been shown to be a powerful diagnostic tool (Devinsky, 2004; Picardi et al., 2007), the use of web-based instruction may offer an efficient method for continuing education on this topic.

One potential factor influencing the lower epilepsy prevalence rate among community-dwellers in this study compared with earlier studies is organizational and

policy-related. New Jersey has been slower than most other states to reduce the size of its institutions for people with developmental disabilities. The state has the third highest rate of institutional placement of people with developmental disabilities in large congregate facilities in the U.S. (Coucouvanis, Prouty, Bruininks, & Lakin, 2006). Nationally, the institutional population tends to be comprised of individuals with more severe disabilities (Lakin, Anderson, Prouty, & Polister, 1999). The apparently low rate of epilepsy in the community, therefore, could be a function of the nature of the state's service system rather than a true picture of epilepsy prevalence in a community-dwelling population comparable to other states.

New Jersey's slower pace in shifting services for people with severe disabilities from institutional to community settings has resulted in an urgent imperative for the state's service system (New Jersey Department of Human Services, 2007), expressed in a legislative mandate to move 1,500 individuals from developmental centers to community settings (P.L. 2006, c. 61). Further, New Jersey Protection & Advocacy, Inc. has filed a lawsuit in U.S. District Court, alleging that the New Jersey Department of Human Services has failed to comply with the U.S. Supreme Court's *Olmstead* decision requiring states to provide services to people with disabilities in the most integrated settings appropriate to their needs (*N.J. Protection and Advocacy, Inc. v. Davy*, 2005). The Department's Division of Developmental Disabilities has identified a history of epilepsy in approximately 50% and active epilepsy in 18% of the 1,005 individuals where the individual, the Interdisciplinary Team, and the family affirmatively desire or have no opposition to the person moving to a community setting. Access to appropriate medical care will be a key component of the services needed by these individuals. At minimum,

there is a need for resources for case managers and other professionals who provide or monitor community services to ensure the provision of appropriate medical care. Ideally, policy makers will adopt strategies that move health care for people with developmental disabilities toward the 21st-century health care system envisioned by the Institute of Medicine – i.e., care that is safe, effective, patient-centered, timely, efficient, and equitable (Committee on Quality Health Care in America, Institute of Medicine, 2001).

In this study, epilepsy was more likely to be present among those with psychiatric comorbidity, those with one or more developmental disability diagnoses, and those with physical comorbidity, establishing a profile of a group with multiple needs for medical and other services. The combination of multiple conditions makes the need for coordination among medical care providers and between medical care and mental health practitioners even more imperative for this subpopulation. It further suggests the need for reimbursement systems that recognize the cost of care management. The potential importance of care coordination underscores the need for case managers in developmental disabilities service systems to be informed about their clients' physical and mental health conditions, and to advocate for access to appropriate treatment.

As hypothesized, epilepsy was associated with the use of more intensive and costly inpatient and emergency room services. This may be a result of the prevalence of medication-resistant epilepsy among individuals with developmental disabilities (Bowley & Kerr, 2000; Branford, Bhaumik, & Duncan, 1998) or other illness factors not captured by the list of conditions in the Charlson Comorbidity Index (Charlson, 1987; Deyo, 1992). However, it also may indicate problems in treatment for the disorder, since epilepsy has been identified as an ambulatory care-sensitive condition. If managed

properly, hospitalization for epilepsy is potentially preventable (Millman, 1993; (Szaflarski, Szaflarski, Privitera, Ficker, & Horner, 2006).

Despite the challenges of epilepsy management, nearly half of the individuals with epilepsy did not have an epilepsy-related physician visit in a two-year period. At the same time, nine out of ten individuals with epilepsy had received one or more prescriptions for anticonvulsant medication. Adherence to the recently added HEDIS quality measure of annual monitoring for patients on persistent medications (NCQA, 2006) would appear to have potential for improving ambulatory care for epilepsy. Moreover, the complexity of epilepsy management documented in this study suggests that a managed approach may have potential for adults with developmental disabilities and epilepsy (Crocker, 2000; Kastner & Walsh, 2006; Kastner, Walsh, & Criscione, 1997a; Kastner, Walsh, & Criscione, 1997b; Walsh & Kastner, 1999). Similarly, integration and coordination of care is one of the key recommendations of a recent Center for Health Care Strategies analysis of chronic conditions among Medicaid fee for service beneficiaries (Kronick, Bella, Gilmer, & Somers, 2007). While Kronick and colleagues acknowledge the lack of an evidence base documenting best practices in management of chronic conditions, they note that identification of comorbidity patterns (such as epilepsy, psychiatric, and physical comorbidity) offer opportunities for interventions that can pay off in improved outcomes and cost control. In order to achieve improved coordination, state financing schemes must recognize care management services and provide appropriate reimbursement. Even in the face of significant concerns about controlling Medicaid costs, care coordination for patients with multiple chronic conditions appears to be a potentially fruitful investment.

In addition, the apparent disparities revealed by the current study, such as African Americans' lower probability of seeing a specialist for epilepsy care, would be particular areas to address in state efforts to design managed systems of care for people with disabilities and those with chronic conditions (Bella, Williams, Palmer, & Somers, 2006). Care management and other elements of managed care, primarily used by states for other groups but recently incorporating persons with disabilities, appear to have potential for improving outcomes and controlling costs. Further, although inpatient length of stay was shorter for patients with epilepsy than their counterparts without epilepsy, there was no difference in annual expenditures. This suggests that individuals with epilepsy had multiple admissions. Therefore, access to an appropriate provider should be a priority of developmental disability case managers, care givers, and residential providers as well as state health care officials and policy makers. Moreover, the findings regarding increased hospital use by those with epilepsy suggest a need for State Medicaid agencies and health professionals to explore approaches for better management of patients with epilepsy and developmental disabilities. This effort should include an examination of reimbursement policies and utilization review requirements that may promote or impede access to optimal management of epilepsy. In particular, promoting the development of a "medical home" for adults with developmental disabilities, especially those with chronic conditions such as epilepsy, holds promise for reducing disparities as well as improving outcomes (Beal, Doty, Hernandez, Shea, & Davis, 2006). The concept of a medical home goes beyond having a regular source of care, and involves a personal physician with whom a patient has a continuous relationship providing and coordinating all aspects of care (American Academy of Family Physicians, 2007). Beal and colleagues' (2007)

found that chronic conditions are better managed in patients with medical homes. Further, medical homes resulted in reduced and even eliminated disparities in access to care.

The apparent disparities in access to medication represent another potential target for improvement through the provision of medical homes for adults with developmental disabilities. Specifically, African Americans' lower expenditures for medications compared with whites and greater odds of a hospital admission compared with whites suggest that African Americans face barriers to ambulatory care (Szaflarski, Szaflarski, Privitera, Ficker, & Horner, 2006) and that African Americans may be at higher risk of preventable hospitalization. Moreover, findings that those of other race/ethnicity were less likely than whites to participate in waiver services and African Americans and those of other race/ethnicity receiving home and community-based waiver services had lower waiver expenditures than whites suggest discrepancies in the provision of waiver services. The large differential may reflect a lower rate of out of home placement, which is more expensive than serving people with developmental disabilities in their own homes. Since the New Jersey Division of Developmental Disabilities offers the same community service programs whether they are funded through the developmental disabilities home and community based services waiver or exclusively through State funds (Lakin, 2000), there may be no disparity when State-funded services are included in the analysis. If there are race/ethnicity differences in patterns of services, both outreach efforts to achieve more equitable access and further research to ascertain the reasons for the differences and to inform outreach initiatives are needed. The profile of apparent racial/ethnic disparities in access to services for individuals with developmental disabilities also underscores the need for cultural competence on the part of medical and

social service providers (Georgetown, 2007; Smedley et al., 2002). Cultural competence involves not only an awareness of social and cultural factors influencing health behaviors and use of health care, but also integration of this knowledge into the delivery of health care services (Beach et al., 2005; Betancourt, Green, Carillo, & Ananeh-Firempong, 2003).

The association of higher service use and expenditures for individuals with psychiatric diagnoses suggests the need for coordination of medical and behavioral health care (Druss, 2002; Mechanic, 1997). Issues such as interaction between anticonvulsants and psychotropic medications (Alvarez et al., 1998; Working Group of the International Association of the Scientific Study of Intellectual Disability, 2001) also highlight the importance of communication, and to the extent feasible, integration of care for patients with such complex needs. It is important for state agencies responsible for developmental disabilities, Medicaid, and mental health services, to promote policies and organizational structures that enhance communication between service providers.

The finding that those with psychiatric comorbidity and those with physical comorbidity were less likely to receive waiver services compared to individuals without any comorbidity implies that individuals with complex needs face barriers to community-based long-term care. This apparent discrepancy merits an analysis of participation in the state's community services programs across all funding sources, similar to the study recommended to assess equity in regard to race and ethnicity. The finding that waiver participants with physical or psychiatric comorbidities had higher expenditures than those without comorbidity suggests the need for attention to care management of social and medical services. Further, the adequacy of current medical and home and community

based services quality indicators should be evaluated in regard to the needs of individuals with physical or psychiatric comorbidities.

Among those with epilepsy, the findings that African Americans had lower odds of seeing a specialist for epilepsy and that only 50% of those from the other race/ethnicity group had an epilepsy-related specialist visit compared to 64% of whites suggest a need for action to ascertain the reason for the differences and to ensure equitable access to services. The greater odds of an epilepsy-related hospital admission among individuals with psychiatric comorbidity indicate their epilepsy may not have been well managed (Millman, 1993).

Dual eligibles' higher odds of an epilepsy-related specialist visit and lower odds of having an epilepsy-related emergency room visit raise concern about the adequacy of ambulatory care for individuals with epilepsy who rely solely on Medicaid (Millman, 1993; Szaflarski, Szaflarski, Privitera, Ficker, & Horner, 2006). This disparity underscores the issue of adequacy of New Jersey's Medicaid reimbursement rates for physicians (Ramírez de Arellano & Wolfe, 2007). At the same time, it is important to ensure that anyone eligible for Medicare take advantage of this entitlement. Since the typical path to Medicare eligibility for individuals with developmental disabilities differs from the general population, there may be individuals falling through the cracks. Rather than qualifying for Social Security and Medicare on the basis of their employment history, people with developmental disabilities are more likely to meet the criteria for disabled adult child benefits. These payments are provided to adults whose disability developed before age 22 and whose parent receives Social Security retirement, disability benefits, or who is deceased and worked long enough to qualify for Social Security.

Unlike adults with developmental disabilities who live with their parents, those have not lived with their family for years may be at risk of missing out on the benefit, since there is no link between them and their parents in Social Security records. State agencies as well as service providers, people with developmental disabilities, families, and other advocates can play a role in promoting full use of this benefit... In this case, the interests of State developmental disabilities and Medicaid agencies align with those of the people they serve, since dual eligibility provides better insurance coverage for individuals and reduces State expenditures, particularly for inpatient and outpatient hospital care.

While there were differences in regard to race and insurance, three-fifths of those with a physician visit for epilepsy in this study saw a specialist at least once. Although neurologists express preferences for more extensive involvement in the management of patients with neurological conditions (Dasheiff, 1999; Swarztrauber & Vickrey, 2004; Swarztrauber & Vickrey, 2002), there is no accepted standard regarding specialty involvement in the treatment of epilepsy (Ross, Estrok, Chopra, & French, 2001). Thus, no firm conclusions can be drawn about the appropriateness of the profile of specialist use in this study. However, the large proportion of patients who receive their care exclusively from generalists highlights the need for primary care physicians to obtain current information about epilepsy management. The lack of objective standards for choosing a physician also underscores the need for alertness to physicians' communication and accessibility on the part of patients and their advocates (Epilepsy Action in Australia, 2007).

In addition to the challenges that epilepsy treatment presents to service providers and policy makers, the intricacy of epilepsy management presents difficulties for

individual patients and their families. Intellectual and communication limitations often associated with developmental disabilities, for example, can interfere with epilepsy diagnosis and treatment (Bowley & Kerr, 2000; Hannah & Brodie, 1998). As a result, identification of epilepsy may be delayed and precise seizure classification can be difficult. A delay in diagnosis can result in care givers lacking needed information for themselves and the person with a disability. Once the epilepsy is treated, medication side effects and drug interactions are common. Communication limitations again can make it more difficult to learn what the individual is experiencing, and thus the adult with developmental disabilities may live with undesirable side effects longer than others without a developmental disability.

Since epilepsy is frequently accompanied by other health conditions such as chronic physical illnesses, mental illness, and other developmental disabilities, a patient may see numerous specialists. While treatment from multiple providers, perhaps at several locations, may represent good access to care, it also can present difficulties in transportation and may complicate instructions for home care. Navigating this health care maze can be difficult for adults with developmental disabilities and their families. For those in group homes and other residential placements, coordination with medical care and other services, as well as medication monitoring and other home care, add another level of complexity. Advocacy groups such as the Epilepsy Foundation of America and its New Jersey affiliate have developed information to help individuals with epilepsy to actively work with their physicians and other health providers; individuals with developmental disabilities are likely to need the support of their families or others to make effective use of these resources (Epilepsy Foundation of America, 2007). These

resources provide tools to help patients to become active participants in their health care by asking questions about relationships between conditions, medication interactions and side effects, preventive screening, and communication between primary care physician and specialists. The challenges of living with multiple health conditions also point to the need for health education for adults with developmental disabilities and their caregivers (Abdullah, Horner-Johnson, Drum, Krahn, Staples, Weisser, & Hammond, 2004; Spitalnik & Risley, 1999). State developmental disabilities and Medicaid agencies can provide support for the development and delivery of health education programs and educational materials, which have been shown to have positive outcomes for individuals with developmental disabilities (Abdullah, Horner-Johnson, Drum, Krahn, Staples, Weisser, & Hammond, 2004; Aman, Benson, Farmer, Hall, & Malone, 2007).

Limitations

The study has several limitations. Since it was an observational study, the findings will be limited to identifying associations rather than determining cause and effect. The study included only patients enrolled with a state developmental disability system, and may not reflect the experience of adults with developmental disabilities who are not enrolled with the service system. The research included only individuals enrolled with Medicaid. Since Medicaid claims do not include Medicare payments for services, this dataset does not include any dual eligibles' ambulatory care encounters reimbursed only by Medicare, and it may understate their total annual health care expenditures (Sambamoorthi et al., 2001). The results also may not reflect the experience of those who have Medicare only or commercial insurance or who are uninsured. Medicaid

beneficiaries enrolled in managed care were excluded, since no claims other than capitation payments to the plans are included in the data set. The findings, therefore, pertain only to Medicaid fee-for-service participants and cannot be generalized to managed care participants. Fifth, it reflects the experience of one state with a comprehensive Medicaid program – New Jersey covers all optional as well as mandatory services permitted under Medicaid, and New Jersey’s experience may not generalize to other states.

Other limitations result from the characteristics of administrative claims data. Many factors, such as patients’ and families’ knowledge and attitudes toward medical care, are not captured in claims files. In addition, cultural and other attitudinal factors such as stigma associated with epilepsy also may present barriers access to care (Andersen, 1995; Gelberg et al., 2000; Paschal, Ablah, Wetta-Hall, Molgaard, & Liow, 2005), but they are not reflected in Medicaid claims. Claims data are limited in their utility for identifying disabling conditions, since disability diagnoses often are not included in claims if they do not relate directly to the purpose of the encounter. Moreover, the ICD-9 diagnoses for conditions such as epilepsy do not provide good measures of severity. While the type of provider and volume of health services - such as the number of generalist and specialist physician visits - can be measured through claims data, claims do not provide information about the interaction between primary care and specialty care. They cannot, therefore, be used to characterize important dimensions of care such as the nature and extent of the collaboration between providers (Pincus, 1987). The data set did not contain geographic variables such as zip code, and the county of residence field was found to be unreliable. Accordingly, no regional differences such as

physician supply or other contextual variables could be ascertained (Phillips, Morrison, Andersen, & Aday, 1998). Only service activities that result in a claim are captured in the fee-for-service data. Care coordination — which assists people with special health care needs to obtain access to medical care and other services (Wehr, 2000), and which is associated with reduced hospitalization of individuals with developmental disabilities (Crocker, 2000; Criscione, Walsh, & Kastner, 1995; Walsh, Kastner, & Criscione, 1997) — is not reimbursed in New Jersey's Medicaid fee for service system, and therefore, is not captured in the data. Finally, claims data do not include measures of patient satisfaction or health outcomes.

Implications for Future Research

This analysis of health service utilization and expenditures of adult Medicaid beneficiaries with developmental disabilities and epilepsy illuminates areas of potential future research. First, additional studies using similar methods in other locations are needed to assess the generalizability of the study findings. Since Medicaid programs vary by state with regard to eligibility and service options as well as health care delivery and reimbursement systems, replications of the analyses with multi-state or nationally representative samples would help to evaluate the extent to which the findings and their implications represent national or state-specific issues. Also, inclusion of geographic variables such as county or zip code and additional health system characteristics such as physician supply and small area variations would strengthen the analyses. Further analyses are needed to identify the characteristics of the population known to have

developmental disabilities that are not reflected in medical service claims, and to assess the policy and service implications of the results.

The present study documented greater odds of inpatient hospitalizations and emergency room use for individuals with epilepsy compared to other adults with developmental disabilities. Future studies should examine patterns of repeated hospital events, which represent potentially avoidable complications for patients and possible unnecessary use of health care resources. Identifying factors associated with multiple hospital events may reveal opportunities for prevention of these events.

Several of the study findings raise concerns in regard to racial disparities. Additional analyses of ambulatory and hospital care for specific conditions, with more precise comorbidity measures, are needed to better understand the current study's findings regarding race/ethnicity differences in inpatient and emergency care. Future investigations of specialist use for epilepsy should include environmental factors such as zip code and, if possible, physician supply. Since the data set for this study included only the services supported by federal matching funds through a Medicaid waiver, future analyses of New Jersey's developmental disabilities community services should include state-funded as well as federally funded services. Research identifying access barriers to medical and social services can point to targets for policy solutions to ensure equitable access to the full range of services, including waiver services.

The questions raised by the study in regard to accessibility of waiver services for individuals with complex needs represent another area for further analysis. The profile of lower participation in waiver services by those with psychiatric comorbidity or physical comorbidity and higher expenditures for waiver participants with those comorbidities

warrants further examination of the factors affecting the accessibility of services for populations with complex needs and the higher cost of serving them.

Three enabling characteristics, dual eligibility, home and community based services participation, and pattern of epilepsy-related physician care warrant further examination based on the results of this study. There is a need for additional research to identify differences in Medicare eligibility among individuals with developmental disabilities and their effect on health care use. Factors such as gender, race/ethnicity, health status, and comorbidity should be included in the analyses (Sambamoorthi, Collins, & Crystal, 2001). Similarly, analyses of subgroup differences in developmental disabilities home and community based services waiver participation are needed to gauge equity of access to waiver services. Further research also is needed to resolve the inconsistency between the finding that pattern of care was not a significant predictor of any of the outcome measures and the results of an earlier analysis of Medicaid expenditures for children with chronic conditions, including epilepsy (Perrin et al., 2002). Geographic variables, which may indicate variations in physician practice (Wennberg, Barnes, & Zubkoff, 1982; Wennberg & Wennberg, 2003) and alternative comorbidity measures, would be of particular interest in regard to pattern of care.

The study's findings raise questions in regard to factors affecting hospital length of stay and annual expenditures. Future studies should include all diagnoses in the hospital claims and explore other comorbidity measures since the surprising result that adults without epilepsy had a much longer length of stay than those with epilepsy may reflect unmeasured differences in health status.

Although medication is the primary treatment for epilepsy, pharmaceutical health services research in this area is scarce (Coulter, 2005; Working Group of the International Association for the Scientific Study of Intellectual Disability, 2001). Studies of anticonvulsant use could improve the knowledge base concerning patterns of treatment for adults with developmental disabilities and epilepsy, their access to treatment, and assessing the quality of care they receive. Potentially fruitful research questions include:

- Who prescribes anticonvulsant medications for adults with developmental disabilities and epilepsy? Do prescription practices for similar epilepsy types vary by specialty?
- Can claims data be used to measure patient adherence in anticonvulsant medication use (Crystal, Akingicil, Bilder, & Walkup, in press)? What provider and patient factors are associated with adherence? Is adherence associated with less epilepsy-related inpatient and emergency room use?
- Does use of newer anticonvulsants vary by predisposing characteristics such as race/ethnicity? Do patient outcomes vary with newer versus older anticonvulsants?

Other areas for future research regarding aspects of epilepsy treatment for individuals with developmental disabilities include the degree to which the care of Medicaid beneficiaries with developmental disabilities and epilepsy conforms to the HEDIS standard of annual monitoring for patients on persistent medications (NCQA, 2006), and analyses of access to newer treatments, including vagus nerve stimulation and

surgery for intractable epilepsy among patients with developmental disabilities (Benbadis & Tatum, 2001; Swarztrauber, 2004).

Only 1.4% of the adults with developmental disabilities in this statewide sample had claims with a substance abuse diagnosis. Further research is called for to estimate the prevalence of substance abuse in the developmental disabilities population, to assess the recognition of substance abuse by developmental disabilities service providers, and to examine access to treatment for those with developmental disabilities and substance abuse.

Finally, this analysis of Medicaid fee-for-service medical care use and expenditures provides a baseline for comparison as New Jersey and other states expand managed care for people with developmental disabilities and other Supplemental Security Income beneficiaries (Center for Health Care Strategies, 2000; The Pacific Health Policy Group, 2005). Initially, it will be important to assess whether indicators such as epilepsy-related inpatient and emergency room use improve under managed care. Although pattern of physician care was not a significant predictor of health service use or expenditures in this study, it remains worthwhile to assess whether patterns of care change under managed care, and whether service use, spending, and health outcomes are associated with the changes in care patterns. Health outcomes and patient satisfaction are of interest not only in regard to managed care; patient and family ratings of their health care experiences are needed to evaluate health care system performance from a consumer perspective.

Summary of Chapter V

This chapter presented a review of the research questions, major findings and study limitations, compared the results with prior research, and described the findings within the framework of the adapted Behavioral Model for Vulnerable Populations. It also discussed the study's implications for policy and practice as well as future research.

APPENDIX

Charlson Comorbidity Index ICD-9-CM Codes

Condition	ICD-9-CM Codes
Myocardial infarction	410, 412
Congestive heart failure	428
Peripheral vascular disease	441, 443.9, 785.4, V434
Cerebrovascular disease	430-438
Dementia	290
Chronic pulmonary disease	490-496, 500-505, 506.4
Connective tissue disease	710.0, 710.1, 710.4, 714.0, 714.1, 714.2, 714.81, 725
Ulcer disease	531-534
Mild liver disease	571.2, 571.4, 571.5, 571.6
Diabetes	250.0, 250.1, 250.2, 250.3, 250.7
Diabetes with end-organ damage	250.4, 250.5, 250.6
Hemiplegia	344.1, 342
Moderate or severe renal disease	582, 583, 585, 586, 588
Any tumor	140, 150, 160, 170, 171, 172, 174-179, 180, 190-195
Leukemia	204-208
Lymphoma	200-203
Metastatic solid tumor	196-198, 199.1
Moderate or severe liver disease	456, 572.2-572.8
AIDS	042-044

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